

# A mixed methods study of lung cancer diagnosis affecting quality of life

DOI: 10.3395/reciis.v2i1.128en



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## Abstract

The aims of this study were to assess Quality of Life (QOL) within patients with a newly diagnosed inoperable lung cancer and then comparing the QOL scores with the findings from a qualitative interview study. A mixed method descriptive concurrent triangulation design was used to achieve the specific aims. Twenty-three patients participated. Quality of life was assessed with two questionnaires; the European Organization Research and Treatment of Cancer, EORTC-C30 and supplement lung cancer-specific module, the QOL-LC-13. Data were analysed in accordance with procedures recommended by the EORTC. These results were then compared with findings from a qualitative interview study. EORTC-QLQ-C30 + LC-13 all questionnaires were completed, since there were just 23 respondents, mean values at an individual level were calculated. Quality of Life was scored by the patient to a mean score of 4.5. In the interviews QOL was expressed as living as usual. It seems as regarding measurement of functional scales and global QOL there are similar findings using a questionnaire or a qualitative interview. Hence, the qualitative interview gave more multiplicity and deeper understanding about the different domains. The findings of this comparison, point out the importance of identifying the different domains of QOL from these patients' perspectives.

## Keywords

Lung cancer, quality of life, life-situation, EORTC QLQ C30- LC13, mixed methods

## Introduction

Lung cancer is the most common malignant disease worldwide and is the most common cause of cancer related to death in men and it seems as the figures are increasing in women (WHO, 2003). In Sweden the reports are quite similar, but the disease is decreasing in men and increasing in women (THE NATIONAL

BOARD OF HEALTH AND WELFARE, 2007). Risk factors for lung cancer are smoking, asbestos, radioactive gas e.g. radon and air pollution. Lung cancer is a disease with many biomedical symptoms such as: dyspnoea, haemoptysis, pain and anorexia (COLLEY, 2000), and psychological symptoms (CARLSEN et al., 2005), followed by few possibilities of being cured, especially with regard to inoperable lung cancer. The treatment of these

patients is directed at relieving local or systemic symptoms including treatment as radiotherapy, chemotherapy and palliative systemic therapy. Even though treatment has been improved, prognosis remains poor (NAPIER et al., 2002), and the treatment approach for these patients is mostly palliative.

### Quality of life

Quality of life (QOL) is a major consideration in this context, and an adequate evaluation and maintenance of the QOL is necessary (FALLOWFIELD et al., 2005; KRISHNASAMY, 2007). Quality of life has been closely linked with symptom prevalence and intensity in patients with lung cancer (MONTAZERI et al., 2001), and the burden of the symptoms in this group of patients has a great impact on psychosocial well-being (CARLSEN et al. 2005).

Despite these problems lung cancer patients have particular concerns about family issues and the future, hence experiencing inconsistencies in care, being perceived and being supported (HILL et al., 2003; KRISHNASAMY et al., 2001; BERTERÖ et al., 2007).

Health-Related Quality of Life (HRQOL) is often used synonymously with subjective health status and defined as subjective impact of disease, impairment and effects of treatment (SPILKER et al., 1996; CARR et al., 2001). The concept of QOL has been narrowed in research studying medical populations in order to assess a number of predefined domains. The European Organization for Research and Treatment of Cancer (EORTC) have operationalized HRQOL in cancer disease terms of functional status, cancer and treatment specific symptoms, psychological distress, social interaction, financial impact and overall QOL (AARONSON et al., 1993; 1996).

This study aimed to explore and describe QOL within patients with a newly diagnosed inoperable lung cancer. The specific aims were to quantitatively and qualitatively explore QOL scores from HRQOL measurements with the findings from a qualitative interview study, whereas the patients spoke freely about their QOL. So, the research question is: Do participant views from interviews and from standardized instrument converge or depart?

### Method

A mixed method descriptive concurrent triangulation design as described by CRESWELL (2003) was used to achieve the specific aims. In quantitative measures may only one aspect of a complex phenomenon such as QOL be explained, whereas a combination of quantitative and qualitative methods contributes to a more comprehensive understanding of study outcomes (CRESWELL et al. 2004). The EORTC QOL study group may have already collected qualitative data to form the basis for their questionnaire. But, have their focus been upon symptoms or health and quality of life measurements? Could there be something found to give a more comprehensive picture or not?

### Participants

The participants were patients with inoperable lung cancer from two different hospitals in Southern Sweden. Selection criteria were (a) being an adult, i.e. older than 18 years of age; (b) being diagnosed with an inoperable lung cancer, and an enquiry if the patient wished to participate in the study six to seven weeks after diagnosis; (c) the patient should be in palliative treatment; chemotherapy or/and radiation therapy; (d) and be willing to share his/her lived experiences with us. Purposeful sampling was used, selecting patients for participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge (KVALE, 1996). A total of 23 persons were approached for participating in the study and all accepted participation.

### Procedure

Ethical approval was gained from the Committee on Research Ethics (Reg.no. 02-191). An enquiry about participation in an interview study as well as answering a questionnaire was given to the patients by the nurses in conjunction with the physician responsible at the lung reception at the hospitals. Both oral and written information was given and the patients were informed about confidentiality, how they were selected and the aim of the study. Signed informed consent was required prior to participation.

Data were collected from August 2004 to April 2005. Those respondents, diagnosed with an inoperable lung cancer six to seven weeks prior, were interviewed and answered some questionnaires about QOL and symptoms after participating in the qualitative interview. In some cases the respondent kept the questionnaire for some days and sent it back in a prepaid pre-named envelope.

Qualitative data were collected using qualitative interviews. A general interview guide approach was used (KVALE, 1996). A guiding question which each informant was asked is: Tell me about your lived experiences when being diagnosed with lung cancer and how this affects your life situation and QOL. Topics related to the interview guide were raised spontaneously by the interviewer or the interviewee, and probe questions were asked to give the patient opportunities to elaborate and give examples of more general statements. The interviews were conducted at a place convenient to the patients. The interviews varied in length between 40 and 100 minutes, were audio-taped and transcribed verbatim. Directly afterwards, the informants also noted on a scale, graded 1 to 10, how they estimated their QOL to be at that moment.

To measure QOL, EORTC core questionnaire, the Quality of Life Questionnaire (QLQ-C30) and the supplement lung cancer-specific module, the QOL-LC-13 were used. The EORTC-QLQ-30 consisted of 30 items and the LC-13 consisted of 13 items (AARONSON et al., 1993; 1996).

The EORTC-QOLQ-30 subscales were developed to assess the various aspects of QOL. These are the

functional status identified in five components: physical, role, emotional, cognitive, and social functioning. Higher scores on functional scales represent a better level of functioning. The global QOL and the patients symptoms identified were fatigue, nausea and vomiting, pain, dyspnoea, insomnia, appetite loss, constipation, diarrhoea, and financial status. Higher scores on the symptom scale represents worsen symptoms. Most items (1 to 28) are scored 1(not at all) to 4 (very much). The exceptions are those items contributing to the global health status/QOL (29-30), which are scored 1 (very poor) to 7 (excellent) (AARONSON et al., 1993; BERGMAN et al., 1994). The EORTC QLQ-C30 +LC30 have been found to be valid and useful tools (AARONSON et al., 1993; FAYERS et al., 2001; MONTAZERI et al., 1988).

Reliability has been assessed of the Swedish version of EORTC QLQ-30, in both healthy people and in a variety of cancer patient groups, with Cronbach' alpha ranging from 0.55 to 0.87 (MICHELSON et al., 2000).

### Qualitative analysis

COHEN et al. (2000) and MOUSTAKAS (1994) phenomenological hermeneutic approach was used for analysis. This form of interpretation is descriptions which in a way capture and mediate the lived experience from the informants. The analysis is performed in five steps.

(1) Every interview transcript was read and re-read and meaning units were thought of. Meaning units are the characteristics found from the phenomenon under study. This reading and re-reading aims to make a first interpretation that will take the analysis process forward.

(2) Each interview was read and re-read and data were underlined concerning the "lived experience" as a person diagnosed with lung cancer. With the aim of understanding wholeness of data, as well as the parts, the transcripts were analysed in order to recognise patterns.

(3) The meaning units for each informant were described by statements. All meaning units identified as having equivalent meaning were grouped into a theme. A description and interpretation of each theme is written, aiming to clarify and describe the meaning of the theme with its basis from the meaning units. This was carried out for every single interview, over and over again. The statements under each theme were described in individual textural descriptions of the experience.

(4) From the individual textural description, a common textural-structural description, a so-called composite description was developed for each theme. This describes the meaning of the theme, representing the group as a whole.

(5) From the composite description of each theme, the essence was constructed, giving the meaning of the experience: Quality of life. The essence was representative of the group as a whole.

### Statistical analysis

In accordance with procedures recommended by the EORTC, score were linearly converted to a scale ranging from 0 to 100 for each patient. For the functional and global health status/QOL scales, higher scores represent a better level of functioning. For the symptom scales, higher scores represent worse symptoms (FAYERS et al., 2001). In order to present individual scoring, since there are just 23 respondents, mean values at an individual level are calculated.

### Results

Demographic and characteristic of the total patient group of 23 patients are presented in Table 1. The respondents were 12 male and 11 female, aged between 36 and 86 (median 67). Seventeen out of 23 were married and 20 respondents had children. Fourteen out of 23 were old age retired.

**Table 1 - Socio demographic and characteristics of the patient group**

Variable		N=23
<b>Age (Years)</b>	36-64	9
	65-86.1 14	
<b>Mean</b>	64.78	
<b>Gender</b>		
	Female	11
	Male	12
<b>Socio demographic data</b>		
	Married	17
	Single/divorced	4
	Widower/widow	2
	Children	20
	No children	3
	Employed, full time or at least part time	9
	Old age retirement	14

## Qualitative findings

The analysis and interpretation of the transcribed interviews identified six themes; experience of uncertainty, experience of hope, network as support, thoughts of death, feeling shame and guilt, and next of kin reactions. The structure of the essence was built by interrelation of the themes and became to be: living as usual

### *Experience of uncertainty*

Experience of uncertainty was hard to handle according to the statements of the patients. There were a lot of questions regarding the diagnosis, the treatment and the outcome of the treatment, which were occupying the informants' thoughts and bringing forth uncertainty. The informants experienced that too much time was spent in waiting; waiting for knowing and living in fear and not knowing if there is a cure or not. Uncertainty was fortified. Then there is knowing with even more worries and uncertainty and again more time spent waiting – for the treatment and its outcome. This uncertainty causes anxiety within the patients, which decreases their experience of quality of life.

### *Experience of hope*

Receiving a diagnosis of inoperable lung cancer is something shocking, but there is hope. There must be a treatment or a cure, since the patients want to stay alive. Life will go on if they as patients manage to cope with the treatment and all its side-effects and hope will be strengthened. Sometimes the informants experience the symptoms/side-effects of the treatment as being worse than the disease itself. If they manage the treatment, they will defeat the disease. Sometimes there is an uncertainty about the outcome, but there is hope. The treatment will prolong their lives. Hope is also about living a good life. The patients expressed wishes about a good quality of life; planning for different activities and hoping that they will have time to enjoy life and that they will not become distressed.

### *Network as support*

When receiving a cancer diagnosis, it is important to feel support; talking about the situation they are in and sharing feelings that arise. All support is valuable but the support received by next of kin is significantly important for the patients. Almost all patients experienced this support, emotional support, as well as practical support at home and during other activities. Some of the patients went alone to get their diagnosis and to treatment or follow-up visits, but they expressed that it was important to inform their next of kin, even if it was hard. However, sometimes the patients kept the bad news inside themselves, aiming to protect the next of kin or waited for the right moment to arrive, when it would be suitable to tell the next of kin. Friends were appreciated as a network, but the informants did not tell them the bad things, instead they put on a mask of confidence and courage.

The health care professionals, and especially the nurses, were experienced as an important factor influencing how the period of disease and treatment was

perceived. The nurses were accessible for conversation and support; at every visit or via contact by telephone. The nurses were also there as a support for the next of kin, and this was appreciated and highly valued by the patients. The patients felt that the physicians were skilled and had a lot of knowledge and experience of the disease, and they felt secure and confident in knowing that: it was experienced as a kind of support.

### *Thoughts of death*

When the informants receive their diagnosis, their first thought is: a cancer diagnosis is equal to death. They have some difficulties in absorbing the information and after a while, depending on personality and support, they start to take action. This could be to put their fear of death into words; talking to next of kin about death and dying, and talking about practical things, such as their funeral. Others do experience thoughts of death, but do not want to put these thoughts into words; instead they think that there is plenty of time to conclude their lives. The patients stated that they were not ready to leave life yet. They wanted to take part in the development of the family, relationships with friends and being a part of normal life. Dying was not scaring, but there was a sad feeling of leaving dear and near ones. There were also worries about becoming a burden to their next of kin, if they did not manage to remain independent until death.

### *Feeling shame and guilt*

The patients experienced that the diagnosis of lung cancer was, in society, in health care and in terms of the people around them, connected with shame and guilt. It was experienced that there was a negative attitude related to lung cancer. Talking to friends or next of kin about having a cancer diagnosis could be allowed, but a lung cancer diagnosis was something else. Some of the informants had been smokers, and others had been living with a smoker for many years. There were feelings of guilt that they had caused their disease, and that they were to blame themselves. Others were blaming themselves for not seeking help; waiting and hoping that their symptoms would disappear. There was a strong feeling of shame connected with this lung cancer diagnosis and sometimes the patients thought that even their next of kin would be stigmatized if people around knew about the lung cancer diagnosis. Relationships with friends were hard to maintain, since they did not want them to understand what kind of cancer diagnosis they had, and they tried to cover up their symptoms and other bodily changes.

The informants' social activities were limited due to these feelings of shame and guilt.

### *Next of kin reactions*

The patients experience that their next of kin are significantly important regarding support, but, at the same time, they are very sensitive about the reactions of next of kin. They worry about how their children or elderly parents will react and manage, not only during

this period of illness but also afterwards. The informants experience this as emotionally distressful.

Sometimes the next of kin reacted more intensely and painfully than the patients themselves, and this was experienced as being distressing by the patients. There was continuously a balancing act performed by the patients in order to protect their next of kin, so they would manage through the period of disease and also after the patients had passed away. They had to balance with their own needs of support, so they also would manage. The patients focus was on worries and concerns about next of kin and that there is a need to support them.

#### *Living as usual*

Although there were a lot of different feelings/experiences, there was a clear message: we want to live as usual. The patients are very omitted in their new vulnerable situation; thrown between hope and despair. There are feelings of shame and guilt and they are in great need of support, while at the same time trying to support their next of kin. Even though next of kin and the family are significantly important for the patients' quality of life, they are also a cause of worry and efforts in staying independent and strong. There is interplay between the patients and next of kin; they know that there is sorrow and emotional distress, but they are avoiding the issue. They all act as usual, carrying on with normal life, carrying out their everyday activities. It was hard to admitting to themselves that they were seriously ill and that they needed to ask for help and support. Maintaining independency and integrity was the guiding star for the informants, as they felt it to be strongly connected to their quality of life. It was important that the patients could maintain their status, being treated as the person they always had been and that they experience that they had a meaning to fulfill in life. They wanted to be valued and needed as the person they were and are, taking responsibility for their daily life, being independent and

having the ability to act. Everything should be as usual; they were living as usual. It was tremendously important that during the period of treatment, there were no side-effects that could in any way affect their independence or give some signals to friends or next of kin that everything is not as usual. Living as usual and acting as usual gave the patients a kind of control and feeling of security that fortified their experience of quality of life.

#### The results from the scale estimation

After the interviews, the patients were asked to estimate their quality of life at that particular moment, on a scale: 1 to 10. The result shows that they estimated their quality of life at this moment as quite good, with a mean value of 6.55 and a median of 7.0. The estimations were quite similar between male and female informants.

#### Quantitative results - Symptoms score

The patients scored on EORTC-QLQ-C30, highest on symptom as fatigue with a mean score of 5.4 followed by pain 2.5 and nausea and dyspnoea with a mean score of 2.4 respectively (Table 2). The figure of fatigue is a response on items asking: Did you need to rest? Do you feel weak? and Were you tired? The figure of pain is a response on items asking: Have you had pain? and Did pain interfere with your daily activities? The items in EORTC-QLQ-C30 are more general statements for cancer trying to capture the last week experiences.

Looking at the supplement lung cancer-specific module, the QOL-LC-13 the patients scored highest on dyspnoea with a mean score of 4.3 followed by cough 1.9 and pain in other parts 1.7 (chest pain with a mean score 1.5) and alopecia with a mean score of 1.6 (Table 3).

Dyspnoea was scored as being there when walking, climbing stairs and/or in rest. Pain in other parts could be pain in parts not related to the lung cancer such as pain in the stomach, the back, the surgery wound, etc.

**Table 2 - QOL domains EORTC QLQ- C 30: individual analysis**

Symptoms functioning scale			Mean score (SD)
<b>Symptoms</b>			
Fatigue	FA	5.4	(1.8)
Nausea and vomiting	NV	2.4	(1.2)
Pain	PA	2.5	(1.2)
Dyspnoea	DY	2.4	(0.9)
Insomnia	SL	1.6	(0.9)
Appetite loss	AP	1.7	(0.8)
Constipation	CO	1.8	(1.0)
Diarrhoea	DI	1.5	(0.8)
<b>Functional scales and global QOL</b>			
Quality of Life	QOL	4.5	(1.4)
Physical functioning	PF	3.6	(1.4)
Role functioning	RF	2.4	(1.1)
Emotional functioning	EF	5.5	(1.9)
Cognitive functioning	CF	2.3	(1.1)
Social functioning	SF	2.9	(1.3)

Symptoms; FA = item no: 10, 12 and 18, NV = item no: 14 and 15, PA = item no: 9 and 19  
The other symptoms are single item

Functional; QOL = item no: 29 and 30, PF = item no: 1 and 5, RF = item no: 6 and 7,  
EF = item no: 21, 22, 23 and 24, CF = item no: 20 and 25, and SF = item no: 26 and 27.

**Table 3 - QOL domains EORTC QLQ-LC13: individual analysis**

Symptom scale		Mean score (SD)	
Symptoms			
Dyspnoea	LCDY	4.3	(1.3)
Cough	LCCO	1.9	(0.7)
Haemoptysis	LCHA	1.0	(0.0)
Sore mouth	LCSM	1.3	(0.7)
Dysphagia	LCDS	1.1	(0.3)
Peripheral neuropathy	LCPN	1.2	(0.5)
Alopecia	LCHR	1.6	(1.0)
Chest pain	LCPC	1.5	(0.9)
Arm/shoulder pain	LCPA	1.4	(0.7)
Pain in other parts	LCPO	1.7	(0.9)

LCDY = item no: 3, 4 and 5. The other symptoms are single items.

### Quantitative results - Functional scales and global QOL

Emotional functioning was scored as a mean score of 5.5, indicating that the patients experienced their emotions as manageable. The items covering this domain were asking: Did you feel tense? Did you worry? Did you feel irritable? Did you feel depressed? Physical functioning was scored with a mean score of 3.6 indicating that they felt a little bit restrained in their daily activities. Quality of life (item 29 and 30) was scored by the patient to a mean score of 4.5 indicating that they felt quite pleased with their life situation during these circumstances.

The lowest mean score was found in cognitive functioning with a score of 2.3 followed by role functioning with a mean score of 2.4. These figures indicate that the patients have some problems with concentrating on things and this could affect their role functioning as well (Table 2).

### Comparison EORTC QLQ-C30 scores and qualitative findings

Regarding symptoms, the patients spontaneously in the interviews talked about dyspnoea and cough as symptoms that were distressing, and this is in agreement with the scores of the lung cancer specific module: whereas the patients scored highest on dyspnoea with a mean score of 4.3 followed by cough 1.9. Fatigue was a symptom that was mentioned in passing in the interviews. The patients related their fatigue to their dyspnoea and explained that this was the cause for not having the energy.

The patients scored a mean score of 5.5 regarding emotional functioning indicating that they experience their feelings as manageable regarding tense, worries, irritation and downheartedness. In the interviews the patients talked about how they experienced uncertainty due to time of waiting before getting the diagnosis and then getting straightforward information about their treatment and prognosis. There were also quite a lot of thoughts about their situation. There were thoughts of death, having the time to conclude their lives and arranging practical issues regarding funeral. Even though, there

was experience of hope, about a prolonged life due to treatment and new research findings making the disease at least stay at *status quo*. An important issue that was mentioned by the patients was next of kin reactions. The patients were affected by how the next of kin felt sadness about their disease and forthcoming death, but there were also feelings of guilt, worries and anger. The patients spent quite a lot of time worrying for the next of kin and how to protect them from frightening messages. Another thing that came through in the interviews and which should probably be placed as emotional functioning is feelings of shame and guilt. Several patients felt that society, the health care system and also some of themselves put on them; that they had caused the disease by themselves.

Physical functioning was scored by the patient with a mean score of 3.6 indicating that they experienced some limitations regarding doing some strenuous activities like carrying heavy bags or needing help with washing themselves, dressing, eating, etc. In the interviews the patients expressed that they tried to live as usual and it was important to manage by themselves. They were imaginative and found different solutions to manage the situation. But sometimes they had to admit that they needed some help and support.

Social functioning was by the patients scored with a mean score of 2.9 regarding how their physical condition or medical treatment interfered with their family life or social activities. Role functioning was scored with a mean score of 2.4 regarding how the patients were able to work, do other daily activities or pursuing hobbies or other leisure time activities. In the interviews the patients stated that it was important with network as support. This network could consist of family, friends, work-mates or health care professionals. It was of great importance that they were treated as the person they are and not an ill person. An important aspect of social functioning could be that feelings of guilt and shame made some of the patients withdraw from social activities and they did not tell their friends or work-mates what diagnosis they had.

Cognitive functioning was by the patients scored with a mean score of 2.3 regarding concentrating on things

and remembering things. The patients did not mention this in the interview, but they expressed that their thoughts and mind was focused on how the next of kin felt sadness, guilt, worries and anger. The patients spent time worrying for the next of kin, planning practical issues and working through own feelings. Some of the patients did make some research on the internet, looking for treatment alternatives, etc. So they did concentrate on things.

Quality of life including health aspects was by the patients scored with a mean score of 4.5 indicating a medium QOL (7 is excellent). When the patients were asked to estimate their quality of life after the interview on a scale 1 to 10, they estimated their quality of life at this moment with a mean value of 6.55 and a median of 7.0. These figures are quite similar (when 10 is excellent). In the interviews the patients meant that QOL was about: living as usual. Maintaining independency and integrity as well as maintaining status is of great importance.

It seems as regarding measurement of functional scales and global QOL there are similar findings using a questionnaire or a qualitative interview. Hence, the qualitative interview gave more multiplicity and deeper understanding about the different domains. It seems as the patients put more into the domains than the questionnaire is asking for. One thing that seems to be missing in the questionnaire is the family, next of kin.

The findings of this study, this comparison, point out the importance of identifying the different domains of QOL and including the next of kin, since they are significantly important for these patients' experiences of quality of life.

## Discussion

The results of this study add to knowledge of lung cancer diagnosis and its treatment affecting the life situation and QOL viewed from different methodological perspectives. The central methodological debate within QOL research is informed by a differentiation between objective and subjective measures (ROGERSON, 1995; ROSENBERG, 1995; CUMMIN, 2000). However, this kind of studies using mixed methods will bring forth a more balanced view (ROSENBERG, 1995), and also point out the combination to be complementary, developmental, initiating and expanding (CRESWELL, 2003; CARACELLI et al., 1993).

The quantitative data showed that the patients' scored highest on symptoms as fatigue followed by pain, nausea and dyspnoea in the EORTC-QLQ-C30, but in the lung cancer specific part the QOL-LC-13 the patients scored highest on dyspnoea with a mean score of 4.3 followed by cough 1.9 and pain in other parts 1.7 (chest pain with a mean score 1.5). These latter results are quite similar to those presented in a review of lung cancer; dyspnoea, haemoptysis and pain (COLLEY, 2000). The patients in the present study scored high on fatigue which is in agreement with the results from a study using EORTC QLQ-30 + LC13 as well (LÖVGREN et al., 2007). There is also agreement with another study looking at sleep disturbance

and impaired daytime functioning within newly diagnosed lung cancer patient (LE GUEN et al., 2007), with focus on functioning. Lung cancer patients also showed lower sleep efficiency and higher sleep fragmentation during night (LE GUEN et al., 2007).

The measurement of functional scales showed that emotional functioning was scored as a mean score of 5.5, indicating that the patients experienced their emotions as manageable, and QOL was scored by the patient to a mean score of 4.5 indicating that they felt quite pleased with their life situation during these circumstances, which is a little bit contradictory to other studies (CARLSEN et al., 2005; HOPWOOD et al., 2000). Patients with lung cancer report more unmet psychosocial needs than patients with other cancer diagnosis (HOUTS et al., 1986). Patients with a lung cancer diagnosis have particular concerns about family issues and the future, hence there is inconsistencies in care and support (HILL et al., 2003; KRISHNASAMY et al., 2001). This was also found in the qualitative interviews in present study.

The lowest mean score was found in cognitive functioning with a score of 2.3 followed by role functioning with a mean score of 2.4. These figures indicate that the patients have some problems with concentrating on things and this could affect their role functioning. These scores are more in agreement with a study about psychosocial effects (CARLSEN et al., 2005).

Physical functioning was scored with a mean score of 3.6 indicating that they felt a little bit restrained in their daily activities. Could this explain the high scoring of fatigue? According to EORTC (AARONSON et al., 1993; 1996), fatigue is not included in any functional scale, it is a separate symptom. Physical functioning could be seen as day time functioning, with different activities during daytime. Lower daytime activities were found in lung cancer patients in a study by LE GUEN et al. (2007).

Quality of life has been closely linked with symptom prevalence and intensity in patients with lung cancer (MONTAZERI et al., 2001), and the symptoms has a great impact on psychosocial well-being (CARLSEN et al., 2005). It is not obvious that the connection is so clear and easy to explain. Several studies (BERTERÖ et al., 2007; MALISKI et al., 2003; BENZEIN et al., 2001) point out that cancer patients balance their life situation: 'taking the bad with something good', e.g. hope. Another interesting aspect is if knowledge about a cancer diagnosis affects QOL? In a study, 129 lung cancer patients were interviewed and QOL was assessed with three different questionnaires. About 23% of the patients knew about their diagnosis and 77% did not know their cancer diagnosis. The result showed that there were no significant differences between the two groups with regard to the assessed QOL, and there were no significant differences in patients' symptoms score except for sleep difficulties. So, knowledge of a lung cancer diagnosis does not affect response to QOL measurements (MONTAZERI et al., 2004). Something notable in that study was that patients who knew their cancer diagnosis showed a slightly better global QOL score than those not knowing.

Qualitative methods enabled an understanding of these persons' experiences of having a diagnosis of inoperable lung cancer. The theme experience of uncertainty could be seen as balancing with the theme experience of hope; which could be facilitated if there was a network as support. This balancing could perhaps be explained by the scoring of emotional functioning, whereas the patient indicated that they found their situation manageable functioning (MALISKI et al., 2003). Feelings of shame and guilt as well as experiencing own as well as next of kin feelings of worries and anger could cause decreased well being (HOUTS et al., 1986), and trying to protect or take care of next of kin (HILL et al., 2003; KRISHNASAMY et al., 2001). The six themes identified in the qualitative interviews gave a structure presenting the essence QOL: living as usual. Living as usual means maintaining independency and integrity and preserve their status and role functioning. The patients express their will of living as usual, but measurements show that there is reduction in physical and role functioning according to MONTAZERI et al. (2003).

Mixed methods generated knowledge about vulnerable peoples' perspectives and experiences of QOL and life situation in these two studies. Qualitative methods fostered in-depth understanding of experiences of living with a diagnosis of inoperable lung cancer and what affected QOL and the life situation. Especially was knowledge about emotional feelings as well as social activities and social network highlighted. Quantitative methods also generated detailed information on physical effects (symptoms), role, emotional effects, cognitive effects, and social functioning, but not in such details.

The last decades QOL has become significant as a medical goal, since it has become obvious that mortality reduction is not enough for a medicine facing chronic, incurable and degenerative diseases. It has also become clear that it is the patient, the person, not the physician or other health care professionals, who has the authority to judge the patient's QOL (SULLIVAN, 2003).

The study has some shortcomings. The sample size is small regarding the measurements with EORTC-QLQ-C30 + QOL-LC-13; it would have been preferable with a larger sample in order to make generalizability. However, the sample is quite large regarding the phenomenological study. The aim was to explore and describe QOL within these patients by comparing the results from quantitative research with results from qualitative research in order to explore QOL and if possible develop the measurements and expand the knowledge. I wish to acknowledge that future research may benefit from exploring vulnerable peoples perspectives. A mixed method design would be useful regarding this issue: Do participant views from interviews and from standardized instrument converge or depart? My answer so far is that in most part they do converge and when they depart it is because of doubleness in interpretation of the content of the questions asked in the instruments. So, that is a reason for letting the patient be the authority to judge his health and QOL and clarify it or express it by own words as well.

## Conclusion

Mixed methods generated knowledge about vulnerable peoples' perspectives and experiences of QOL and life situation in these two studies. This mixed methods study show that in most part the instrument and the interviews do converge and when they depart it is due to doubleness in interpretation of the content of the questions asked in the instruments.

## Acknowledgement

I would like to thank all persons who participated in this study. I am also grateful to the Medical Research Council of Southeast Sweden (FORSS) and Gunnar Nilsson's Cancer foundation for making this study feasible through financial support. I am also grateful to EORTC who allowed me to use the questionnaire on a small sample in order to triangulate it with qualitative research.

Potential conflicts do not exist.

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