Discussing potential recurrence after lung cancer surgery: uncertainties and challenges

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# Discussing potential recurrence after lung cancer surgery: uncertainties and challenges

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# Discussing potential recurrence after lung cancer surgery: uncertainties and challenges

## Abstract

Patients with lung cancer who undergo surgery may potentially be cured. The resulting pathological staging gives an indication of 5-year survival and whether further treatment is recommended. To date, there is little research evidence regarding the way potential recurrence is communicated to patients by staff. This qualitative research used case studies to explore how information disclosure about possible recurrence was managed following lung cancer surgery and aimed to identify practice implications for clinical teams. Twelve patients were recruited and first post-operative surgical and subsequent oncology or follow-up consultations were recorded and transcribed. The perspective of the professionals involved in these clinics was ascertained through 30 in-depth interviews. Key themes in the data were identified using Framework Analysis. Recurrence risk was communicated to patients in a number of ways and levels of clarity and openness. Information provided by participants about early warning signs of recurrence varied. Findings indicate information provided was linked to the patient's prognosis and individual professionals' underlying communication approach. This study provides a unique insight into the views of lung cancer specialists regarding information disclosure and reveals the challenging nature and complexity of discussing recurrence following lung cancer surgery.

## Introduction

For patients who have a lung cancer that is amenable to surgery, having an operation is often seen as offering hope of a cure (Powell et al., 2015). Recent international survival data indicates that five-year survival for patients diagnosed with stage 1A lung cancer is 83%, while those diagnosed with a stage 3A cancer is 36% (Goldstraw et al., 2016). Dealing with the possibility of cancer recurrence can be a day-to-day reality following treatment. How this reality is presented and discussed with patients and how they are supported following surgery is therefore of clinical importance.

Patients are offered surgery based on clinical stage of the lung cancer as well as overall fitness for surgery (National Collaborating Centre for Cancer, 2011). Patients who have surgery will have a definitive pathological staging as a result of analysis of the whole tumour and associated lymph node samples. Depending on this staging, patients may or may not be offered adjuvant treatment (Lim et al., 2010). Meta-analyses of trials suggest that adjuvant chemotherapy can add around 4% improvement in absolute survival at 5 years (NSCLC Meta-analysis Collaborative Group, 2010). Following surgery and any adjuvant treatment, patients undergo a period of regular surveillance, typically over a period of five years. There is lack of consensus on the most effective strategy and frequency for following up patients after surgery (Schmidt-Hansen, Baldwin, & Hasler, 2012).

Patients generally consider the consultation following surgery to be very significant, representing a transition from one phase of their illness to another

(Thorne & Stajduhar, 2012).  Such transitions create challenges, particularly regarding communicating potential risk of recurrence. Patients' preferences for information may vary; while some patients may find discussion of potential recurrence very challenging, or even irrelevant, some patients may also see it as an essential element of their information needs (Thorne & Stajduhar, 2012). Patients may use this information for various reasons, including decision-making about further treatment, managing inherent uncertainty, or gaining a sense of control over their illness (Thorne, Hislop, Kuo, & Armstrong, 2006). Current national and international guidelines on communication with patients suggest that patients should be empowered to take a shared role in decision-making about their care (National Cancer Taskforce, 2015). However, British Thoracic Society guidelines urge caution when discussing definitive lung cancer prognosis and stage, due to the complexities and the potential for questions patients may not be emotionally equipped to deal with (British Thoracic Society, 2013). Such divergences in guidelines can create a dilemma for practitioners.

Prognostic communication can have an impact on patients' sense of hope, both positively and negatively (Thorne, Oglov, Armstrong, & Hislop, 2007).  Two published reviews have explored prognostic communication in the wider cancer population (Hagerty, Butow, Ellis, Dimitry, & Tattersall, 2005; Johnson, Tod, Brummell, & Collins, 2015). Much of the evidence on prognostic communication has focused on the breast cancer population. Clinicians may convey a sense of optimism for cure following surgery, despite the inherent risk of recurrence in the future (Step & Ray, 2011). Furthermore, studies of post-surgical clinics suggested that goals for communication for both patients and clinicians were to

facilitate hope (Mendick, Young, Holcombe, & Salmon, 2011). While clinicians gave some biomedical information in all consultations, hope was conveyed by positive evaluations of prognosis and further treatment. Where prognosis was poorer, clinicians focused more on factual biomedical information and positive evaluation was limited to factors such as surgical recovery (Mendick, Young, Holcombe, & Salmon, 2013). In this way, hope was maintained by focusing on things other than long-term outcome.

Prognostic forecasting is inherently imprecise and uncertain. Uncertainty also arises from the unpredictability of events for an individual patient. Individuals are prone to the "*irreducible randomness and indeterminacy of natural events*" (Han, Klein, & Arora, 2011, p832). Managing and communicating uncertainty and risk can be challenging particularly in high stakes situations such as discussing recurrence risk after lung cancer surgery.  Patients and professionals may have differing beliefs and understanding of these aspects of uncertainty. This can lead to very different attitudes when seeking or delivering information and the values attached to information based on statistics. Moreover, people can struggle to interpret statistical and population based information in relation to individualised risk (Han et al., 2009; Powell et al., 2015). Patients' subjective and emotional response to such information forms an intrinsic, and often dominant, part of patients' understanding of their situation (Zikmund-Fisher, Fagerlin, & Ubel, 2010).

Reyna, (2012) describes two different mental representations of information presented to patients: 'verbatim' and 'gist' memory. Gist memory focuses only on

'fuzzy' detail and incorporates the subjective, emotional and psychological elements to create meaning. This works in parallel with the exact recall of verbatim memory. People have a preference for encoding meaning at the gist level, but seek further detail if and when they consider it necessary (Reyna, Nelson, Han, & Pignone, 2015). In the context of recurrence risk communication, it is likely that most patients will take away only a stripped-down impression of the information they are given. However, when provided with numerical information, this can become particularly poignant and memorable for patients with cancer (Thorne et al., 2006). Hence statistical information presented during consultations may be recalled, but the context lost, leading to its implications being misconstrued.

Risk constructs can be presented in many different formats and range from implicit information to specific probabilities. Different formats will be better suited to conveying risk in different situations (Zikmund-Fisher, 2013). The key distinctions lie between presenting the possibility that an event can happen, thus avoiding any precision, and giving probability estimations, detailing risk with more precision by using numbers. Different levels of detail can be conveyed by placing these risks in context; by comparing with other situations and by presenting risk in relation to particular circumstances or choices. Use of these different forms of risk communication tailors risk information to the level of specificity perceived as appropriate to the situation.

There is a paucity of research that examines the specific issues around communication and disclosure of possible recurrence for patients with lung

cancer following surgery. This qualitative study aimed to partly address the evidence gap.  It explored how information regarding possible recurrence was presented to patients and to gain insight into the way in which professionals manage this process in lung cancer clinical practice.  The specific study objectives were to:

- Identify what information is given to patients regarding the long-term risk of lung cancer recurrence and/or survival after surgery
- Identify who gives this information.
- Explore the perceptions of different professionals regarding their role when discussing long-term risk of recurrence or survival after lung cancer surgery, including how they discriminate what information to disclose.

## Methods

Due to the exploratory nature of this research it was important to gain an in-depth understanding of the way in which the subject of potential recurrence was managed, both by clinical teams and by patients and to examine underpinning attitudes and decisions. Therefore a qualitative research approach was taken (Ritchie, Lewis, McNaughton Nichols, & Ormston, 2014). Case study methodology provided a mechanism to explore communication of recurrence over time and in clinic settings (Yin, 2014). The post-surgical clinic is usually where the pathology results are first presented to the patient and was taken as the starting point of the study. Formal research ethics committee approval was gained (reference 15/LO/1183).

## Sample identification and recruitment method

Patients in the study were referred to two UK specialist thoracic surgery units from three, secondary care local lung cancer multidisciplinary teams (MDT). The study was conducted at the surgical units and at the local lung cancer hospitals. Figure 1 outlines the sample recruitment and data collection points in the study. Lung cancer nurse specialists (LCNS) based at the surgical centres, not otherwise involved in the study, identified potential patients while admitted for their surgery using predetermined inclusion/exclusion criteria (see box 1). Purposive sampling was used to identify a wide range of lung cancer patients in terms of age, stage and previous health experience, all undergoing potentially curative surgery, in line with the qualitative methods used. Written consent was obtained from patients and staff members involved in the study.

## Sample size

Twelve patients were recruited and formed the cases of the study. A total of 20 health professionals were involved in the observed consultations with these patients and were recruited to the study. They consisted of eight surgeons (four consultants, four registrars; three female, five male), four oncologists (all consultants; two male, two female), two chest physicians (both consultants, one male one female) and six LCNS (all female). If professionals saw more than one study patient they were interviewed for each occasion. In total, 30 interviews were conducted across the 20 health professional participants (see table 1 for details of the patient cases and the clinical staff involved).

Ideally recruitment should continue until data saturation has been achieved across all themes. In reality this was a challenge due to the limited number of oncologists and professionals undertaking follow-up within each MDT pathway. However, the sample did contain a wide range of experience from both the patient and professional perspective (Baker & Edwards, 2012; Hennink, Kaiser, & Marconi, 2017).

### Data collection

Observation of the first post-operative surgical and subsequent oncology or follow-up clinics were conducted. All patients attended a post-operative surgical clinic. Depending on the practice of the MDT, patients were seen either at the thoracic unit, or at the local lung cancer hospital. Six patients were referred for consideration of adjuvant therapy and were seen locally in an oncology assessment clinic. Six other patients were referred for follow-up care with their local lung cancer team and the first appointment was observed. The researcher (MJ) attended clinics as a participant observer with the patient. All consultations were audio recorded, transcribed and written notes taken.  Surgical clinics lasted an average of 17 minutes (range 7 – 31 minutes). Oncology clinics lasted an average of 39 minutes (range 19 – 48 minutes) and follow-up clinics an average of 24 minutes (range 7 – 43 minutes).

One-to-one interviews were completed with the surgeon, oncologist, chest physician and or LCNS who saw the patients in the clinics to ascertain their perspective and understand rationale for particular information giving.

Interviews took place as soon as possible after the clinic by one researcher (MJ), following a semi-structured topic guide (Tod, 2013). (Interview topic guide: see box 2). Interviews lasted an average of 30 minutes (range 10 – 60 minutes).

### Data analysis

Clinic consultations and interviews were transcribed verbatim. Observational comments and field notes were added to the transcripts for inclusion in the analysis. Framework Analysis was used (Ritchie et al., 2014). This involved a process of data familiarisation and development of an initial descriptive coding schema. Other members of the research team (AT, KC & SB) reviewed a number of these transcripts for coding consistency and validity of the themes. An initial thematic framework was developed and an iterative process of applying the thematic framework, modifying and re-applying, facilitated its development to achieve the best possible fit with the data. The computer assisted qualitative data analysis tool, NVivo 10 (QSR International Pty Ltd 2014), was used to index and sort the data by applying the final thematic framework (Silver & Lewins, 2014). Matrices were constructed, allowing data to be visualised and analysed across and within cases (Ritchie et al., 2014). Abstraction and interpretation of the data was facilitated by further analysis of groups of themes to identify linkages and patterns in the data.

## Results

Findings from clinic observations and professional interviews were combined and presented below. Three key themes were identified in this data. The first theme **The range of the risk of recurrence information** was divided into three

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sub-themes; ***Probability versus possibility***, ***Effect of prognosis on risk of recurrence information*** and ***Uncertainty challenges***. The second theme explored **Discussing early warning signs of recurrence**. The final theme explored professionals **Getting the balance right** for patients.  Excerpts from the original data are presented throughout to illustrate the findings.

### Theme 1: The range of risk of recurrence information

Information presented regarding risk of lung cancer recurrence was given in a range of ways. Recurrence was discussed in relation to surgical findings, the potential role of adjuvant treatment, follow-up and surveillance and the recognition of early signs of recurrence. Recurrence information was identified in the clinic transcripts and classified according to risk communication typologies closely based on those derived by Zikmund-Fisher (2013). Examples taken from the clinic transcriptions for each typology are displayed in table 2. The most explicit form of recurrence information was classified for each encounter and displayed in table 3. Cases were grouped into patients who were perceived by their surgeon to have a relatively "good prognosis" and patients with poorer prognosis, labelled "intermediate prognosis".

### *Probability vs possibility*

Information was given in a range of ways, from using vague 'implicit possibility' of recurrence, to giving 'absolute probability' of recurrence or 5-year survival (See table 2 for examples). One surgeon explained why he felt the survival statistics should be given routinely to patients, both as part of the surgical

informed consent process, and as part of discussing the post-operative surgical outcome.

> *"I would try and give the number every time I have it. Because we have that information available for each stage of the cancer, each type of the cancer, given the fitness. Although we do not have very reliable predictors for the morbidity, we do have [...] very strong available evidence in terms of five-year survival for a given stage."* [Surgeon 8 interview about Patient 11]

Other staff avoided giving numbers to patients unless patients 'pushed' for this, or even avoided giving this sort of information at all. Professionals gave a range of reasons during the interviews. Staff identified the problem of applying population statistics to individual patients.

> *"[...] although we've got good population statistics, really what matters to the individual patient is what's going to happen to them, and obviously she's either going to live or die and unfortunately we really can't tell.  So unless somebody is pushing, I tend not to give a lot of figures about five-year survival because we genuinely don't know which side of that they're going to come down on."* [Oncologist 1 interview about Patient 1]

Some staff talked about the difficulties patients had interpreting this sort of data, leading to an increased risk of misunderstanding and raising anxiety.

> *"I think they can get so bombarded by statistics and a lack of clarity about it that they can end up coming away from the consultation not sure whether they have made the right decision or not."* [LCNS 3 interview about Patient 5]

Others highlighted the potential to damage patients' hope.

*"So if I tell him now in five years [he] might be dead or [he] might be alive 50/50. How do you think it's going to impact his psychology? […] I remember him when he went home; he was more depressed and unwell looking. Now when he came [to clinic today] he said, 'I'm feeling good'. And that keeps you alive." [Surgeon 6 interview about Patient 10]*

Findings showed a wide range of strongly held views amongst clinical staff about offering assessments of prognosis to patients, which clearly influenced their practice.

### *Effect of prognosis on risk of recurrence information*

Where staff perceived a good prognosis patients were told about their good outcome from surgery.

*"[…] for the patients who perhaps come back and their histology is good in terms of staging and in terms of complete resection, then I make that very clear in the consultation and I'll often sort of say, you know, the points to take away are that it was early lung cancer, that we've got it all out, and that at this stage we don't need any further treatment. So I think it's important that, if that's the case, that people go away feeling […] that it was all worthwhile […]." [Surgeon 4 interview about Patient 6]*

Consultations differed as to how much this was explicitly flagged as good news, but patients were all told further treatment was not required. With the exception of Patient 11, who had already been given this information by the surgeon, patients went on to ask about cancer recurrence. However, not all patients

received answers in terms of probability. Questions were mainly answered with 'categorical possibility', such as "*the risk is very low*", or *"it is unlikely".* In contrast with the surgical clinics, in the follow-up clinics recurrence was frequently not discussed, or only implied in discussion about on-going monitoring.

Despite wishing to convey certainty about the future to patients, staff were cautious about the concept of cure.

> *"[...] people want to hear the cure word or use the cure word and we tread very carefully with that generally, or those of us that work in lung cancer for long enough." [LCNS 4 interview about Patient 6]*

Staff talked about there being no guarantee of cure and this concept was used during clinics.

> **Surgeon 2:** *It is unlikely, but we cannot say one hundred per cent that you won't have a reoccurrence again. [Surgical clinic transcript Patient 4]*

Patients with a less favourable prognosis were seen as more of a communication challenge.

> *"I think it becomes really difficult when you have anything more than your stage 1 cancer. Anything in between stage 4 and stage 1 becomes a difficult discussion because now you're not dealing with good numbers or terrible numbers, it's somewhere in between [...]." [Surgeon 5 interview about Patient 9]*

For patients with an intermediate prognosis, surgeons presented factual biomedical information such tumour size, or lymph node involvement. Where

cancer recurrence was specifically mentioned, this was in terms of possibility, or implied by talking about referral to an oncologist. Only one patient in this group asked any questions about recurrence. Staff presented an ambiguous situation and avoided discussion of any negative survival statistics. Staff emphasised hope in less factual terms.

*"I'm trying, when I'm explaining to him, to say that the glass is not half empty, but half full, you know what I mean? I'm saying to them yes, you are getting lung cancer. But. Always but." [Surgeon 3 interview about Patient 5]*

Oncologists used discussion of possible cancer recurrence with all the patients referred to them as lead-in and context for introducing potential further treatment. However, discussions about recurrence were presented in terms of possibility rather than probability. Oncologists sometimes used 'comparative possibility' of recurrence to explain the rationale for chemotherapy.

***Oncologist 1:*** *[...] when it has travelled to the lymph nodes, unfortunately it does mean that it is a bit more likely to flare up in the future. Because it has proven its ability to travel from one part to another [...]. [Patient 8 oncology clinic transcript]*

Oncologists discussed benefit of adjuvant treatment with the patients referred to them in terms of survival advantage or reducing recurrence with adjuvant therapy. Several patients were given an 'incremental probability', indicating the increase in 5-year survival with chemotherapy, based on results of clinical trials.

***Oncologist 1:*** *Because we know sometimes it can come back, people have looked at over the years at deciding whether giving some chemotherapy at*

*this sort of stage might help. And the answer is that it does make a bit of difference. So if you were to take a group of 100 people and gave all that 100 people chemo, it would help about six of those people not to run into troubles over the next five years. [Patient 2 oncology clinic transcript]*

The oncologist left unspoken the underlying risk of recurrence with which to contextualise the benefits. None of the patients asked for this information. One of the oncologists commented on this being a common phenomenon.

*"When I say you have a chance of a cure, the chemotherapy increases that chance of a cure by 5 in a 100 for every person that I treat, my obvious question would be, so what's my chance anyway? And she didn't ask that, but virtually nobody else does […]." [Oncologist 4 interview about Patient 12]*

When asked if she would offer this information to patients, she said no, adding:

*"Because they don't ask. Very much […] the oncology training is towards the patient as an individual requesting information, and being given the information at the pace they want it, at the time they want it."*

### *Uncertainty challenges*

Patients with microscopically incomplete resections (denoted as R1) posed difficulties for clinicians. Predicting what impact this would have on the long-term outcome for patients was a challenge due to lack of evidence specific to this group.

*"[...] so if you look at the survival curves you only have T stages, N stages, and there's no survival curve for R. So I wouldn't know what her five-year survival is." [Surgeon 5 interview about Patient 9]*

Conveying the uncertainty and complexity of this situation to patients also posed challenges.

**Oncologist 3:** *So the surgeon has got rid of what they could see. Under the microscope they can see that it goes to the cut point. So microscopically, under the microscope, it may have stopped right at the cut point and actually they have done a brilliant job and cookie-cuttered it out. Or it could have been beyond the other side of the cut point. If it is on the other side of the cut point, it may scar and <u>die</u>, or it might persist and grow and then be able to come back at that point. [Patient 9 oncology clinic transcript]*

Another case that was challenging to provide a prognosis for was patient 6. She had been diagnosed with stage 3B cancer, initially received palliative chemotherapy, followed by maintenance therapy and was finally referred for surgery. The post-surgical pathology showed no active cancer. She asked about her risk of the cancer returning in the future, but staff were unable to offer clear estimations of the chance of cancer recurrence.

**Patient 6:** *Is it liable to pop up again?*

**Surgeon 4:** *With anyone with lung cancer we very much work on averages and what happens in most people. So even with people who do follow what we would expect, things are never straightforward. And even more so in your case, we just don't know the answer. [Patient 6 surgical clinic transcript]*

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Despite this, the surgeon went on to acknowledge to her that the signs were good. Her oncologist was also unable to give a definitive answer during the interview.

> *"So she's not completely risk-free, but what the percentage is... Because this is such an unusual case. I mean, in [...] the many years I worked [...] treating lung cancer, I've never seen this. We just have to watch and see. I can't put a figure on it at all I'm afraid." [Oncologist 2 interview about Patient 6]*

### Theme 2: Recognising early signs of recurrence

Information about recognising early warning signs of recurrence was very limited in all the clinics. During the surgical clinic, only Surgeon 8 provided any information on the signs of potential recurrence and what to do about this if it occurred.  For most patients seen in the follow-up clinic there was only either a vague mention of new symptoms, or not discussed at all. In one exception the patient was given specific information on symptoms to look out for, even though recurrence or role of adjuvant adjuvant therapy was not explicitly discussed.

> ***Chest Physician 1:*** *And we will see you again in three months. If you start noticing that you are getting more breathless or that you get a new persisting cough, blood in your phlegm, or anything that is concerning you, you have got our contact details. [Patient 10 follow-up clinic transcript]*

During the oncology clinics some patients were given information about early signs of recurrence. The guidance offered tended to emphasise the subtle nature

of the symptoms that might indicate a possible recurrence and the importance of not assuming all new symptoms were due to cancer.

> ***Oncologist 3:*** *Listen to that core message of happy, not happy, comfortable, not comfortable, rather than the little niggles. Because the little niggles that come and go are very rarely anything to do with cancer. So if it comes and goes away on its own, isn't cancer. [Patient 9 oncology clinic transcript]*

Where they occurred, these explicit acknowledgements of possible cancer recurrence appear aimed at addressing the inherent uncertainty and fear of cancer recurrence.


Several professionals were concerned about the timing of discussions with patients about awareness of early signs of recurrence. Some were concerned about giving patients mixed messages during the surgical clinic by talking about good outcomes and discussing potential recurrence at the same time. Even later on during follow-up, staff were cautious about 'frightening people' too early on after surgery with discussion about possible recurrence.

> *"I just don't know that seeing somebody potentially eight weeks after an operation saying you might not be cured and it might come back, I don't feel is the right thing to do […]." [LCNS 2 interview about Patient 3]*

Some professionals spoke about introducing the topic over several clinic visits in the context of the rationale behind surveillance. However, none of the participants was able to specify when the best time would be.

Professionals described giving information that was aimed at supporting hope, aiding treatment understanding, or facilitating decision-making. Choices made by professionals about what information was disclosed and the depth it was given, were complex, often tacit, and tailored to a context. Individual professionals differed in their communication ethos and where they situated themselves between being an optimist or a realist. While Surgeon 8 was alone in seeing his role as giving objective scientific evidence, many other staff spoke about the need not to be brutal or "*all doom and gloom*" and to *"be encouraging"*. Many spoke about tailoring the information to the individual and the difficulties in getting the balance right for people.

Several professionals felt that it was essential to provide hope by delivering an optimistic message, even if the news was not particularly good.

> *"[…] what I've learned from my previous consultant is even if the news is not that good, you need to find a reason of hope in that news. Like in his condition he's got T2a N1 disease but there's no M. And it's only one lymph node, it's only N1, not N2. So that's a good thing because he could have been worse." [Surgeon 6 interview about Patient 10]*

But other staff talked about providing a more realistic message. One surgeon spoke about the different approaches that colleagues sometimes take:

> *"I mean it is very easy to give good news all the time. I don't think it's always appropriate. […] But that depends on whether you subscribe to like always say the good thing, patient feels hopeful, helps them in the treatment or whether you think you should be realistic and not create unrealistic*

*expectations. And I don't, there's no guidance in that. I think it is very much dependent on your own point of view and approach to it […]." [Surgeon 5 interview about Patient 9]*

Many of the staff interviewed also stressed the need to provide an approach that was balanced and both helped to support hope as well as give a realistic view. Achieving the right balance between optimism and realism, hope and bleakness and detail or more general information was important for all the professionals. The balance point varied between cases and professionals, and appeared to be influenced not only by the clinical scenario and the patient, but also by individual clinicians' communication beliefs and attitudes.

## Discussion

These findings provide a unique insight into the views of professionals caring for lung cancer patients regarding information disclosure. They reveal the challenging nature and complexity of discussing recurrence following lung cancer surgery. Clinicians in this study varied in how they discussed issues related to recurrence. Styles of communication differed amongst patient professional pairs, and some differences were noted between the same professional when consulting with different patients.

A spectrum of approaches was adopted in relation to risk communication and there were many similarities to the findings of Mendick et al. (2013). Professionals were largely cautious about presenting information about

recurrence beyond giving a possibility that it could happen. Good prognosis appeared to be conveyed to patients often without explicit discussion of recurrence, allowing patients to then ask for more information. This information was seen as hopeful and used to support patients' positive views of surgery and the future. Even for these patients, many professionals regarded specific numeric probabilities of recurrence as damaging to hope and not useful to individual patients. This indicates the inherent uncertainty in such information and mirrors some of the findings of Thorne et al. (2006). Where prognosis was perceived to be less positive by clinicians, this was conveyed indirectly, such as discussing the referral to an oncologist. Recurrence was presented in terms of possibility only. Even when discussing adjuvant treatment patients did not ask about their underlying risk of recurrence or chance of survival and none of the oncologists in the study offered this. The benefits of adjuvant therapy were presented as absolute survival increase, or as comparative recurrence rates, with and without treatment. Zikmund-Fisher (2013) discussed these formats of risk communication as being suitable for treatment decision-making. However, where benefits of treatment were presented only in terms of comparative possibilities (as with Patient 8), it could be questioned whether this truly provides sufficient information for decision-making and informed consent.

One explanation for this observed difference in whether patients ask further questions about their prognosis is that patients using gist level information, including tone and body language, rather than the verbatim account, in order to make an assessment of their outcome (Reyna, 2012). The manner that hope was conveyed to patients with a good prognosis, rather than explicit facts, may

determine whether patients felt safe to ask further questions, in the expectation of receiving further information likely to support hope. Other patients, although not explicitly told they had a poorer prognosis, may have taken the gist of the consultation and have realised that asking further information would not support hope.

Information about signs and symptoms of recurrence and what to do about these were not consistently discussed with study patients following surgery, even when not having on-going treatment. The National Cancer Survivorship Initiative advocates giving information on symptoms that might indicate recurrence or progression of disease at the end of primary treatment (NCSI, 2014). The current study indicates that barriers may exist to implementing this with post-surgical lung cancer patients. This may in part be due to professionals' desire to support patient hope (Thorne & Stajduhar, 2012). The lack of consensus on optimal follow-up programmes (National Collaborating Centre for Cancer, 2011) could also reduce clinician's confidence in post-operative follow-up, and so the whole approach to detecting early recurrence. There are limited options for treating patients with relapsed lung cancer and this may also influence attitudes to long-term surveillance and the value of increasing patient anxiety levels by discussing possible signs of recurrence. However, with recent developments in radiation and systemic therapy, as well as possible further resection, this situation may well begin to change (Goldstraw et al., 2011).

Choices that staff make about information for post-surgical lung cancer patients are complex. These findings suggest that both clinicians and patients appeared to

be managing uncertainty as a dynamic process during these information exchanges. The findings are supported by previous literature and suggest a tacit agreement exists between professionals and patients with lung cancer to manage uncertainty in a way that promotes hope (Johnson et al., 2015). Professionals talked about presenting information honestly and realistically, not damaging patients' fragile hope by giving too much or the wrong type information. This was a priority for most clinicians, mirroring the findings of Mendick, et al. (2011). Some staff participants took either an optimistic or realistic approach to information giving. Most staff, however, emphasised the need to maintain a careful balance in their communication to meet the patient's individual information needs. Judging this balance would appear to require a skilled clinical relationship that takes as its starting point the expertise of the clinician and the inevitable vulnerability of the patient (Salmon & Young, 2017).

## Study strengths and limitations

This is the first in-depth exploration of the discussion of recurrence risk following lung cancer surgery. Examination of the multidisciplinary approach to these discussions, as patients move between teams, allows an understanding of how this disclosure process happens over time. Triangulation of the data between clinical observation of what was said, together with the professional's rationale for the information that was given, allows a greater depth of understanding of the decision making processes involved in selecting the type and format of information. As a qualitative case study, the sample was robust and was based on a good range of patients. The different cancer stages within

this study population exposed the difference in approach to information giving used by staff, when confronted with patients with divergent prognoses.

However, patients were referred to a limited number of oncologists and staff undertaking long-term follow-up, resulting in some clinicians seeing multiple study patients. This may have limited the range of views and practices observed in the non-surgical element of the study in particular. In common with other qualitative studies, potential observer bias and the risk of *post hoc* justification among interviewees can clearly influence the results.

Nevertheless, it is possible to draw out themes relevant to wider lung cancer practice. The idiosyncratic nature of clinical encounters is particularly highlighted, with clinicians drawing on their own personal values and style and working in the "art" of clinical practice, tailoring the approach to individual patients' lives and health circumstances. Insight into the decisions around how long-term outcomes following surgery are presented provides a greater awareness of the underlying aims of communicating this information and recognition of the significance and complexity of the communication of prognostic information at this phase of treatment. This study highlights how nuanced and subtle some of this communication can be, with skills largely developed through experience. This understanding can be used to develop the skill sets and competencies of clinical staff to achieve the right balance in communicating about potential long-term outcomes that seeks to match patients' coping strategies. Further research will include the patient views of these clinic consultations with the ultimate aim of highlight potential strategies

to support patients in survivorship and inform further research to develop potential interventions and communication strategies.

## Conclusion

This study enhances the understanding of the challenges in communicating risk of recurrence following lung cancer surgery. It highlights how complex it is for clinicians to balance hope and uncertainty, whilst conveying the information that a patient may need.  Awareness of the strategies that clinical staff employ, often unconsciously, when talking with patients about difficult subjects, could help staff tailor their communication to individual patient information needs and coping style. It is important to recognise how significant and meaningful these consultations are for patients, and how subtle and complex the communication within them really is. Staff providing this care need to have the skills and support necessary to ensure this care is provide as well as possible.

## Acknowledgement

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Table 1: Details of patients and professionals included in the study

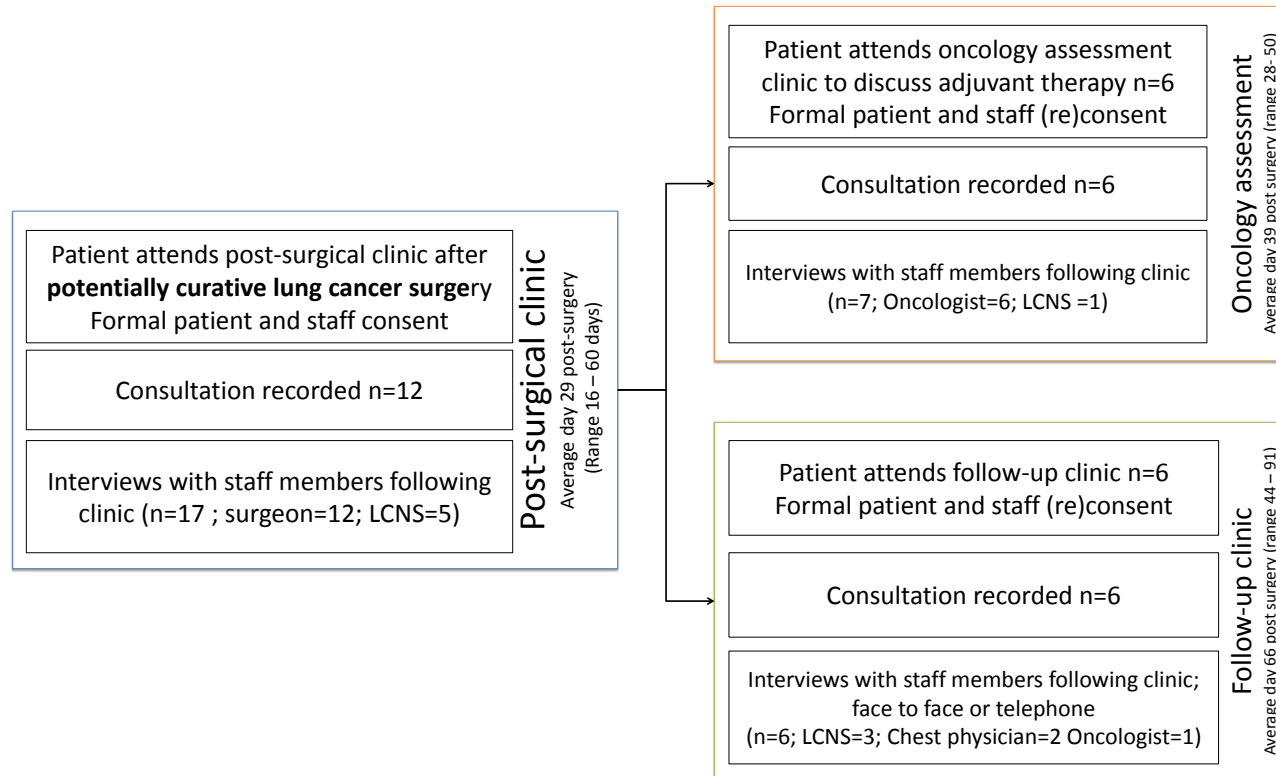| Subject | Age | Diagnosis | Stage | Operation | MDT Outcome | Professionals involved and interviewed |
|---|---|---|---|---|---|---|
| Patient 1 (Female) | 75 | Large Cell Neuroendocrine Carcinoma | 2A | Pneumonectomy | Refer to oncology | Surgeon 1 Oncologist 1 |
| Patient 2 (Female) | 68 | Squamous Cell Carcinoma | 3A | Bi-lobectomy | Refer to oncology | Surgeon 1 Oncologist 1 |
| Patient 3 (Female) | 58 | Adenocarcinoma | 1A | Segmentectomy | Follow up with LCNS | Surgeon 2 LCNS 2 |
| Patient 4 (Female) | 56 | Adenocarcinoma | 1A | Lobectomy | Follow up with LCNS | Surgeon 2, LCNS 1 LCNS 2 |
| Patient 5 (Male) | 73 | Adenocarcinoma | 1B | Lobectomy | Refer to oncology | Surgeon 3, LCNS 3 Oncologist 1 |
| Patient 6 (Female) | 61 | Adenocarcinoma | Occult carcinoma | Lobectomy | Follow up with oncologist | Surgeon 4, LCNS 4 Oncologist 2 |
| Patient 7 (Female) | 59 | Adenocarcinoma | 1A | Lobectomy | Follow up with LCNS | Surgeon 5, LCNS 1 LCNS 2 |
| Patient 8 (Male) | 74 | Squamous Cell Carcinoma | 2A (R1) | Sleeve lobectomy | Refer to oncology | Surgeon 3 Oncologist 1 |
| Patient 9 (Female) | 60 | Adenocarcinoma | 2B (R1) | Lobectomy plus chest wall | Refer to oncology | Surgeon 5 Oncologist 3 |
| Patient 10 (Male) | 77 | Adenocarcinoma | 2A | Lobectomy | Follow up with chest physician | Surgeon 6 Chest Physician 1 |
| Patient 11 (Male) | 73 | Adenocarcinoma | 1B (initally reported 1A) | Lobectomy | Follow up with chest physician | Surgeon 8 Chest Physician 2 |
| Patient 12 (Female) | 69 | Adenocarcinoma | 2B | Sleeve lobectomy | Refer to oncology | Surgeon 9, LCNS 6 Oncologist 4, LCNS 7 |

Table 2: Taxonomy of risk concepts based on Zikmund-Fisher (2013) with examples from clinical transcripts in the study.

| Risk concept | Illustrative example |
|---|---|
| Possibility:<br>The event might happen or might not happen | *Surgeon 1: because some of the glands inside the lung contained tumour, there is a theoretical risk of recurrence*<br><br>(Patient 1– surgical clinic) |
| Implicit possibility:<br>The event might happen or might not, but conveyed by means of a proxy, (eg discussing follow up) | *LCNS 2: so we are finished from the tumour point of view for the time being. Don't anticipate having to do anything different. And the plan would be to follow you up for the next few years*<br><br>(Patient 4 – follow up clinic) |
| Categorical possibility:<br>The event might or might not happen and the likelihood is conveyed as a category (eg high chance, low risk) | *Patient 3: And what's the possibility of it coming back?*<br><br>*Surgeon 2: Well, what's.. it's real really small, so the possibility is very low*<br><br>(Patient 3 – surgical clinic) |
| Relative possibility:<br>The event is more or less likely to happen due to a particular circumstance that exists | *Oncologist 3: And it is a little bit more likely to [come back] if the layers of the lung are involved*<br><br>(Patient 9 – oncology clinic) |
| Comparative possibility:<br>The event is more or less likely to happen in this circumstance as opposed to another circumstance | *Oncologist 1: The intended benefits are to reduce the risk of recurrence of the lung cancer. I am afraid it is not a hundred per cent guarantee, but it does reduce the risk*<br><br>(Patient 8 – oncology clinic) |
| Absolute probability:<br>The numerical estimate of the chance the event will happen | *Surgeon 8: The chances of it coming back is very small. Given the early stage of tumour it is only about ten to fifteen per cent.*<br><br>(Patient 11 – surgical clinic) |
| Incremental probability:<br>The numerical estimate of the change in the chance that an event will happen | *Oncologist 4: if I give a hundred people like you chemotherapy, five extra people would be cured of the cancer in addition to the surgery […] So there is a definite benefit to having the chemotherapy, but it is quite a small benefit*<br><br>(Patient 12 – oncology clinic) |
| Comparative probability:<br>The numerical estimate of the chance of the event will happen given one circumstance and the numerical estimate in an alternative circumstance | *Oncologist 3: I would <u>estimate</u> that the benefit from radiotherapy if I had a hundred of you in a room, would be, from a local control point of view, would be around about sixty per cent, maybe down towards fifty per cent without radiotherapy, and we would be going up into maybe the seventies and eighties with radiotherapy […] So it doesn't mean that it can't come back*<br><br>(Patient 9 – oncology clinic) |

Table 3: Typology of Recurrence risk communication and recurrence risk in relation to adjuvant treatment in each clinic observation

| Patient (Gender, stage) | | Typology of recurrence information given | Typology of recurrence information given |
|---|---|---|---|
| | | **Surgical clinic** | **Follow-up clinic** |
| **Patient 3** (Female 1A) | "Good prognosis" patients | Categorical possibility (patient question) Adjuvant treatment not indicated (surgeon initiated) | Recurrence not discussed Adjuvant treatment not indicated (LCNS initiated) |
| **Patient 4** (Female 1A) | | Categorical possibility (patient question) Adjuvant treatment not indicated (surgeon initiated) | Implicit possibility Adjuvant treatment not indicated (LCNS initiated) |
| **Patient 6** (Female occult ca) | | Categorical possibility (Patient question) Adjuvant treatment not required (husband initiated) | Possibility (patient question) Adjuvant treatment not required (oncologist initiated) |
| **Patient 7** (Female 1A) | | Absolute probability (Patient question) Adjuvant treatment not indicated (patient question) | Categorical possibility (Patient question) Adjuvant treatment not indicated (patient initiated) |
| **Patient 11** (Male 1A/B) | | Absolute probability (Surgeon initiated) Adjuvant treatment not indicated (surgeon initiated) | Recurrence not discussed Adjuvant treatment not indicated (physician initiated) |
| | | **Surgical clinic** | **Oncology assessment clinic** |
| **Patient 1** (Female 2A) | "Intermediate prognosis" patients | Possibility (surgeon initiated) Possibility of adjuvant benefit (surgeon initiated) | Possibility (oncologist initiated) Incremental probability of adjuvant benefit (oncologist initiated) |
| **Patient 2** (Female 3A) | | Implicit possibility Comparative possibility of adjuvant benefit (surgeon initiated) | Possibility (oncologist initiated) Incremental probability of adjuvant benefit (oncologist initiated) |
| **Patient 5** (Male 1B) | | Implicit possibility Comparative possibility of adjuvant benefit (daughter's question) | Categorical possibility (patient question) Comparative possibility of adjuvant benefit (oncologist initiated) |
| **Patient 8** (Male 2A, R1) | | Implicit possibility Implicit possibility | Relative possibility (oncologist initiated) Comparative possibility (wife's question) |
| **Patient 9** (Female 2B, R1) | | Recurrence not discussed Implicit possibility of adjuvant benefit | Relative possibility (oncologist initiated) Comparative probability of adjuvant benefit (patient question) |
| **Patient 10** (Male 2A) | | Possibility (Patient question) Comparative possibility of adjuvant benefit (surgeon initiated) | (**NB Seen in follow-up clinic**) Recurrence not discussed Adjuvant treatment not discussed |
| **Patient 12** (Female 2B) | | Recurrence not discussed Adjuvant treatment not discussed | Possibility (oncologist initiated) Incremental probability of adjuvant benefit (oncologist initiated) |

Figure 1: Study recruitmernt and datacollection points
(LCNS = Lung cancer nurse specialist)

Box 1: Inclusion and exclusion criteria

| Inclusion criteria | Exclusion criteria |
|---|---|
| <ul><li>Patient has had a surgical resection for primary lung cancer</li><li>Patient is aware they have or are likely to have lung cancer</li><li>Patient has not yet been seen in the first follow-up clinic</li><li>Patients referred from hospitals that are included in the study</li><li>Able to speak fluent English</li></ul> | <ul><li>Patients who do not meet the inclusion criteria</li><li>Patients under 18 years of age</li><li>Patients unable to give informed consent to participation in the study</li><li>Patients undergoing surgery where the aim is not curative (ie surgical biopsy, tumour de-bulking, "open and close" surgery).</li><li>Patients with a diagnosis of carcinoid tumour with no atypical features</li><li>Patients with a diagnosis of mesothelioma</li><li>Patients judged by the clinical team to be emotionally or psychologically unstable</li></ul> |

Box 2: Interview topic guide for interviews with professionals following consultations

| Interview topic guide |
|---|
| 1. Introduction to the interviews. |
| 2. *Explore staff member's perception of this patient's risk of recurrence* |
| 3. *Explore their perception of the role of adjuvant therapy in this case* |
| 4. *Understand how the decision was made as to what information to present to the patient in relation to histopathology and surgical findings* |
| 5. *Use key points in the clinic encounter to ask why they chose to use a particular phrase or to give/not give particular information* |
| 6. *Explore what the staff member is trying to achieve when giving information to patients regarding diagnosis and prognosis* |
| 7. *What do they see as the benefits of information giving regarding detailed clinical information and risk of recurrence*? |
| 8. *What do they see as the risks or problems with giving detailed clinical information and risk of recurrence*? |
| 9. *Explore who they feel has responsibility, or is best placed, within the patient's MDTs to discuss diagnosis and prognosis or risk of recurrence with patients* |
| 10. *Explore the staff member's concept of the way that <u>this patient</u> manages the emotional challenge of living with the risk of lung cancer recurrence.* |
| 11. *What does the staff member see as their role in helping patients face this challenge?* |
| 12. *Explore what the terms* "hope" and "uncertainty" *mean to the staff member in the context of cancer* |
| 13. *Explore the implications of these concepts for lung cancer patient management* |
| 14. Interview close |