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Balancing a Changed Life Situation: The Lived Experience From Next of Kin to Persons With Inoperable Lung Cancer

Karin Steinvall, Helena Johansson and Carina Berterö

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TITLE: Balancing a changed life situation. The lived experience from next of kin to persons with inoperable lung cancer.

Short running title: Balancing a changed life situation

Karin Steinvall, RN, lecturer^{1,3}, Helena Johansson, RN, lecturer^{2,3}, & Carina Berterö, RN, PhD, Professor³

¹ *Close Health Care in western county Östergötland, Motala Hospital, Motala, Sweden.*

² *Specialized Medical Clinic, Motala Hospital, Motala Sweden, and* ³ *Division of Nursing Science, Department of Medical and Health Sciences, Faculty of Health Sciences, Linköping University, Linköping, Sweden.*

Corresponding author:

Carina Berterö, RNT,BSc, MScN, PhD, Professor
Department of Medical and Health Sciences
Division of Nursing Science
Faculty of Health Sciences Tel +46 13 227768
SE-581 85 Linköping Fax +46 13 123285
e-mail: carina.bertero@liu.se

Karin Steinvall; karin.steinvall@liu.se

Helena Johansson: helena.johansson@liu.se

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Abstract

The purpose of this study was to identify and describe the experiences of quality of life/life situation among those who were next of kin to persons with inoperable lung cancer. Data were collected in qualitative interviews, where 11 next of kin articulated their lived experiences, and were interpreted through interpretive phenomenology. Four themes were identified: changed life situation, experiences of uncertainty due to awareness of the ill person's changed health status, interpersonal relationships, and false hopes due to health care professionals' treatment. These four themes gave a structure presenting the essence: balancing a changed life situation. The findings of the study point out the importance of promoting support for the next of kin, since they are significantly affected by the changed life situation. There is a need to identify their needs and to support them.

Keywords: next of kin; quality of life; life situation; inoperable lung cancer; interpretive phenomenology; balancing life

Introduction

Lung cancer is the most common malignant disease worldwide, and is the most common cause of cancer-related deaths in males. In many countries it seems that the figure is increasing in females.¹ There are approximately 900 000 new cases each year in men and 330 000 in women.¹ In Sweden, approximately 3000 new lung cancer cases are reported annually, with the disease decreasing in men but increasing in women.² Lung cancer is divided into two forms: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC).^{3,4} The prognosis depends on when the diagnosis is made, hence most inoperable lung cancers show few possibilities of being cured. Almost 80 % of inoperable lung cancer diagnoses lead to palliative care.^{2,5,6,7} Management of patients with inoperable disease is directed at relieving local or systemic symptoms. This treatment includes radiotherapy, chemotherapy and palliative systemic therapy. The prognosis remains poor, even though treatments have been improved.^{6,8} Paramount in palliative care is control of pain and other distressing symptoms.^{9,10} Apart from physical aspects, palliative care also addresses psychological, social and spiritual aspects. The next of kin should be provided with support and counselling for the duration of the disease as well as after the person has passed away.^{9,10,11}

The next of kin is the person whom the patient perceives as the closest person to them. It may be the wife/husband or partner, but it can also be a friend.^{9,12,13}

Information is something that is appreciated by the next of kin.^{9,11,13,14} They have a desire to be informed of what may happen, in order to be prepared, and they also wish to have feedback on their activities as informal carers.¹⁵ It is also important for them to receive information about the prognosis and the progress of the disease. This information should first be given close to the time of diagnosis, hence it is important to repeat it over time. This kind of information should be given in such a way that hope is maintained.^{16,17,18}

Support from people close to them is important for the next of kin, such as that from friends and others who are present and are not afraid of tears or outbursts, those who understand and show empathy both in joy and sorrow. Being provided with this kind of support, as well as with clear information from health care professionals, could help to maintain quality of life for the next of kin.¹⁰

The next of kin's participation in care has been described as 'participation in darkness' or 'participation in light'. To be next of kin in darkness means that you are not participating in the caring encounters, only receiving information from the patient. To be 'next of kin in light' means that there is a relationship involving the patient, the next of kin, and health care professionals. There is an open and respectful integration.¹⁴

The next of kin play an important and necessary role in the life of a person with a cancer diagnosis. Sometimes, when the patient is in an advanced stage of the disease, there may be difficulty in expressing needs and symptoms. The health care professionals may then turn to the next of kin in order to obtain information and a measure of the severely ill person's symptoms and distressing problems.¹⁹

Important factors affecting the families and their life situations relating to quality of life are: social support, the effects and severity of the disease, work and social status, relationships and family.^{20,21,22} Both the patient and the next of kin are dependent on each other's life situations and quality of life.^{21,22,23} The next of kin have a higher quality of life than those with lung cancer, but this quality of life is not only affected by the disease of the patient, but also by the health status of the next of kin.²³ The next of kin want to feel comfortable with assistance and that they have done what is necessary. They do not want to feel guilt due to not being a good

next of kin or informal carer, or that they have been using the term ‘burden’ in relation to their ill relative.²¹ These aspects, their individual health status and quality of life, are important and crucial to how they manage to support the person with lung cancer. Disparities between the patients’ and the next of kin’s experiences of quality of life and of managing stress in relation to non-small cell lung cancer has previously been studied.²⁴ It was found that coping strategies were similar in both groups. The most-used coping strategy was optimism. Supporting coping was also used as well as relying on themselves. Patients and next of kin experienced to a high degree that they had good social support, which showed that they appreciated the resources available to them.²⁴

The purpose of the study was to identify and describe the life situations experienced by the next of kin of persons with inoperable lung cancer.

The next of kin are not caregivers, but probably act as informal caregivers from time to time.

Methods

An interpretive phenomenological approach influenced by Heidegger²⁵ was used in this study, in an attempt to understand the lived experiences described by the next of kin of persons diagnosed with an inoperable lung cancer. As human beings, we are living in the world and are a part of it; we are ‘being’ in the world. We express, interpret and understand our world by putting our experiences into words.^{25,26} Interpretation is the way in which understanding ‘develops itself’. To interpret something is to understand something.^{25,26} Interpretive phenomenology has its basis in philosophy, and interprets how human beings experience and understand their lives.^{27,28} The next of kin have, in their own words, expressed their experiences of being next of kin to someone diagnosed with lung cancer.

Sample and informants

The participants were those who were next of kin to persons with inoperable lung cancer who were being treated at a lung clinic at a hospital in south-east Sweden. The selection criteria were (a) that participants should be adult, i.e. older than 18 years of age, (b) that they should be next of kin to a person diagnosed with an inoperable lung cancer, and that the patient had agreed they could participate in the study six to eight weeks after diagnosis, (c) that the patient should be in palliative treatment, receiving chemotherapy or/and radiation therapy and (d) that the next of kin should be willing to share his/her living experiences with us. Purposeful sampling was used, selecting the next of kin for participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge.^{27,28}

Approval from the Committee on Research Ethics was obtained (Reg.no. 165-06) and all data were treated carefully and confidentially. An enquiry about participation in the interview study was given to the patients by the nurses, in conjunction with the physician responsible, at the lung reception at the hospital. In this way, both oral and written information about the study was given to the patients. The patients decided whether an information letter should be given to their next of kin. The patients and the next of kin were informed about confidentiality, about how they were to be selected, and about the aim of the study. Signed informed consent was required prior to participation.

A total of 23 patients were approached and 11 agreed to participate. The characteristics of the next of kin participating in the study were: 7 males and 4 females, aged between 56 and 73 years (median 68 years). All 11 informants were married or cohabiting with the ill person. All of the informants had children.

Data Collection

Data were collected using qualitative interviews during the period from June 2007 to June 2008. Before the interview, there was some small talk to establish a more intimate relationship, and afterwards, there was talk about and reflection on the interview.

A general interview guide approach was used.²⁸ A guide question, which each informant was asked, was: “Tell me about your experience of being next of kin to a person diagnosed with lung cancer and how this affects your life situation and quality of life”. 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. Two interviews were conducted at the next of kin’s homes, and nine in a special room at the hospital. The interviews varied in length between 30 and 90 minutes, and were audio-taped and transcribed verbatim.

Data Analysis

The analysis has its starting point during the data collection, when the researcher tries to understand and find a meaning in what is narrated by a sensitive listener²⁸, and then the analysis continues with transcription. In this process, the spoken language comes to stand as text.^{26,29}

In our study, a phenomenological hermeneutic approach was used for analysis.^{27, 29} This form of interpretation was description, which in a way captured and mediated the lived experience from the informants. The analysis was performed in several steps:

(1) Every transcript was read and re-read and meaning units were thought of. This reading and re-reading was aimed at deepening understanding of the data, in order to make an initial interpretation that would push the analysis process forward. The meaning units were the characteristics found in the phenomenon being studied.

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

(3) The meaning units for each informant were expressed as statements. All meaning units identified as having equivalent meanings were grouped into a theme. A description and interpretation of each theme was written, aiming to clarify and express the meaning of the theme with its basis in 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 (related to the text) of the experience.

(4) From the individual textural description, a common textural-structural description (related to the text-structure of the phenomenon), 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, a major theme, the essence, was constructed, giving the meaning and essence of the experience: affected life situation/quality of life. The essence was representative of the group as a whole.^{28,29}

All transcripts were analysed and interpreted independently, and the findings were compared among the three researchers, in order to reach consensus on the interpretations.

Results

The analysis and interpretation of the statements in the transcribed interviews identified four themes and an essence. By interrelation of themes, the structure of the phenomenon, the

essence, became: balancing a changed life situation. The themes contributing to this structure were: changed life situation, experiences of uncertainty due to awareness of the ill person's changed health status, interpersonal relationships, and false hopes due to health care professionals' treatment. Quotations from the interviews are presented to clarify the interpretations.

Changed life situation

The next of kin experienced that the core of being next of kin to a person with inoperable lung cancer is a changed life situation, increasing workload both at home and outside the home. There could be tasks with which the next of kin had never before been in contact, but which were now a matter of course. These tasks could be housework, cleaning the flat, and supporting the ill person with practical issues. A positive mission for the next of kin is to take the ill person to the hospital. The next of kin are and want to be involved in the ill person's caring encounters with the health care system. Being there at these encounters enables them to obtain the same information as the ill person, but they do not want to take a prominent role in this situation. This means that the next of kin want to be a support to the ill person and mediate a sense of security. There are mixed feelings about these issues; the next of kin want to be a part of all activities and want to feel comfortable in the situation, performing a task that they can handle. Some things that make them insecure are that they do not know what is expected of them in this situation and they cannot plan their daily lives in advance. They need to live and plan for each day on that day. This results in limitations to their daily lives, and they are caught between the will and desire to help the ill person and, at the same time, the necessity to satisfy their own needs. The needs of the next of kin are to be able to organise their own time and to do activities by themselves and together with others or the ill person. Not having the possibility of fulfilling their own needs results in a feeling of isolation within them, as one wife expresses it:

“...he walks in the garden and (sight) he has not been a part of shopping or other activity yet, he shall come with me in the car, and that have he done ones ...and then we drove up to the cemetery to his parents grave and so...I would like to come out a little bit more” (I:11).

The ill person is consciously or unconsciously protected by the next of kin from unpleasant information and from feelings associated with sorrow, sadness and frustration. The next of kin do not want to see the ill person sad. One strategy used by the next of kin is to protect the ill person by not showing sadness or burdening them with their own feelings. Instead the next of kin speak about positive things, that the ill person has some improvement in health status etc. These actions are carried out in the belief that they help the ill person.

“I should need to do this a bit more often, relieve the pressure (laughs) or release all the valves. ... Yeah it actually feels so, but I would not do it in front of him, no you know that I do not want to do. It happens, we have a house of two storeys so I say I go downstairs and wash up and clean up a bit even though nobody has been there since the kids moved away. And then it happens that I cry a little bit I feel that I just need to place the regulator afterwards it feels better, it feels...the chest pain and headaches may even disappear” (I:7).

Experiences of uncertainty due to awareness of the ill person’s changed health status

There is awareness within the next of kin that the ill person has become a cancer patient with an inoperable lung cancer; and this is always in their mind. They are aware of the causes of inoperable lung cancer, such as smoking or exposure to asbestos. The next of kin experience that adapting to the situation takes time and they have to adjust to it gradually. Often they make comparisons with other people suffering from other forms of cancer, noticing that the

disease has in some cases been curable, not thinking of the differences between different forms of cancer and treatments. There is an understanding that the ill person will pass away because of the lung cancer, but these thoughts are suppressed. The next of kin experience an awareness of the diagnosis and its consequences, but it is difficult mentally and practically to prepare for it. There is uncertainty and the future lies beyond all human control; nobody knows what the future will hold.

“...it started as cough that was never completed, so it had probably already begun then, I guess” (I:10).

The diagnosis brings forth both uncertainty and anxiety. The next of kin describe these feelings as thoughts you do not manage to control. There are thoughts about the future: What will happen? What is the prognosis, and is the disease really incurable? There are thoughts about the future, and concerns about being left alone and the consequences that this brings. There are also concerns that the ill person will be worried or anxious due to these issues and consequences. These thoughts and feelings come forth, especially at night, and result in disturbed sleep. Worry and anxiety cause physical symptoms such as cramps in the chest and tension headache.

“... this was a totally new situation, I have never ever before left somebody at the hospital...I do not know what this is// ... When I got home I sat down with my PC and then the cramps came across my chest and it took a while before it released, uh yes it circled quite a lot of thoughts...//

(I:4).

Interpersonal relationships

The relationship between the next of kin and the ill person is very important and must continue to function. The next of kin want to speak with the ill person and process what has

happened. There are some contradictions in this; on the one hand they want to talk about the situation, and on the other they want to protect the ill person from unpleasant feelings. Some manage to balance these actions, while others have difficulty. The next of kin want the relationship to be as before the diagnosis, but they also realise that they could support each other if they can manage to talk about their situation. Several relationships between the next of kin and the ill person have strengthened, and they try to take care of life and their time left together; take each day as it comes, do their best and a little extra. They re-evaluate life and priorities. Some people find it difficult to reach out to each other and speak about the situation. In these relationships, the focus will be on living as before the diagnosis.

“It’s ... things get another value, you value things very differently when a person becomes ill than when you are healthy” (I:6).

The next of kin perceive relationships in the family as very important. Support from and contact with children and grandchildren are included in these relationships. Being together during holidays as well as during hospital visits is very important and should be a natural part of life. Family communication is a part of the relationship and it should be open, honest and straightforward, but should be according to the next of kin’s conditions. Children and grandchildren should be there, but they should not make demands.

“They (the children) have been welded together and supported each other amazingly, they included me; they supported me, came home and stayed the nights just as you want it to be ... we support each other, we try to meet and socialise, phone contact ... good to know that there is sibling love, they have supported each other and helped each other and then I think...you are happy as father” (I:4).

In addition to the contact within the family, the next of kin want contact with former friends and neighbours. This contact should be as before, the friends should behave as usual but be open to speaking about the situation. Sometimes friends and neighbours are out of contact due to difficulties in talking about the situation. Contact and relationships with work colleagues are enormously important; perceiving themselves as one of them, being a part of the community.

“...some friends, they think like this: she has lung cancer, I think she is dying, so I do not dare talk to her, I do not dare to call, makes it too hard for me to call and hear about it” (I:5).

False hope due to health care professionals' treatment.

The next of kin experience a strong hope of recovery and a continued life with the ill person. In this hope, there are thoughts that the ill person will respond to the palliative treatment and that health will be improved or at least kept in a stable condition. There are hopes that the next of kin and the ill person will have more time together; that they can live together for years to come. The hope of the next of kin is mainly a result of their great confidence in the health care professionals, and also of the credit they give to the care and palliative treatment offered. They wish to have honest information about the disease, such as the prognosis, and other assistance provided in the care for the ill person. Sometimes information is presented as an improvement or an arrest in symptoms after palliative chemotherapy or radiation, and this information is interpreted by the ill person as well as the next of kin as relating to a hope of recovery. In the caring encounter, it is mediated that “it looks better” and this is interpreted by the next of kin that the disease may be about to be cured. Therefore, with this in mind, a caring encounter can give hope about recovery and continued life, but on ‘false’ grounds. Although the treatment session about 10 weeks before gave information that the disease was not curable, the latest

information available to date is that the tumour is in status quo or is reduced in size, which is significant for the next of kin.

“But, they say in there (at the hospital) that it looks good... it’s going in the right direction... and the doctor who says, it has indeed shown...the X-ray pictures (laughs) and I understood that there is some... course in the right direction” (I:3).

The hope may be strengthened by their previous knowledge and experience, perhaps prior to the illness, of situations in the family or among friends and colleagues. There may be people who received a diagnosis of cancer of any kind and lived with it for a long time, or who have been cured.

These experiences, together with caring encounters, as well as research, give the next of kin a confidence in the health care system and a hope that there may be a recovery.

However, there are situations relating to the caring encounter when security and hope are not mediated. Instead, there are worries and uncertainty. It may be in the visit to the emergency room, where they found it hard to sit and wait with the ill person, who had pain and trouble breathing. It may also concern the long waiting times between diagnosis, treatment and outcome. As next of kin, they want to be confirmed as persons involved in the situation and they express a need for support from the health care system.

“Well, I think it is extremely important that you get support when needed from health care when it holds...when there are problems” (I:8).

Balancing a changed life situation

The essence, balancing the changed life situation, is by interrelation of themes the structure of the phenomenon, clarifying the experiences the informants had. Although there were a lot of different feelings/experiences, there was a clear message: we want to live as usual and try to balance our lives.

The next of kin experience that their lives are constantly about balancing. They have to balance their daily lives to satisfy the ill person's practical and supportive needs, while satisfying their own conscious and subconscious needs. It can be a balancing act to find time for activities that they did before the disease, time for self-reflection on their own life situation, and time for distraction. Distraction is about focusing on enjoyable things and not on the disease and its consequences. Balancing also means, on the one hand, talking about the changed life situation and showing emotions in the form of anxiety and sadness. On the other hand, the next of kin want everything to be as 'normal' in relation to the ill person and other people. This means maintaining relationships and contacts as previously, and it is important for the next of kin that the people involved do not disappoint them. It is also desirable to have a balance in relationships; to show emotions and to express them, to talk about the disease and to be sad even though the desire is that the relationship should be as it was before the disease. This means socialising as previously, without talking about the disease and its effects on life. Another balancing act is that the next of kin is aware that the ill person is not going to be cured, but on the other hand has the hope that he or she will recover. This hope is reinforced in the caring encounters which present the outcomes of palliative treatment. The next of kin hover between two 'extremes'; the hope that the ill person will recover and/or be cured, and awareness of the ill person's impending death. Most of the next of kin choose hope in this situation.

The next of kin struggle between feelings of anxiety and uncertainty and hope, even if that hope is established on false grounds. They try to achieve a balance between these different elements, to deal with their own lives and with their everyday life with the ill person, balancing between the old and the new life situations.

“...it's so dammed that it might or might become (living with uncertainty), you have to make the best of the situation” (I:2).

Discussion

Research approaches such as the one used in the present study, Heidegger's interpretive phenomenology, encourage the voicing of the next of kin's experiences and emphasise understanding of the phenomenon, an understanding of the real world of these next of kin, expressed in their own words.²⁵⁻²⁷

The essence of our study is: *Balancing changed life situation*, which should give an understanding about what quality of life means to the informants.

In the present study, it was noticed that the next of kin do not know what is expected of them in this new situation, a finding we have not seen in other studies. So they work with what they can control and feel confident with. Could it be that expectations of the next of kin have not been sufficiently mediated in the caring encounter, or have the next of kin received the information but chosen to repress it? The next of kin are essential and fulfil an important purpose for the patient. This is in agreement with findings that the next of kin are important resources, not just for the ill person, but also in the caring encounter.³⁰ Hence they need continuous support and continuous information in the caring encounter, a view also supported by another study³¹, along with the acknowledgement that they have an important role to fulfil in the ill persons' lives. Our study shows that the next of kin experience that they are protecting the ill person from unpleasant information and emotions connected to sorrow, sadness and frustration, which is also shown in the study about inoperable lung cancer patients.³² There are some contradictions in our findings, since the next of kin also wish to maintain an open and honest relationship with the ill person. Creating an open and honest relationship can be difficult when the ill person and the next of kin are keeping up a front with each other.

The next of kin have great confidence in the health care system and in the information which presents hope for recovery and continued life, as has been confirmed in other studies.^{9,11,13-14} But the experience of false hope due to health professionals' treatment has not been shown as clearly in these studies as it is in the present study. We have found that the next of kin have a strong false hope for recovery and continued life due to health professionals' treatment, and strong confidence in the results from treatment given in the caring encounter, such as, for example, that the tumour has shrunk from radiation treatment. In the early stages, the health care professional gives information about diagnosis and prognosis. The relief of symptoms, and the fact that life-sustaining treatment can reduce symptoms, may be interpreted wrongly, leading to the hope that things will be fine again; recovery is in sight. The idea may be to provide information that the progress of the disease has been slowed, allowing more time together, but this may be interpreted incorrectly and give false hope. We have not seen this in previous studies, and consequently it can be regarded as a new and prominent finding. This finding should be made visible and taken into consideration in the health care system and in caring encounters. In this study, information is given about the illness and 'successes' with treatment, which are interpreted positively by the next of kin and give them hope. This finding is confirmed by other studies.^{9,13,17,33} This hope is based on successes seen during the treatment, which encourage the next of kin to forget the previous diagnosis and prognosis, and lend them a 'false' hope. Their interpretation of the information is that the ill person will be cured. Our findings show that the next of kin need more support in this, since hope about the future is one of the big issues they deal with, which is also in agreement with the findings in another study.³⁴ Hope is defined as a positive emotion, orientated toward the future and with expectations including realistic goals.³⁵ The hope consists of being cured or living in hope, i.e. reconciliation and gratification with life and death.³⁶

The next of kin in our study experience quality of life through support from their own family, but also from friends and acquaintances. It is important that they receive support from those around them, and the friends should be there as support for them and should not pull away even in the face of difficult emotions. These findings are in agreement with other studies.^{10, 37} A balancing act between assisting and supporting the ill person and satisfying their own needs seems to be required even for friends, acquaintances and others in the family. It depends on whether the next of kin want emotional support from those around them, or want everything to go back to the way it was before the ill person fell ill. Something we can reflect on is whether

we as health care personnel view the ill person as in a palliative phase of the illness, while the next of kin still do not. They still see hope in the treatment and hope of a continued life together - a future. The next of kin in our study are affected by physical symptoms like spasms in the chest and tension headaches, connected to feelings of anxiety and uncertainty. This is a common reaction³⁸ where feelings of powerlessness and helplessness are experienced. It can also be seen in a study of palliative care patients³⁹ that the next of kin are affected in a negative way, both physically and mentally, by being close to a patient with a palliative diagnosis.

Is it possible to overcome anxiety and uncertainty? By talking to the next of kin, the health care personnel can reduce both of these. It is important to involve and talk to the next of kin in the caring encounter in order to counteract anxiety, abate hopelessness and sustain hope.³⁰

Conclusion

There are several components in balancing the changed life situation, such as balancing the next of kin's own needs against the ill person's needs. Their own needs include reflecting on their own life situation while also having time for their own activities. Another balancing component concerns on the one hand the desire to talk about the situation and show emotions, while on the other hand to act as usual. This concerns both the relationship with the ill person and all interpersonal relations. Awareness that the ill person will not recover is set against hope of recovery, and the next of kin choose hope. All in all, the result is that the next of kin have to find a balance between the previous and the new life situation in order to sustain their quality of life.

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