

## ORIGINAL ARTICLE

# Dominant restitution narratives of 'being lucky': An ethnographic exploration of narratives about operable lung cancer

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**Abstract**

**Objective:** Patients with operable lung cancer experience physical and psychosocial challenges early in their treatment trajectory. However, these patients have unmet needs for a dialogue with clinicians and report that especially psychosocial challenges are not addressed in the clinical encounter. Aiming to understand the reasons for this, this study explores dominant narratives about operable lung cancer.

**Methods:** An ethnographic study was conducted at a Danish hospital providing surgery for lung cancer. Interactions between patients, relatives and clinicians were observed during hospitalisation. Ten patients were included from September 2019 to March 2020.

**Results:** One overarching dominant narrative of 'being lucky' was found, supported by three narrative subthemes, related to different aspects of the treatment. First, the possibility of surgical treatment was 'like winning the lottery'. Second, surgery was a minor intervention like 'a quiet day at the office'. Third, even if adjuvant chemotherapy was necessary, as long as the surgery went well, it was 'good news' in the outpatient clinic.

**Conclusion:** 'Being lucky' is a dominant restitution narrative about operable lung cancer. A predominance of restitution narratives implies that clinicians are the active party, while patients remain passive, which limits their perspective and thus silences their concerns unrelated to curative treatment.

**KEYWORDS**

lung cancer, narrative, qualitative research, supportive care, surgery

## 1 | INTRODUCTION

Lung cancer is the most prevalent cancer, with over two million people diagnosed annually, and the most deadly cancer worldwide (WHO, 2020). Surgery is the preferred treatment for non-small cell lung cancer (NSCLC), and in Denmark, around 4500 people are diagnosed with NSCLC annually, and about 1000 people undergo lung

cancer surgery (DLCG, 2020). Five-year survival following surgery has almost doubled since 2003 to about 60% (DLCG, 2020). By comparison, the 5-year survival rate of patients receiving life-prolonging and/or palliative treatment is only 3% (DLCG, 2020). Thus, surgery is crucial to patients' survival.

However, research shows that lung cancer surgery is associated with physical and psychosocial challenges; lung cancer patients have

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one of the highest levels of emotional distress among all cancer types (Bergerot et al., 2021; Carlson et al., 2019). In lung cancer surgery patients, pain, lack of energy, shortness of breath, drowsiness and worrying increased significantly in the first month after surgery and then decreased over time (Oksholm et al., 2015), indicating that the time around surgery is a particularly difficult period. There is sparse qualitative research on patients with operable lung cancer. Existing research shows that patients experience various challenges and unmet needs. Missel et al. (2015) found that patients' cancer diagnosis came as a shock that was difficult to grasp. Furthermore, patients expressed a need for a dialogue with clinicians to articulate their new situation, thoughts and concerns (Missel et al., 2015, 2016). In addition, Kyte et al. (2019) found that patients experienced an unexpected symptom burden, struggled to receive necessary support and were not heard. Several studies confirm that patients and clinicians have limited dialogues about illness and treatment and that psychosocial needs and challenges are rarely addressed (Golden, Thomas, Deffebach, et al., 2016; Golden, Thomas, Moghanaki, & Slatore, 2016; Rankin et al., 2018). Hill et al. (2003) interviewed patients recently diagnosed with lung cancer, finding that less than half of their concerns were addressed in dialogues with clinicians and that physical symptoms were addressed more frequently than psychosocial issues, even though patients found the latter more important. There would thus seem to be inadequate dialogues of illness, worries and concerns between clinicians and lung cancer surgery patients.

There is little research exploring how patients with lung cancer and clinicians engage in dialogue about illness and treatment. One study by Johnson et al. (2018) found that lung cancer is described in positive terms with an emphasis on hope; surgeons found it essential to deliver information in an optimistic way, even when the information was not particularly good. There is a paradox in the experiences described by lung cancer patients, where a high prevalence of emotional distress and physical and psychosocial challenges contrasts with an unmet need for support from clinicians, who tend to present the disease in a positive light. This study attempts to investigate this paradox by adopting a narrative approach in exploring dominant narratives about operable lung cancer. Accordingly, the research question guiding this study is: *What narrative(s) about operable lung cancer are dominant in the surgical treatment trajectory?*

## 2 | METHODS

### 2.1 | Study design and setting

The author conducted ethnographic fieldwork inspired by narrative ethnography. Of particular interest was *narrative practice*, meaning stories as they are being put together in social interactions in a specific context (Gubrium & Holstein, 2008). The setting was a Danish hospital offering surgical treatment for lung cancer. Participants were patients with a histologically confirmed diagnosis of NSCLC and were selected using purposive sampling (Crabtree & Miller, 1999). This was to ensure a wide range of patients with lung cancer in terms of age,

**TABLE 1** Inclusion criteria

Inclusion	Adults over 18 years of age Diagnosed with NSCLC Referred to surgical treatment Able to speak and understand Danish Able to consent
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**TABLE 2** Patient characteristics

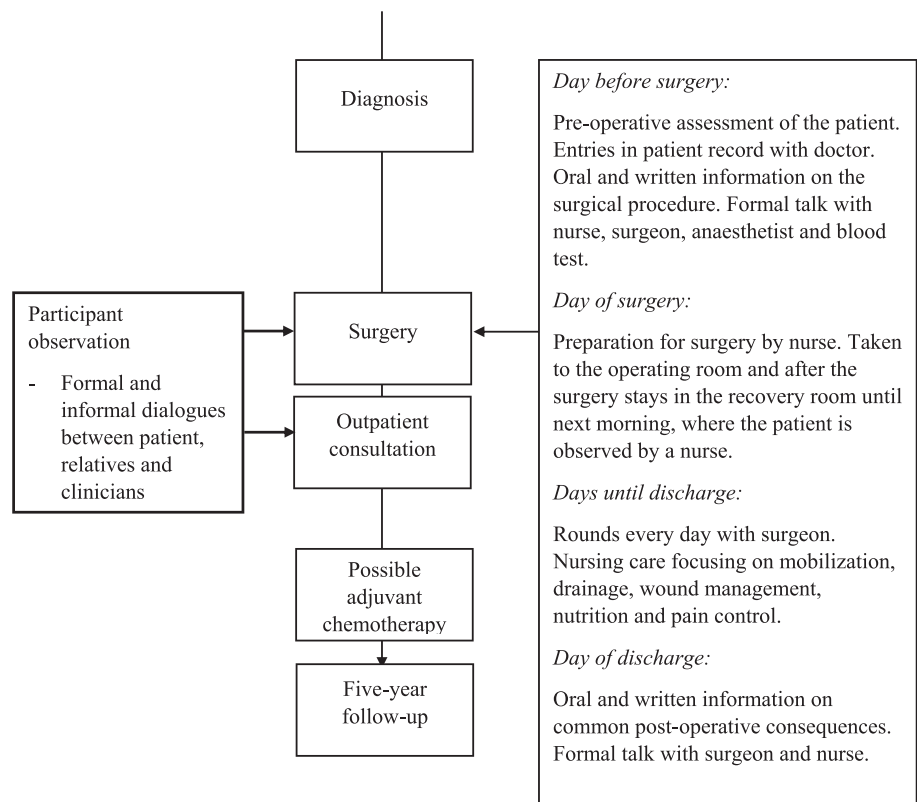
Demographic and medical characteristics of the study population (n = 10)		
Gender	Male	4
	Female	6
Mean age (range)		69 (52–85)
Marital status/cohabiting	Married/permanent relationship	6
	Single/divorced/widowed	4
Employment status	Full-time employment	3
	Retired	7
Cancer stage	IA	2
	IIA	1
	IIIA	2
	IB	1
	IIB	3
	Metastatic disease	1
Days of admission for surgery, median (range)		4 ½ (3–22)
Adjuvant chemotherapy	Yes	3
	No	6
	Recommended, but patient refused	1
Surgical procedure	Video-assisted thoracoscopic surgery	10

sex and cancer stage. A secretary, not otherwise involved in the study, approached eligible patients during admission for surgery using predetermined inclusion criteria (Table 1). From September 2019 to March 2020, ten patients were recruited (Table 2). The study adhered to the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

### 2.2 | Theoretical perspective

This study's theoretical perspective views narratives as stories produced in interactions, called 'small stories' (Bamberg, 2006). 'Small stories' are a preferred theoretical basis for exploring narratives about ongoing events (Bamberg & Georgakopoulou, 2008), here the diagnosis and treatment of lung cancer as it is produced and unfolded in patient–clinician interactions. The 'small stories' approach

**FIGURE 1** Illustration of treatment trajectory and occasions of observation



acknowledge the situated nature of narrating. This perspective inspired the methodological approach with data collection focusing on narrative practice, but also data analysis, focusing on analysing 'small stories' with many different people's voices producing the narratives. The concept of narratives and stories is used interchangeably in this paper.

### 2.3 | Data collection and analysis

The fieldwork focused on narratives in interactions between patient, relatives, clinicians and the researcher. The term 'clinicians' is used as an overall term, but when presenting data, the profession of the clinicians is made explicit. Formal and informal dialogues were observed and field notes taken during observation or soon afterwards, aiming to reproduce both words and context (Emerson et al., 2020). Patients were observed one at a time and followed from their pre-operative assessment to post-operative care and discharge (Figure 1).

Thematic narrative analysis (Riessman, 2008) was used, focusing on the content in order to answer the research question *What narrative(s) about operable lung cancer are dominant in the surgical treatment trajectory?* In thematic narrative analysis, the narratives are kept intact in the analytical process (Riessman, 2008), but the excerpts presented in the results section of this article should be viewed as a part of a larger narrative. The analytical process consisted of identifying the dominant narrative themes and subthemes by reading each patient's narrative as a whole. After this, the

narratives were read across the patient trajectories to clarify overall dominant themes in the data. During the analysis, data and findings were discussed in two workshops with three other researchers not otherwise involved in the study, in order to ensure trustworthiness. The results section contains selected empirical excerpts, which should be seen as exemplifying the theme presented. The discussion introduces sociological narrative theory, describing three culturally available types of illness narratives, namely *Restitution*, *Chaos* and *Quest* (Frank, 2013) (Table 3). By drawing on this narrative theoretical framework, the aim is to discuss the derived consequences of the results and to ensure transferability.

### 2.4 | Ethical considerations

The study was approved by the research ethics committee at the institution where the study was affiliated and was conducted in accordance with the Helsinki II Declaration. All participants, patients, relatives and clinicians, were given oral and written study information before giving their consent. Patients provided written consent, since the data contained personal information. All names are pseudonyms and identifiable information was anonymised.

## 3 | RESULTS: 'BEING LUCKY'

*The nurse says good morning to Gitte, a 70-year-old woman who underwent surgery for lung cancer*

TABLE 3 Illustrations of three types of illness narratives

Restitution	Chaos	Quest
<p>'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (Frank, 2013, p. 76)</p> <p>These narratives are about a process from being healthy, through sickness and back to healthy again. The desire in these narratives is to have health restored again, but it has limited narrative possibilities as the patients perspective are rarely present (Frank, 1994, 2013).</p>	<p>'Life never getting better' (Frank, 2013, p. 97)</p> <p>These narratives reveal vulnerability, futility and impotence. May be viewed as 'anti-narrative'. Attention to chaos narratives is to listen to what cannot be said (Frank, 1994, 2013).</p>	<p>'Illness as journey' (Frank, 2013, p. 116)</p> <p>These narratives are about viewing illness as useful. Suffering is recognised and understood as something that can gain insight and meaning (Frank, 1994, 2013).</p>

yesterday, and leaves the ward to get a bandage. Gitte is in bed with her eyes open. There is silence. After a while she says to the researcher: 'I was in a research study called "A long life" and at first just had some blood tests. Then I was offered a scan. Then they found this on the scan'. The nurse comes back. Gitte repeats: 'Yes, I was scanned for "A long life," and then they found this'. The nurse says: 'You're lucky they discovered it so it could be operated. That's not always possible'. Gitte answers: 'Yes, that's right'. Then the nurse asks if Gitte is in pain and explains something about her drainage. (Field notes, Gitte)

This situation shows how short interactions can produce narratives of 'being lucky' among patients with operable lung cancer. In order to illuminate what this overarching theme consists of, and what it is related to, three narrative subthemes will be presented. Each subtheme is related to a different element of the treatment trajectory: the diagnosis is 'like winning the lottery' because surgery is possible, the surgical treatment is 'a quiet day at the office', and there is 'good news' at the outpatient clinic even if the patient needs adjuvant chemotherapy.

### 3.1 | 'Being lucky' because the possibility of surgical treatment is 'like winning the lottery'

Most patients in this study were diagnosed with lung cancer without knowing that they were ill. In many cases, both clinician and patient said that the cancer was found 'just by chance', as in the situation above with Gitte and in the following situation with Lone. The dialogue is between Lone, her husband and the researcher the day before Lone's surgery.

The researcher: 'It did not sound like you had symptoms of lung cancer'. Lone replies: 'No, I just had this lump of fat on my back, and as it was a bit too big to examine from the outside, they did a scan, and then I was called in for another scan and then things happened

quickly'. Lone's husband interrupts: 'But it's like winning the lottery' and looks at the researcher seriously. Lone continues: 'My sister died of lung cancer four years ago. It was also discovered by chance, but unfortunately it had spread. So of course that's in the back of my mind'. The researcher: 'I can easily understand that it feels like winning the lottery, but it's a rather unusual lottery'. Lone's husband says: 'It is like winning the lottery, it's the biggest prize'. He laughs, but still in the same serious way. (Field notes, Lone)

Winning the lottery is very much related to the narrative of 'being lucky'. It is entirely random, just as in Lone's story about her sister. There the cancer was also discovered by chance, but it had spread and she could not be cured. Therefore, Lone's possibility to be cured is like winning the lottery and 'the biggest prize', as her husband says, is life. This theme of 'being lucky' is related to possible surgery as curative treatment. Lone won the lottery because she can be cured, which illustrates the preferred way of talking about illness found in this study, namely highlighting the possibility of survival. Nevertheless, having her sister's illness and death in the back of her mind strongly emphasises that Lone is lucky. Many other patients in this study refer to relatives or friends that have died of cancer when they talk about their own illness. An example is Harald, who spontaneously begins to talk about his wife the night before his surgery when the nurse is preparing him for surgery. Harald: *My wife was also in this hospital five years ago. She had intestinal cancer. It was around Christmas time. I told her to go to the doctor, but the doctor would not listen, so the cancer was found too late and she died.* References to relatives who were in worse situations further reinforce the narrative of being lucky, which shows how this dominant narrative is strongly affected by other cancer narratives.

### 3.2 | 'Being lucky' because surgical treatment is like 'a quiet day at the office'

The patients were told about their operation by a surgeon the day before. The field observations revealed that the surgeon provides

information, while the patient and any relatives mostly listen. The narratives are thus highly influenced by the surgeon's words, while the patients are mostly silent. In the following dialogue on the ward, Ole says nothing, while his wife has a few questions. Ole has previously had the same operation for another lung disease.

*The surgeon explains what happens before, during and after surgery and then says: 'As I like to say, it's like a quiet day at the office. Everything will be nice and easy. When you go home, after 14 days you'll come to our outpatient clinic to see if there was anything in your lymph nodes. I do not expect anything. Then we'll also talk about chemotherapy'. Ole stares widely and very intensely at the surgeon. He changes from being attentive to almost looking frightened. The surgeon adds: 'Almost everyone has chemotherapy. It's fine. It's a different chemotherapy. It's preventative, so it cannot be compared to chemotherapy when there's active cancer'. The surgeon and Ole's wife discuss which hospital will give Ole chemotherapy, and then the surgeon sums up: 'But as I said, I expect things to be nice and easy tomorrow'. (Field notes, Ole)*

The surgeon's description of Ole's operation as 'a quiet day at the office' indicates that he sees it as straightforward and probably successful. This is the main narrative in this conversation about lung cancer surgery. The narrative is centred on the treatment, not the patients' possible concerns. We see this in the dialogue with Ole, where the surgeon tells Ole what will happen, but does not explore how Ole feels about his situation. Similarly, Gitte's situation is presented as 'lucky', but the nurse does not ask for Gitte's view. The surgeon's description of the surgery as 'a quiet day at the office' suggests complete control over the situation. Several surgeons also mentioned their extensive surgical experience with remarks such as 'I do this type of operation every day', thus producing a narrative that surgery is a normal, everyday matter. Ole is invited to become part of the surgeon's narrative that his operation will be like 'a quiet day at the office'. Several of the dialogues noted during such interactions mention possible chemotherapy. Ole is clearly affected by this; he says nothing, but his facial expression and body language change dramatically. Ole's non-verbal response receives a kind of reply when the surgeon plays down the treatment: 'Almost everyone has chemotherapy. It's fine'. Such dialogues produce a narrative that patients soon recover from surgery and if chemotherapy is needed, most people have it and it is also 'fine'. Thereby Ole is left alone with his bodily and non-verbal narrative about chemotherapy as something that worries him.

### 3.3 | 'Being lucky' because of 'good news' at the outpatient consultation

Patients have a consultation at the outpatient clinic about 2 weeks after surgery. At this crucial consultation, patients are either told that

they have completed treatment and only need check-ups or that they need adjuvant chemotherapy or further treatment. The consultation is set to last about 10 min, and patients mostly have their relatives with them. A dominant narrative here is 'good news', irrespective of any need for adjuvant chemotherapy, as long as the surgery was successful. Ejner has arrived at the clinic with his wife Gerda.

*Surgeon: 'What we removed during surgery was sent off for examination, which shows that it's lung cancer, which we knew. We removed lymph nodes around the lobe, and there was no cancer. That's crucial. So we have removed everything. Inside the lobe there are also lymph nodes and there was one with cancer. So you need chemotherapy, that's the way it is. It's preventative treatment'. Ejner and his wife sit opposite the surgeon looking intently at him, and his wife asks: 'Isn't chemotherapy very unpleasant?' Surgeon: 'Chemotherapy is many things. If it's an active cancer, then chemotherapy is a tough treatment, but this is preventative. You could say it's a kind of safety net for you. But of course chemotherapy is not a walk in the park'. There is a short pause. Surgeon: 'That's good news for the weekend'. After another short pause, Ejner's wife asks: 'I heard some people get it in a drip?' Surgeon: 'I do not think so. The disease has been removed now, chemotherapy is just to be 100% sure'. Ejner's wife: 'Yes, now it's gone and has not spread'. Ejner sits looking at the floor. Wife: 'Well, that's good news. Great that you do not have to lie down with a drip'. (Field notes, Ejner)*

Here Ejner learns that he will be referred for chemotherapy. The surgeon calls the chemotherapy 'preventative' and says 'we have removed everything'. It is therefore 'good news for the weekend', as the surgeon puts it. Ejner's wife later also uses the expression 'good news' about Ejner not needing a drip, thus focusing on a positive aspect of a difficult situation. This dialogue shows that although Ejner needs chemotherapy, a narrative is produced that this is 'good news' because the cancer has not spread. However, his wife challenges this narrative to begin with and suggests it is unpleasant to have chemotherapy, thus trying to create a more nuanced narrative, where not everything is 'good news'. The surgeon calls it 'a safety net' but also 'of course, not a walk in the park'. However, the surgeon attempts to focus on the positive aspects, namely that 'we have removed everything'. In contrast to Ejner's consultation, some patients are told that they do not need more treatment and will be referred to check-ups for 5 years. Here, it is often mentioned that they are 'cured', as Inge is told by the surgeon: 'We did not find any cancer in the lymph nodes. That means no chemotherapy, no radiation, so I'd say you are cured'. But later in the consultation the surgeon says: 'But a long life has taught me I cannot promise anything'. This is thus a narrative of being cured with a hint of uncertainty. Such uncertainty does not have a dominant role in the dialogues in these consultations. No patients in the observations mention worries

about relapse, and only a few surgeons, like Inge's surgeon, hint that there is no assurance that the lung cancer will not return. However, Ole's non-verbal reaction to possible chemotherapy and Ejner's wife's various questions may indicate that concerns and worries are present.

## 4 | DISCUSSION

This study showed that 'being lucky' was an overarching dominant narrative of operable lung cancer. The analysis argued that this narrative was related to the possibility of surgery and thereby potential cure. This was supported by different subthemes that all focused on treatment as a good and minor interference in the patient's life. In this section, these results will be discussed to illuminate the possible consequences of the 'being lucky' narrative by drawing on narrative theory highlighting three types of narratives (Table 3) as well as previous research.

According to Frank's narrative theory, the culturally preferred way of talking about illness is to create restitution narratives. These narratives focus on restoring health, while sickness is seen as a minor interruption. Consequently, 'Medicine's hope of restitution crowds out any other stories' (Frank, 2013, p. 83). The overarching narrative theme of 'being lucky' can be viewed as a restitution narrative because of its focus on cure. Further, the analysis revealed that this theme was maintained by highlighting surgery as the best thing that could happen in this situation, most prominently through the sub-theme of 'winning the lottery'. In this theme, another essence of restitution narrative emerges, namely, the patient's passive role and the clinicians' active role. Describing the patients' situation as 'winning the lottery' clarifies that patients cannot control the situation, just as no one can control a lottery, and patients thus become passive. The only active party is the clinicians, since they have the skill and responsibility to cure the patient. In Frank's words this means that the patient becomes 'a mute object' (Frank, 1994, p. 6) or as the analysis shows, constrained in ways of talking about treatment that do not focus on medical treatment and cure. The analysis shows that such alternative ways of talking about illness are only expressed non-verbally, as in Ole's situation when the surgeon talks about chemotherapy. However, since the context of this study is a hospital ward where the treatment of patients with operable lung cancer aims to cure them, it is not surprising that restitution narratives dominate. Paradoxically, Salander et al. (2014), in their qualitative study about living with incurable lung cancer, find that even in the case of incurable lung cancer, treatment was idealised as possibly leading to a cure. This might suggest that restitution narratives are not only dominant where cure is possible.

So how can we understand why the restitution narrative of 'being lucky' dominates? As mentioned in the introduction, a study by Johnson et al. (2018) found that surgeons wanted to boost patients' hopes with an optimistic message, even when the prognosis was rather poor. The desire to induce hope and downplay illness and treatment is similarly found in the present study when the

surgeon call surgery 'a quiet day at the office' and adjuvant chemotherapy is deemphasised by calling information at the outpatient clinic 'good news'. One could say that these themes present patients with a way of viewing their illness without giving them time to talk about it in other ways. They are invited to be part of the clinicians' narrative where illness is seen as a minor interference. Also, if the surgeon calls an operation 'a quiet day at the office' or uses the expression 'good news' about chemotherapy, it may be difficult for the patient to create a counter narrative and talk about worries and concerns. Drawing on Frank's theory of three types of illness narratives, we could say that Ole's and Ejner's situations are examples of a *chaos* narrative. In these narratives no one has control, and as Frank points out, it is difficult to put chaos narratives into words (Frank, 2013). The analytical point about neglected chaos narratives of worries and concerns is supported by several studies that show how patients' psychosocial concerns are not addressed in dialogues with clinicians (Sjödén, 2000; Thisted et al., 2020). Prip et al. (2019) support this, since their study of clinician-patient communication in an oncology clinic indicates that communication is centred on the treatment, not the patients' concerns. Another study also found that patients who undergo gynaecological cancer surgery repressed their own wishes during hospitalisation since the clinicians tended to refer to gynaecological cancer surgery as 'a minor issue' (Thisted et al., 2020). Consequently, they felt alone and lacked support from the healthcare system because they will be 'quickly fixed and cured' (Thisted et al., 2020), which is similar to the findings in this study.

This study revealed no signs of Frank's third type of narrative called *quest*. The quest narrative is characterised by accepting the illness and using it to gain something (Frank, 2013). This may be due to the limited time span of the patients' illness trajectory that this study focuses on. However, the interesting point about the absence of quest stories in this study is that these, according to Frank, speak from the ill person's perspective (Frank, 2013). The lack of the patients' perspective is supported further by the fact that 'being lucky' is a restitution narrative where the patient is the passive recipient. In this way, by adopting Frank's theory of three types of illness narratives, this discussion has shown that the patient perspective regarding worries and concerns is silenced in the dominant restitution narrative about operable lung cancer.

### 4.1 | Methodological considerations

The study's ethnographic method combined with the 'small stories' approach are seen as a strength. This enhanced the possibility of attention to important dialogues not otherwise made visible. However, the author has previously been employed at the study setting which could be a limitation because of the influence of pre-existing perceptions. As a way to address this issue, workshops were implemented. The workshops could further have benefitted from participations of patients, relatives and clinicians. This could have nuanced the findings further.

## 5 | CONCLUSION

The study shows that 'being lucky' is a dominant narrative about operable lung cancer and is supported by three narrative sub-themes, all of which focus on making light of lung cancer treatment and emphasising cure. Furthermore, this dominant narrative about 'being lucky' is a restitution narrative. A predominance of restitution narratives implies that clinicians are the active party, while the patient remains passive, which leaves no room for any concerns that the patient may have and thus complicates the inclusion of the patient perspective on illness and treatment.

### 5.1 | Clinical implications

Clinicians should be aware of the powerful narratives they use in dialogues with patients and relatives and make sure that patients' concerns and worries can be addressed. This requires an openness to the patients' perspective and for the clinicians to engage in dialogues with patients and relatives about illness, and not only in a perspective of restitution but also dialogues about psychosocial challenges, worries and concerns.

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### CONFLICT OF INTEREST

I, the author, declare no conflict of interest to report.

### DATA AVAILABILITY STATEMENT

Research data are not shared, due to ethical restrictions.

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