



Significant others' lived experiences following a lung cancer trajectory – From diagnosis through and after the death of a family member

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A B S T R A C T

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Survivors
Transition

Purpose: The purpose of this study was to illuminate the meanings of significant others' lived experiences of their situation from diagnosis through and after the death of a family member as a consequence of inoperable lung cancer.

Methods: The data was collected through narrative interviews from eleven significant others and interpreted using a phenomenological hermeneutic approach.

Keyresults: Four themes emerged: being unbalanced, being transitional, being cared for, and moving forward.

Conclusion: The significant others' experiences can be viewed as a transition process, beginning with a sense of dislocation in life and continuing through struggling, enduring and conquering the consequences of the altered life situation until finally approaching a point characterized by a sense of stability. Different strategies of adjustment and adaptation to the new living conditions are considered. Furthermore, the results indicate the need to develop a framework for family-centered health care in order to enhance the wellbeing for the significant others both in the anticipatory grief phase and during the bereavement phase.

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Introduction

Lung cancer is the most common form of cancer in Europe and the most frequent cause of cancer death (Boyle and Ferlay, 2004). In Sweden, 3203 people were diagnosed with lung cancer in 2007 of whom 1627 were men and 1576 were women. The five-year survival rate is approximately 12–15 percent (The Swedish National Board of Health and Welfare, 2008) and approximately 60% of non-surgically treated patients die within the first year after diagnosis (Regional Oncologic Centre S-G, 2004). Adults with lung cancer often experience multiple symptoms (Cooley, 2000; Cooley et al., 2003) and feelings of distress occur more frequently in patients with lung cancer as compared to other types of cancer (Zabora et al., 2001; Degner and Sloan, 1995).

Cancer is a condition that affects the entire family (Blanchard et al., 1997). Furthermore, many studies have found that significant others make a large contribution to the care of their dying intimates (Andersson et al., 2007; Wennman-Larsen and Tishelman, 2002; Visser et al., 2004). The significant others often

feel a major responsibility for the sick relative and, therefore, focus on the dying persons needs (Andersson et al., 2010; Wennman-Larsen and Tishelman, 2002). This includes making adjustments to everyday life in order to care for the sick relative (Andersson et al., 2010). In this situation the significant other needs to handle his/her own stressful emotions as well as to be able to care for the sick relative (Ekwall and Hallberg, 2007; Thomas et al., 2002), which may have negative consequences for significant others' health and social functioning (Nijboer et al., 1998; Wideheim et al., 2002; Hebert and Schulz, 2006).

The emotional reactions related to the impending death of the sick relative and the expected emotional and practical consequences the loss will cause can be described as an anticipatory grief. The anticipatory grief makes it possible for the significant others to psychologically prepare themselves for the upcoming loss which can facilitate the adjustment to the bereavement. At the time of death the phase of bereavement and grief initiates consisting of cognitive, emotional and behavioral reactions. These reactions, as a response to the loss, are normal and seen as a psychological process where the person over time works through the loss (Grassi, 2007).

It has been shown that significant others of persons with lung cancer experience changes regarding the quality of their relationship with their sick relative. Both positive and negative changes

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have been reported, but change towards low levels of relational quality was most common (Wennman-Larsen et al., 2008). Persson et al. (2008) compared health-related quality of life (HRQOL) in significant others of patients dying from lung cancer with a general population during the illness trajectory and until six months after the sick relative's death. The results revealed that significant others scored a lower HRQOL as compared with the general population sample at the time of the diagnosis, and this result remained six months after the relative's death. In a study by Persson and Sundin (2008), the results reflected significant others' experiences six months after the lung cancer diagnosis and revealed that the diagnosis changed the significant others' lives in different directions. They had to struggle to endure and to overcome difficulties and distress on the way to regaining a functioning life. The relationship to the sick person has changed with increased feelings of closeness but also loss of intimacy and reciprocity. But, to our knowledge, no previous studies have focused on illuminating the significant others' lived experiences both during the illness trajectory and after the person with lung cancer's death. This type of knowledge is important for how to possibly understand previous reported results showing various impact on quality of life during an illness trajectory. In addition increased understanding of significant others' experiences is crucial for developing support in order to prevent illness and improve wellbeing both during the anticipatory grief and the bereavement phase. Thus, the purpose of this study was to illuminate the meanings of significant others' lived experiences of their situation from diagnosis through and after the death of a family member as a consequence of inoperable lung cancer.

Method

The method phenomenological hermeneutic inspired by the philosophy of Ricoeur (1976) concerning a reciprocal relationship between phenomenology and hermeneutics, was used for the interpretation in this study. Lindseth and Norberg (2004) describe this methodological approach as focusing on the essence and the underlying meaning in different phenomena of lived experiences. Phenomenology seeks knowledge on the basis of the genuine, human experience and aims to describe the phenomena as shown as "going to the things themselves" and in the natural experience, i.e., the life-world. Hermeneutic research is a tradition using humans' lived experience to understand how humans interpret their world. Through interpretation, an understanding will be shared. Phenomenology tries to elucidate the hidden meaning of life experiences, while hermeneutics tries to find meaning through interpretation of the expression of life.

Participants

Significant others to persons who passed away as a consequence of lung cancer six months prior were recruited from an ongoing longitudinal study, focusing on their health-related quality of life. In the longitudinal study significant others were identified by the person with lung cancer as someone they lived/spent most time with and/or someone they expected help from if needed (Persson et al., 2008). Additional criteria for inclusion in this cross-sectional study was that the significant others had been involved in the illness of the person with lung cancer in a way that had affected their own situation in one way or another. The participants resided in the Stockholm area. Of the original participants, many were excluded since the sick relative had passed away in an early phase or because the sick relative had survived the next few years after enrollment. The remaining participants were asked to participate, which resulted in a final sample of 11 significant others. The

participant characteristics are described in Table 1. The interviews took place within the first year of bereavement.

Data collection

Audio-taped narrative interviews were conducted privately between the interviewer and the participant. The time and the place were selected by the participants and the length of the interviews varied between 60 and 120 min. The participants were asked to narrate experiences of their own situation today and during the next of kind's illness. Two questions were posed in every interview; "would you please narrate how you experience your situation today from what you have been through?"; "Would you please narrate how you experienced the illness situation?" To elicit a greater understanding, the interviewer asked probing questions in response to the narration such as, "Can you tell me more about that?", "What does that mean to you?" and "In what way"? The interviewer attempted to create a sense of trust and openness in the interview situation and acted mainly as a listener (Mishler, 1986). All interviews were transcribed to enable text analysis.

Data analysis

By transferring the spoken language, the interviews, into text and then interpreting the text, a phenomenological hermeneutic understanding of the significant others' experiences was obtained. To reach an understanding of the lived experience, the phenomenological hermeneutic method uses the interpretation to "explain" and to "understand" what the text is talking about. Thus, meanings of the lived experience can be conveyed to others through narratives (Lindseth and Norberg, 2004). Ricoeur (1976) states that the person behind the text shouldn't be understood; it is the text itself which should be understood. The purpose of the interpretation of the text is to get closer to the meanings of the text (Ricoeur, 1976, p. 12). To understand a text in this way is to move away from what the text says to what the text is talking about, what is shown in front of the text to what the text points to (Ricoeur, 1976, p. 88–91).

Lindseth and Norberg (2004) described three methodological phases of the phenomenological hermeneutic method of interpretation which include a dialectic movement under the entire process. In the first phase, the naïve understanding phase, the interview texts were read several times, as open mindedly as possible in order to grasp the essential meaning as a whole. The naïve understanding guided the second phase - the structural analysis, where the text was interpreted and explained. Several structural analyses were performed in relation to the ideas obtained from the naïve understanding. In these thematic structural analyses, meaning units were constructed in accordance with its meanings. The meaning units were then condensed abstracted and formulated into subthemes and themes. In the third phase, the comprehensive understanding phase, the text was reflected on in relation to the aim of the study, the naïve understanding, findings of the structural analysis, the authors' pre-understandings, relevant

Table 1
Descriptive information about significant others ($n = 11$).

Characteristics	$N = 11$
Mean age (years)	57,9
Range between age (years)	35–79
Women/men	9/2
Partner/child/other family	7/3/1
Months between diagnosis and death	8–16/12
Range/median	
Months between death and interview	3–11/8
Range/median	

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