A sense of understanding and belonging when life is at stake—Operable lung cancer patients' lived experiences of participation in exercise

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Conflict of interest statement

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Author contribution

All authors contributed to the concept and design of the study. MM and MNS performed data analyses. MM, BB, MNS and MS contributed to drafting of the manuscript. All the authors read, critically reviewed and approved the manuscript.
ABSTRACT

Objective: To explore the lived experiences and social benefits among patients with operable NSCLC who participated in an exercise intervention.

Methods: Eighteen patients enrolled in an exercise intervention at two weeks post-surgery participated in qualitative interviews at three time points. A phenomenological hermeneutical approach comprised the epistemological stance inspired by Ricoeur’s philosophy. Analysis and interpretation provided descriptions that captured the meaning of the patients’ lived experiences.

Results: The exercise intervention was significant in terms of the patients’ social capital, and the patients experienced themselves as part of a community. Patients gained access to resources that derived from human interaction in the exercise group, and their illness and treatment became easier to manage when shared with others in the same situation. The intervention helped to create a community for patients after lung cancer surgery, and the patients experienced a feeling of belonging and equality with the other participants.

Conclusions: The group-based exercise intervention created opportunities for mutual understanding between patients, making illness and treatment easier to manage. The patients experienced support to reformulate their identity during the exercise intervention in their interaction with peers in the group.
Keywords: NSCLC; Surgery; Exercise; Patient experiences; Peers; Social support; Qualitative study

INTRODUCTION
Non-small cell lung cancer (NSCLC) is a common disease and is associated with high mortality (Ferlay et al., 2010). The number of patients with NSCLC undergoing surgery with a curative intent is 25% and their five-year survival rate is 48% (Lang-Lazdunski, 2013). Video-assisted thoracoscopic surgery (VATS) has been introduced to reduce perioperative morbidity, mortality, and postoperative pain following lung resection compared to open surgical resection (Begum et al., 2014; Hansen et al., 2011). Despite positive physical benefits of VATS, recent studies emphasized that emotional, existential, and social concerns of a lung cancer diagnosis appear to be a great challenge after surgery (Missel et al., 2014; Missel et al., 2016). Furthermore, surgery still may be associated with long-term and late effects of the resection reported as a reduction of pulmonary capacity, cardiorespiratory capacity, and decreased quality of life (Messaggi-Sartor et al., 2018).

Exercise has been introduced to improve physical capacity and quality of life and to reduce long-term and late effects of treatment in adult cancer patients, mostly investigated in patients with breast and colon cancer (Buffart et al., 2017; Sweegers et al., 2018). Research on exercise in patients with lung cancer has previously been given low priority however, recent evidence has shown that exercise for surgically treated patients with NSCLC is both safe and associated with improvements in cardiorespiratory capacity and self-reported outcomes (Cavalheri et al., 2014; Crandall et al., 2014; Granger et al., 2011; Missel et al., 2015). Against this background, a randomized clinical trial (the PROLUCA study) was developed to investigate the efficacy of a postoperative exercise intervention (Sommer et al., 2014; Sommer et al., 2016).

In the PROLUCA study, patients participated in a group-based exercise intervention. Studies have demonstrated how patient-patient interaction in general might be an important part of the social support system during hospitalization and how a companionship between strangers may emerge. However, it is

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also reported how the relationship might be ambiguous (Andersen et al., 2015; Birkelund & Larsen, 2013; Borregaard & Ludvigsen, 2018; Larsen et al., 2013). Studies on exercise for patients with cancer have also reported social benefits of participating in group-based interventions (Adamsen et al., 2017; Backman et al., 2016; Missel et al., 2015), however, the meaning of participating in group-based exercise for patients after lung cancer surgery is sparsely investigated. The objective of this qualitative study was to explore the lived experiences and social benefits among patients with operable NSCLC who participated in an exercise program.

METHODS

In this qualitative study the meaning of the exercise intervention for patients after lung cancer surgery was assessed based on patients’ experiences.

Philosophical underpinnings

The philosophical approach was grounded in phenomenology and hermeneutics. In phenomenology, the researcher investigates the meaning of something, trying to get a grip on the essence of what is expressed as peoples’ lived experiences. Similarly, hermeneutics uses lived experiences as a tool for a better understanding of the social or cultural context in which these experiences occur (Galagher & Zahavi, 2012). Investigating the exercise intervention from a phenomenological hermeneutical perspective, therefore, stresses that what is experienced by the patients is an important source of information. The present study is inspired by Ricoeur’s narrative philosophy (Ricoeur, 1984). The threefold mimesis is central in Ricoeur’s narrative philosophy and relates to the hermeneutical circle as a basic condition for understanding. The threefold mimesis can be seen as an epistemological approach for understanding a person’s actions (Ricoeur, 2002), which, in this study, has inspired the research process in a depiction of a three-fold process (Missel & Birkelund, 2011): Mimesis I (prefiguration): the life lived before it is formulated as spoken or written narrative (data collection); mimesis II (configuration): the language stage, formulating a narrative (from speech to text); and mimesis III (refiguration): the actual comprehension stage, when the text is interpreted (analysis and interpretation) (Missel & Birkelund, 2011; Ricoeur, 1984; Ricoeur, 2002).
Recruitment and Participants

Participants were selected purposefully using a criteria sampling strategy (Crabtree & Miller, 1999) in order to identify participants who have had experiences of participating in group-based exercise. Participants were recruited from patients enrolled and participating in the exercise intervention (the PROLUCA study) (Sommer et al., 2014). The sampling criteria were: 1) diagnosis of NSCLC; 2) referral for surgery; 3) age >18 years; 4) ability to speak and understand Danish; 5) enrolled in an exercise intervention initiated two weeks after surgery; and 6) available to participate in three interviews up to four months after surgery. The first author (MM) informed the patients about the interview study and eighteen participants were approached and provided written informed consent. Medical data were drawn from patient records. The patients participated in three separate interviews (1-3 days after surgery, seven weeks, and four months after surgery). Following the eighteen interviews, patient responses proved to be redundant and a satisfactory saturation point was met.

Exercise intervention

The 12-week exercise intervention comprised 24 group sessions in community-based training facilities at the Copenhagen Centre for Cancer and Health (http://www.kraeftcenter-kbh.dk/en). The intervention consisted of two 60-minute weekly sessions of supervised strength and cardiovascular exercises described in detail by Sommer et al. (Sommer et al., 2014). To enhance intervention fidelity, an exercise training protocol described the components of the exercise in detail; how participants were expected to increase exercise intensity and the practical aim of strength exercise. Additionally, the participants were equipped with heart rate belts during the cardiovascular exercise and given an exercise log file to document strength exercise intensity and progression. All participants received usual care while participating in the intervention and the intervention did not interfere with the participants’ treatment trajectory.

Ethical considerations

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The study was approved by the Danish Data Protection Agency, file no. 2007-58-0015 and was undertaken in accordance with the guidelines of the Danish Ethics Research Committee. The exercise intervention study was approved by the Ethics Committee of the Capital Region of Copenhagen (file no. H-3-2012-028) and Clinicaltrials.gov identifier (NCT01893580). In addition, the study was carried out in accordance with the Declaration Helsinki II and the participants received written information about the purpose of the study and their right to withdraw at any time with no consequences to their treatment, in compliance with requirements of the ethics committee. The participants provided informed oral and written consent before the interview and were informed that interview data would be treated confidentially.

**Interviews**

Human events are characterized by unreflecting preunderstanding, which Ricoeur calls prefiguration (mimesis I) (Ricoeur, 1984; Ricoeur, 2002). Narratives order these uncommunicated experiences and, thus, narratives are part of a process of attributing meaning, in which people try to understand their life (Frank, 1995; Hardy et al., 2009). With the aim of gathering the patients’ in-depth narrative accounts of their lived experiences of participating in exercise after lung cancer surgery, open questions were used, such as: ‘Could you please tell me about your experiences from the exercise program?’ Additionally, the patients were also encouraged to narrate about how they experienced exercising in a group. The interviews were all conducted face-to-face by the first author who is a clinical nurse specialist in the surgical lung cancer field and an experienced qualitative researcher but who did not participate in either the care of the patients or in the exercise intervention. Interviews lasted 25 to 90 minutes for an average duration of 45 minutes. All interviews were recorded and transcribed. The patients’ stories were thus transcribed into a textual configuration or shaping of the patients’ unarticulated experiences (from prefiguration to configuration) (Ricoeur, 1984; Ricoeur, 2002). According to Ricoeur, people’s narratives contain surplus meaning and hermeneutics is concerned with interpreting this surplus meaning (from configuration to refiguration).

Eighteen patients participated in the first interview, sixteen in the second, and fourteen in the third. Return to work and hospitalization for causes other than lung cancer, were reasons for non-participation in the second and third interviews. One patient died before the third interview and one
patient was grieving from recently losing her spouse. The final data corpus emanated from fifty patient interviews at three different time points.

Analysis and interpretation

For Ricoeur, interpretation is the central methodology in phenomenological research. With Ricoeur, the concept of interpretation involves a process that consists of naive interpretation, structural analysis, and comprehensive understanding (Ricoeur, 1976). Naive interpretation is superficial interpretation, whereby the narratives are read and re-read to see what the texts mean to the researcher. This interpretation gave us an overall view of the narratives. Structural analysis deals with patterns in the text that can explain what the text is saying. Explaining a text involves an objective approach to the text. The text already starts to become objective at the mimesis II level, when speech is transcribed into text. Thus, we have created distance from the patients whose statements are the basis of the text, enabling us to undertake a structural analysis. Explaining what the text expresses means moving from what the text says to what the text is talking about. During the structural process, we analyzed and structured the narratives based on units of meaning, extracting meaning or themes that recurred in the narratives. The units of meaning were condensed such that the essential meaning was expressed as concisely as possible. These units of meaning were then further condensed and gathered into themes (Lindseth & Norberg, 2004; Ricoeur, 1976). Interview text was analyzed separately at each time point and provided the basis for the themes that emerged. Longitudinal analysis across the three interview time points was performed to identify how the themes changed over time (Calman et al., 2013). The comprehensive understanding continues with a discussion of the themes that were identified in the structural analysis, the purpose being to reach a new understanding of the possible dimensions of the patients’ experiences with their illness. The deeper interpretation of the narratives is an understanding process in which theoretical perspectives are drawn on to help clarify and understand phenomena in the patients’ lives (Missel & Birkelund, 2011). Researcher triangulation in the data analysis process was used (MM/BB/MNS/MSS).

RESULTS

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Characteristics of the patients included in this qualitative study are shown in table 1. Eight participants dropped out of the intervention. Reasons for non-adherence included chemotherapy side-effects (nausea, fatigue) (n=3), other reasons (n=1), fractured arm (n=1), work (n=1), terminally ill husband (n=1) and death (n=1). The mean attendance rate for the eleven participants who completed the intervention was 82% (range 58-100%).

The social benefits of the group-based exercise were significant for the patients’ lived experiences of the intervention and were related to patients experiencing a sense of belonging but also to finding that exercising with others in a similar circumstance was meaningful and created a sense of community. The comprehensive understanding illuminated the meaning of the patients’ experiences of participating in the group-based exercise program expressed as the patients’ sense of understanding and belonging when experiencing that their life was at stake. Two sub-themes will be illuminated in the following.

**The altered intersubjective world and the social benefits of group-based exercise**

Human beings live in a social world in mutual relationships with others, which, according to Schutz, is a world of shared, subjective experiences, where everyday life has a meaning that is taken for granted and is the basis for social life and action (Schutz & Luckman T., 1974). The diagnosis of lung cancer fundamentally changed the habitual aspects of patients’ social relations and thus confronted and challenged everyday social life with what it was like before the illness.

The analysis revealed how the patients found it difficult to watch their loved ones suffer on their account and, consequently, they tried to protect them from their own emotional and existential worries. The price patients paid was, in some way, to deny their need to discuss their situation while dealing with considerable stress in their lives: “I know he [husband] fully understands that I’m ill and have had surgery, but I don’t tell him that I am worried. There’s no reason to make him worried or plant certain thoughts in his head” (patient 7). At the time of diagnosis, the patients experienced withdrawal of their family and relatives on account of the serious nature of their illness, which was experienced as
exceedingly distressful. After surgery, family and relatives expected the patients to resume and fulfil their previous role in the intersubjective world, which could be an attempt to distance themselves from the patients’ experiences with the illness. This aspect of changes in the patients’ intersubjective world could make patients become isolated with regard to their cancer experiences.

Based on the patients’ experiences of their disrupted intersubjective world, the group-based exercise intervention helped them to re-think the ways in which they could interact with their loved ones. Through the exercise program, they found other kinds of relations meaningful for a period of time. Before the patients started in the exercise group, they had expectations that it would give them something special that the other participants had the same disease and had been through the same: “It makes a difference that when you go into the [exercise] room, the people on the exercise bikes have also had lung cancer. I like the fact that you can learn from each other's experiences” (patient 5).

Some patients were worried, however, about joining the group. Despite the reservations of some patients, the analysis and interpretations revealed social benefits of taking part in the group-based exercise intervention in which the patients experienced themselves as part of a community: “It's great being able to talk with the others in the group who all have the same illness as me. It binds us together and you don't feel so alone. Spending time with the others means a lot. Talking to them has helped me greatly. We’re all very different, but it's fun. If I hadn't put my name down for this group, I would have really missed out” (patient 10). The exercise intervention was, though, significant in terms of the patients’ social capital. Social capital, according to Bourdieu, is the value of an individual by virtue of their social network or membership of a particular group (Bourdieu, 1986). Thus, in this study, patients gained access to resources that derived from human interaction in the exercise group, and their illness and treatment became easier to manage when shared with others in the same situation: “I really appreciated the exercise class, also socially. After cancer you feel very vulnerable, but I felt comfortable in the group. It was good that we had all been through the same thing – the same illness and the same surgery – because we could compare notes and find out from each other how we were coping with various problems. That way we were a good support for each other ” (patient 3). Merleau-Ponty introduces the concept community of being (Merleau-Ponty, 1973 p140), that we are in the same world as other people. This community of being can be converted into a community of doing (Merleau-
Ponty, 1973 p140), if we do something together. The exercise intervention helped to create a community of doing for patients after lung cancer surgery, and the patients experienced a feeling of belonging and equality with the other participants. The patients derived benefits from sharing experiences with their illness with other patients in the same situation, which helped them gain knowledge through others’ experiences, realize they were not alone, created an atmosphere of unconditional acceptance and respect, and minimized fear: “It’s been nice to exercise with others who have been in the same situation as me. It wouldn’t have been the same if they had had something else wrong. In one way or another we managed to ..., well, it was like we were family. We managed to have a really good relationship with one another, and we could also exchange experiences and stuff like that” (patient 11). The exercise intervention was, as such, serving as facilitating the community of understanding and belonging for the patients.

The shared community in group-based exercise as facilitator in transitions

Another finding of the interpretation was that illness was not merely a matter of dysfunction of the patient’s physical body but illness and surgery also affected the patients’ existence as a whole, with an alteration in the patients’ identity: “You have to get used to having lung cancer, and then you become one of them. For me, that was weird. It was weird and alien and hard realizing that you were going to be part of a group of cancer patients (patient 17)”. From the time of their diagnosis and throughout the treatment trajectory, the patients experienced their illness as a disruption of their daily routines and the familiar embodied actions that helped to understand and cope with the world. As a result, the patients lost their sense of security and control and came to see the world as unpredictable. On the other hand, when the patients were able to perform various everyday tasks by themselves, they had the feeling of being in command of their own bodies and a sense of being in control. The resumption of daily practical activities was a process in which patients adjusted to a new awareness of everyday life, a new perception of themselves, and new relations through the four-month period. In this process, the patients described how a strategy such as “talking about their experiences with the illness’ with fellow patients in the exercise group” helped them to work with the physical forms of expression and unfamiliar sensations and feelings, such as sadness and worry, into their embodied being: “A lot of it is about being together with people who don't think it's at all weird talking about yourself the whole time. You
don’t feel lonely, and it gives you a mental boost to talk with other people” (patient 2). Though, through the four-month illness and treatment trajectory, the patients found themselves in a transition characterized by a movement over time in which they gained a new understanding of themselves.

Meleis describes illness as representative of transitions central to nursing practice, emphasizing that certain transitions may make patients vulnerable (Meleis et al., 2000). Patients undergoing healthy transitions are able to achieve confidence and coping capacity in their new situations. A healthy transition is characterized, for example, by preparation and knowledge about what to expect during a transition and what strategies may be helpful in managing it (Meleis et al., 2000). The present study supports the theory of transition in suggesting that when patients told their illness stories to fellow patients during the exercise intervention, it appeared to facilitate healthy transitions in a process of healing of the patients’ life-world. As such, the shared sense of community with fellow patients in the exercise program proved to have particular value as a transition facilitator: “We’re all equal in the exercise group and nothing counts as strange. Most of the people want to tell their story and that’s perfectly all right. That’s what’s so special about being a group of people of different ages who’ve been through the same thing. I think many of us really appreciate being with like-minded people who have been through exactly the same thing and listening to each other’s story, which can put your own story into perspective” (patient 12). According to Meleis (Meleis et al., 2000), having a new sense of identity reflects healthy outcomes of the transition process and transition experiences are thus proposed to result in identity reformulation. Narrating one’s own illness story to fellow patients in the exercise intervention constituted and maintained the individual’s identity. This narrative self-understanding was crucial for the patients’ identity, and the analysis and interpretations thus showed how the patients gained a new understanding of themselves during participation in group-based exercise through support from fellow patients: “It is a kind of sanctum. We inspire each other to come to the class and it’s nice being part of a group, finding someone waiting there for you. We meet to exercise and build up our physical strength again but of course we spend time chatting and finding out how we’re each getting on” (patient 16). Together and over time during the intervention, patients came to common perceptions about how others are and how they themselves are, making them aware of their own identity. The
fellowship between the patients varied in style, where some of the patients became close and confidential, whereas others kept a little distance, despite the proximity.

**DISCUSSION**

The study revealed what it meant for the patients to participate in group-based exercise and how the shared community with fellow patients became significant. The study demonstrated that the patients’ intersubjective world was upset when diagnosed with lung cancer and how patients denied their own need to discuss their situation with their loved ones. The group-based exercise intervention, however, created a community for the patients in which they were valued as an individual with a significant story to share. In the exercise group, the patients experienced that they were not alone, and illness and treatment became easier to manage when shared with fellow patients. Isaksen and Gjengedal have showed how shared experiences with illness among hospitalized patients can have a positive impact on the level of courage and fighting spirit, as well as reduce loneliness (Isaksen & Gjengedal, 2000). A recent study by Borregaard and Ludvigsen of peer support among surgical lung cancer patients during admission also illuminated how exchanging emotional thoughts was easier with a fellow patient as they would be familiar with the feelings, worries, and aspects of illness experiences that were difficult to share or express with relatives (Borregaard & Ludvigsen, 2018).

The community of doing something together in the exercise group facilitated that the patients gained access to resources that derived from human interaction; the patients experienced a feeling of belonging and equality with the other participants. Midtgaard et al. have shown that belonging to a group in an exercise intervention was characterized by a special esprit de corps across the spectrum of different cancer diagnoses (Midtgaard et al., 2005). Other research has confirmed that patients can derive benefits from sharing experiences with their illness with other patients in the same situation (Drageset et al., 2015; Krumwiede & Krumwiede, 2012).
The patients experienced being in transition from an unpredictable time with a threat to their existence and an alteration in their identity, to gaining a new understanding of themselves over time. Participation in the exercise group helped the patients to undergo a healthy transition. The continuity of relationships with fellow patients and the possibility to tell their illness stories in the shared community with the other patients was found in our study to have particular value as a transition facilitator that re-formulated, constituted, and maintained the patients’ identity. Studies have suggested that when people are removed from their familiar context of everyday life, telling of one’s own experiences of illness might be helpful in the process for restoring meaningful order to the disruption of meaning caused by the illness (Frank, 1995; Ricoeur, 1984; Ricoeur, 2002). Other exercise studies have also reported how patients may appreciate the opportunity to exchange experiences with others in the same situation during breast cancer treatment (Backman et al., 2016; Mishra et al., 2012).

Some patients in the present study expressed concerns about participating in the exercise group due to their vulnerable and distressful situation. They were worried that it would be too confrontational to meet with the other patients. Despite these preliminary concerns, all patients in our study were grateful for the experienced social benefits and support from the fellow patients they received by participating in the exercise intervention. It has been demonstrated in other research that some patients may choose not to join a supportive group-based intervention because it may serve as a reminder of their own vulnerability (Guenther et al., 2012). Research has also reported that exchanging emotional thoughts while interacting in a dynamic tension between being close and maintaining a distance between strangers with a common disease may be a challenge (Album, 1996; Andersen et al., 2015; Borregaard & Ludvigsen, 2018). In the present study, the community of doing exercise in the group seemed to meet the challenges of discomfort in the relationships. The intervention facilitated an opportunity for the patients to be close and share stories of their illness experiences while allowing them to turn to the exercises if distance was needed.

The study indicates that an exercise intervention initiated early in the treatment trajectory is meaningful for patients after operable lung cancer, especially regarding the social benefits of the community with
fellow patients. The questions for future research on the social challenges as a side effect of cancer and the social benefits illuminated in this study and other literature involve whether the family or close relatives of cancer patients should be included in the shared community explored in the present study. A study by Adamsen and colleagues described how relatives of patients with breast cancer or prostate cancer were included in a physical activity intervention, which helped strengthen the relationship between the participating relatives and the patients as a basis for their shared social life (Adamsen et al., 2017). Research is required to explore the potential social benefits or challenges of including relatives in programs facilitating human interaction and sharing of illness experiences. Mutual understanding between patients who have gone through similar illnesses and treatments has thus been found to be of particular value, both in this study and in other literature, but the best way to support the patients’ challenged and altered intersubjective world has not yet been explored. A concern in including close relatives in such group-based interventions might be the clear statements of the patients in the present study and other research that interacting with fellow patients is different and offers therapeutic opportunities that differ compared to interacting with relatives or nursing staff. In the present study we did not include any relatives in either the intervention or interviews.

**Methodological considerations**

It is worth considering the fact that 44% of the patients reported that they were walking or cycling for pleasure and 55% included regular exercise as part of their daily lives which is fairly high in this patient population. The sample of the patients included in the presented interview study may thus be a select group of operable lung cancer patients which should be taken into consideration regarding the transferability of the findings.

The qualitative interview method was selected to gain insight into the patients’ perspectives of participation in an exercise intervention. While the study used a qualitative design, by its nature, the results did not prove effects of the intervention but highlighted the patients’ perceived benefits of participating in it. Thus, in this study, the focus was on the patients’ lived experiences in order to understand the meaning of the investigated phenomena, and as such, the qualitative interview method is considered appropriate (Crabtree & Miller, 1999). Ricoeur’s steps in the analytical process were clearly set out and have been followed. The process from prefiguration through configuration to refiguration
reflects the shift from lived life to narrative accounts of lived life to the final interpretation, which provides an insight into universal phenomena. The data collection method produced a large quantity of data, which had implications for the subsequent analysis. The analysis process helped to provide an overview of the data through the systematic creation of an overall picture (naive understanding), thematization (structural analysis), and a deeper understanding of the patients’ experiences (interpreted comprehensive understanding).

A main concern or limitation in this study might be that the study patients were grateful for the opportunity to participate in the intervention and this may have influenced the positive descriptions of their participation benefits and the absence of critique regarding the programme.

REFERENCES
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<td>VATS†† (%)</td>
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* WHO
† Saltin-Grimby Physical Activity Level Scale (SGPALS)
‡ Numbers do not equal 100% because of overlap between categories
§ COPD: Chronic obstructive pulmonary illness
** Within the last five years

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<table>
<thead>
<tr>
<th>Type of surgery:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Lobectomy (%)</td>
<td>16 (89)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Days of admission for surgery, median</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (range)</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>7 (2-32)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Adjuvant chemotherapy (%)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8 (44)</td>
</tr>
</tbody>
</table>

†† Video-assisted thoracoscopic surgery