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PATIENTS' ATTITUDES TO RISK IN LUNG CANCER SURGERY: A QUALITATIVE STUDY

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Highlights

- Patients were willing to accept high levels of perioperative mortality risk.
- Decisions seemed to be separate from understanding of risk estimates.
- Many indicated a preference for clinicians to make the treatment decision for them.
- There was desire to 'get rid of cancer' and perception of no alternative to surgery.
- Patients did not believe that adverse outcomes would happen to them.

Abstract

Objectives

Lung cancer surgery leads to long term survival for some patients but little is known about how patients decide whether to accept the associated surgical risks. The objective of this qualitative study was to explore patients' attitudes to the risks associated with lung cancer surgery.

Methods

Fifteen patients with resectable lung cancer, recruited via multi-disciplinary team meetings at an English tertiary referral centre, participated in semi-structured interviews to explore their attitudes to the morbidity and mortality risks associated with lung cancer surgery. Transcripts were analysed using the framework method.

Results

Participants reported being '*pleased*' to hear that they were suitable for surgery and felt that surgery was not a treatment to be turned down because they did not see any alternatives. Participants had some knowledge of perioperative risks, including mortality estimates; however, many voiced a preference not to know these risks and to let the medical team decide their treatment plan. Some found it difficult to relate the potential risks and complications of surgery to their own situation and appeared willing to accept high perioperative mortality risks. Generally, participants were willing to accept quite severe long-term postoperative breathlessness; however, it was apparent that many actually found this possibility difficult to imagine.

Conclusion

Patients do not necessarily wish to know details of risks associated with lung cancer surgery and may wish to defer decisions about treatment to their medical team. Investment in the doctor-patient relationship, particularly for the surgeon, is therefore important in the management of patients with lung cancer.

Keywords

Lung neoplasm; Thoracic surgery; Risk; Mortality; Morbidity; Qualitative Research.

Introduction

Lung cancer is frequently associated with a poor prognosis, but for those in whom surgical resection is possible there is potential for longer-term survival. The risks associated with surgery are predominantly those of early mortality; early, intermediate and long term morbidity; and tumour recurrence.(1-3) For patients with resectable lung cancer, the decision whether or not to have surgery lies with the multi-disciplinary team (MDT) and the patient. It is usually the surgeon who communicates an estimated level of risk, both of postoperative mortality and morbidity to the patient. Given the risk of death and morbidity related to surgical resection, and the potential for much longer-term survival if the tumour is resected, (3) it is important that we understand patients' perceptions of risk and how much risk they may be willing to accept.

We aimed to explore patients' attitudes to the postoperative mortality and morbidity risks associated with surgery for lung cancer, and how these affected treatment decisions.

Methods

Setting & participants

Potential participants were identified from lung cancer MDT meetings at a tertiary referral centre in England. Eligible patients were over 18 years of age, able to provide written informed consent, had a diagnosis of lung cancer stage 1a to 3a (potentially resectable), and were aware of their diagnosis. Potential participants were not eligible if they were unable to communicate in English.

Eligible patients were approached by a member of their clinical care team. Clinicians were given the option of declining to discuss the study with a patient if they felt it inappropriate (for example if the patient was very distressed about their diagnosis). Patients who expressed an interest in taking part were provided with an information sheet and gave verbal consent to being contacted by a researcher. Researchers allowed at least 24 hours after patients had received this written information before contacting them by telephone to ascertain whether they wished to participate in the study.

A favourable opinion for the study was given by National Research Ethics Committee East Midlands – Nottingham 1 (Reference 12/EM/0123).

Data collection

Participants provided written informed consent before the interview. Face-to-face, semi-structured interviews, lasting approximately 60 minutes (range 27-73 minutes) were conducted in the patient's own home or in a private room at the research institution. Travel expenses were reimbursed. At the start of the interview a confidentiality statement was read and participants were informed that they could withdraw from the study at any stage.

A semi-structured discussion guide was developed to explore knowledge, beliefs and understanding associated with the lung cancer diagnosis and treatment plans, particularly focusing on surgery and the associated risks (Figure 1). The guide promoted

an open dialogue between patient and interviewer to allow the identification of new concepts.(4)

Towards the end of the interview patients were asked to consider hypothetical scenarios where they were given different levels of 30-day mortality risk (2%, 5%, 15% or higher), 5-year survival (70%, 50% and 30%), and post-operative dyspnoea (using the MRC breathlessness scale, (5)). Visual aids were used to portray percentages and patients were asked to explain their reactions and attitudes to these hypothetical scenarios and how they might affect their decisions about treatment.

Interviews were digitally audio-recorded and transcribed clean verbatim by an external specialist transcription company.

Figure 1: Initial discussion guide

Interviews were conducted by a clinical research fellow (HP) who is a speciality registrar in respiratory medicine. Shortly after each interview the patient's hospital notes were accessed in order to complete a case report form which included demographic information and treatment plan.

Recruitment, data collection and preliminary analysis of transcripts took place continuously until no new core themes were being interpreted within the dataset.

Analysis

Transcripts were checked for accuracy by the and data were analysed using the framework method as described by Gale et al.(6) Data from the first two interviews were discussed by members of the research team (HP, DRB, JD and MB) which resulted in some minor changes to the interview guide.

Open coding was performed by the interviewer and themes and sub-themes were validated through independent coding by two different members of the research team (MB & LLJ). Data were charted into a framework matrix according to themes and sub-

themes which facilitated comparisons of opinions from different participants. NVivo software (V10, QSR International Ltd, Melbourne, Australia) was used to assist with applying the analytical framework and constructing charts for each theme.

Results

Sixty-two potentially eligible patients were identified from 38 MDT meetings between February and September 2013. Thirty-four of these patients could not be approached in line with the study protocol. The clinical care team approached 28 patients of whom two declined permission to be contacted by the researcher. Upon contact, seven patients (3 male, 4 female, median age 60 years) declined to take part. Nineteen patients agreed to be interviewed; however, it was not possible to arrange an interview with four of these prior to their pre-operative assessment appointment.

During one interview it became apparent that the participant may have some undiagnosed cognitive problems and therefore the interviewer did not feel it appropriate to continue the interview past the introduction and background questions. Therefore, complete interview data were available for 14 participants. Two patients had likely cancer based on CT and PET scans and the remainder had biopsy proven lung cancer. Recruitment in the context of the patient's clinical pathway is depicted in Figure 2 and patient demographics are given in Table 1.

Figure 2: Recruitment diagram

Table 1: Participant demographics

Four overall themes which provide insight into patients' attitudes to risk and the decision making process surrounding surgery were identified (Figure 3).

Figure 3: Summary of main themes with sub-themes

1. Treatment options

Alternatives to surgery: Most patients were aware that chemotherapy and radiotherapy are treatments for cancer; in fact several had been treated with one or other modality for a different tumour site previously. In this context however, the majority reported that surgery was the only treatment option that had been discussed:

“Because as I say everybody seems quite confident that surgery is the one thing for me.” 002 81F

A few patients had met with a clinical oncologist (as well as a surgeon) prior to the interview; one was told that radiotherapy was not an option due to previous treatment but another elected to have radiotherapy rather than surgery because he felt that breathlessness was his main problem and having part or all of one lung removed would not help this symptom.

Suitability for surgery: Most patients were relieved to hear that surgery was an option for them and seemed pleased that something was going to be done.

“I could have jumped up and hugged him...I thought “oh lovely”, something could be done about it, I can have it operated on” 024 70F

“So it was something of a relief to think that something was going to be done, practical... it was a relief to find out that they had a plan of action, and they didn't include chemical therapy” 010 64M

The patient who ultimately chose radiotherapy, and the patients who had not seen a surgeon prior to the interview, did not express a view on hearing that they were suitable for surgery. Another patient felt “bitter” about being diagnosed with lung cancer after quite a prolonged diagnostic process, and stated that they were not happy about being suitable for surgery, because they did not want another operation.

2. Perioperative risks

Quotes to illustrate this subtheme are shown in Figure 4.

Knowledge and awareness of risks: Most patients recalled specific mortality risk estimates given to them by the surgeon or respiratory physician, and many also said they had been told about possible early complications including infection, bleeding, air leaks and blood clots (Figure 4). Despite being able to recall their individual perioperative mortality risk estimates most patients said that they would rather not know about the risks or level of risk because they were going to have the operation anyway; knowing the risks would just cause additional worry.

One patient who had not yet seen a surgeon did express a desire to know the risks because he wanted to know how likely he was to survive the operation; however, he also said that the level of risk would be unlikely to affect his decision as he had already made up his mind to have surgery if it was offered to him.

Acceptance of high mortality risk: When presented with the hypothetical scenario of being told that their risk of dying within 30 days of the operation was 15% or higher, all but one patient said they were willing to take the risk, some even agreeing immediately that they would take a 50:50 chance. Typically, participants reported this was because they felt that surgery was the only option or that it was up to their doctors to decide whether surgery was the right treatment for them. Some patients went on to state that these risks were necessary for getting rid of cancer, or that there was no alternative; whilst others adopted an 'it won't happen to me' attitude, believing that the bad outcomes would happen to other people.

Figure 4: Quotes illustrating attitudes to perioperative risks

3. Long term outcomes

Possibility of recurrence: Most patients appeared to take long term survival after surgery for granted. When initially asked what they knew about the possibility of recurrence almost all denied any knowledge of this being likely. When this was raised as part of the scenarios however, all were actually aware that in some cases cancer can 'come back' after surgery and they were not upset at this scenario, citing the media and friends/relatives as sources of this knowledge.

Long term morbidity risk: Some patients felt that it was not worth living with major disability as a result of surgery, but most said they were prepared to accept this to live for longer. A patient who described quite disabling breathlessness (MRC 3) at the time of the interview was willing to accept deterioration to MRC 5 in exchange for removing the tumour; however, some patients who were not at all breathless also said they would be willing to accept MRC 5. A minority of patients were clear that severe post-operative

breathlessness would be a reason to decline surgery. Some patients gave mixed messages regarding quality of life and the desire to live longer which seemed to be because they found it difficult to imagine being very breathless.

4. Key people in decision making

Surgeon-patient relationship: Patients reported unquestioning confidence in their surgeon's ability which appeared to be due to their trust of the medical profession in general. Participants reported that having a good impression of the surgeon was important in establishing trust. A patient who had not yet seen the surgeon expressed a particular desire to know all about the surgeon:

“Well, depending on how old he is I suppose to start with, how long he’s been a surgeon, how long he’s been doing these operations, how long he’s been in that department” 021 71M

Who makes the decision?: Some participants indicated a preference that the decision regarding their treatment plan should be made for them by their doctors who “know best”. They implied this was closely related to confidence in their surgeon's abilities and trust that they would do what was best. Participants said that the doctor was better equipped than they were to decide on the treatment plan because of their medical knowledge and because they had all of the test results. One patient was particularly angry because he felt he had to make the decision himself when the doctors were in a much better position to do so.

Discussion

Main findings

The aim of this study was to explore patients' attitudes to risk in lung cancer surgery and how these affected treatment decisions. Most patients were able to recall specific risk estimates and possible complications but despite this, many seemed not to want to know this information and in many cases decisions about surgery seemed to be separate from their understanding of mortality risk estimates. Decisions to have surgery appeared to have been made based on the desire for something to be done to get rid of the cancer, the perception that there was no alternative, and / or a willingness to follow whatever treatment pathway their doctor suggested, rather than weighing risks against benefits.

Patients indicated that doctors know enough to make the right decision for them, and thus placed their trust in this knowledge and the surgeon's ability. Although patients reported being willing to accept high levels of perioperative mortality risk when given hypothetical scenarios, this was in the context of a preference for clinicians to make the treatment decision for them, as well as a perception that there was no alternative. Patients in our study were prepared to live with the long term disability and breathlessness associated with lung resection in higher risk individuals; however, this may be because they could not imagine this level of disability or they did not believe that it would happen to them. Clinicians should therefore be aware that what may seem of importance to them may not be the same for their patient, whose decision may rest on the factors identified in this study combined with a limited appreciation of post-operative morbidity and long term survival.

Findings in the context of existing literature

There is very little previous work of this nature. In 1978, McNeil and colleagues published a study of risk-taking behaviour in people with lung cancer, specifically asking whether or not they would 'gamble' on 50:50 odds of different long term survival against early death in the context of treatment decisions.(7) They recruited 14 patients with

operable lung cancer, and questioned them after they had begun treatment; 8 had started radiotherapy and 6 had recently had an operation as primary treatment. This combination of timing of interview and the predominance of radiotherapy in the treatment plans potentially explains why the researchers found a degree of immediate risk aversion; older people in particular seemed to prefer treatments with a shorter overall survival but a smaller chance of immediate death. Since they did not use a qualitative methodology we are unable to understand why patients made these decisions or whether they understood the concepts of risk which they were asked to consider.

Cykert et al conducted a survey of 386 US patients who had early-stage lung cancer, before their treatment plans were determined, and found that a perception of lower quality cancer communication was associated with decisions not to undergo lung cancer surgery.(8) This may reflect the importance of trust in the clinician's ability to make the 'correct' decision that was found in our study.

The degree to which patients want to be informed and how much of a role they wish to play in making treatment decisions varies considerably.(9, 10) We found that patients were often keen to defer the weighing of risks against benefits to the 'experts' and many expressed a wish that the doctors decide on their treatment plan. It is possible that there is a generational difference in the level of information and degree of shared decision making that patients desire. People with lung cancer are predominantly from an older generation and this may partially explain their preferences. This idea is supported by the findings of Lonsdale et al in a questionnaire study where general surgical patients under the age of 50 were more positive than older patients in their desire to know about the risks of anaesthesia.(9) It is also likely, however, that cancer patients are different to general surgical patients and in a study of 1012 women with breast cancer, in which the median age of respondents was 58 years, only 22% wanted to select their own treatment; 34% wanted the doctors to make the decision with the remainder preferring a collaboration.(10)

Strengths & Weaknesses

The main strengths of our study are the novelty of the research and the use of qualitative data collection methods to explore the reasons behind attitudes to risk in lung cancer patients. Our sample is relatively small, participants were recruited from a single site and the demographic of the patients who participated differed from those who declined to be contacted or interviewed (self-selection bias). Sampling in qualitative research is not designed to be representative of a wider population;⁽¹¹⁾ however, we acknowledge that the views of these participants may differ from those who declined to take part. Patients who were in favour of surgery may have been more likely to agree to take part in the study and only one of the patients interviewed decided not to have surgery. This is a relatively unusual treatment choice in our clinical experience and therefore we did not think it feasible to continue recruitment with a view to interviewing more patients who had made a similar choice.

We interviewed patients after they were given a diagnosis of lung cancer and before they had their pre-operative assessment. This timescale ensured that patients' views were unaffected by the outcome of any treatment; however, we acknowledge that patients may have received more information and had further discussions with the surgeon after they participated in the study, potentially even changing their treatment plan, at the pre-operative assessment visit.

The background of the interviewer is an important consideration in studies such as this. Our interviewer was medically trained but was intentionally not aware of details of cases prior to the interview. We acknowledge that the interviewer's own attitudes and pre-conceptions about risks of surgery may have influenced the direction of the discussion.

Clinical relevance & conclusions

One of the next steps in improving lung cancer survival may be to offer surgery to an increasing number of patients with borderline fitness levels who may be at higher risk of perioperative mortality and postoperative morbidity. Our study suggests that investment

in the doctor-patient relationship is important when helping patients to decide whether to accept these risks, and that clinicians should be aware that patients may wish to defer decisions about treatment to their medical team. This has implications for the process of informed consent and further research is needed exploring the communication of risk in this context.

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Fig. 1 Initial discussion guide.

- Introduction and statement of confidentiality
- Background information
 - How they came to be diagnosed
 - Current treatment plan
- Knowledge of lung cancer and treatment options
 - Sources of information
- Risks of surgery
 - What risks are they aware of
 - Whether and how these were explained by surgeon or other means
 - Explore decision making process
- Attitudes to different levels of risk

Using hypothetical scenarios and visual aids to depict percentages

 - Early mortality
 - Morbidity
 - Recurrence and 5-year survival
- Conclusion and thanks for participation

Fig. 2 Recruitment diagram in context of clinical pathway.

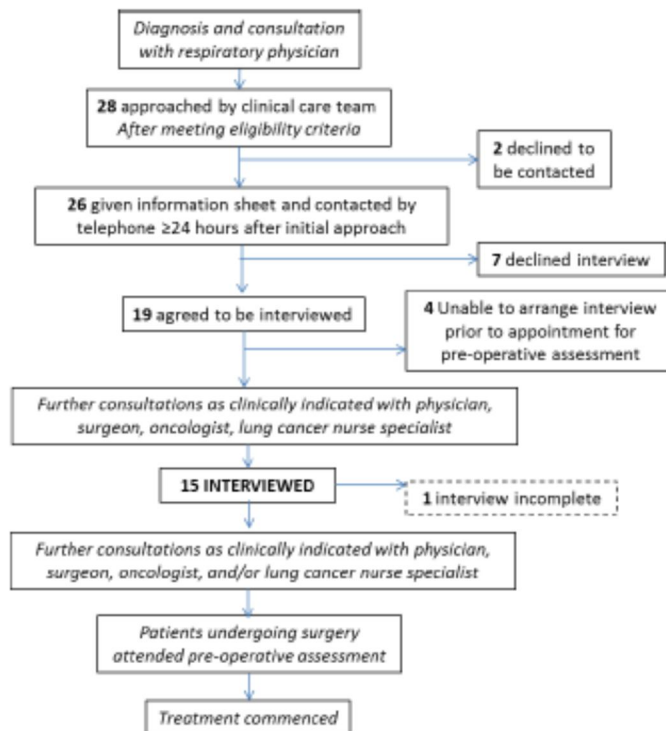


Fig. 3 Summary of main themes with sub-themes.

Theme	Sub-themes
1. Treatment options	Alternatives to surgery Suitability for surgery
2. Perioperative risks	Knowledge & awareness of risks Acceptance of high mortality risk
3. Long term outcomes	Possibility of recurrence Long term morbidity risk
4. Key people in decision making	Surgeon-patient relationship Who makes the decision?

Fig. 4 Quotes illustrating attitudes to perioperative risks.

<i>Knowledge and awareness of risks:</i>	
"Well they always tell you there's risks don't they with all operations. You sign the papers don't you, to say you're having it done whether there's risks or not.I don't think anybody would like to know really" 016 76F	
"He told me it's 3% they lose in theatre which is 3 people out of 100. I said "it's just your luck isn't it?", it is really. I hope I don't." 004 81M	
"He told me all the things that they do normally tell you when you're having operation, so many deaths in so many, such and such a things and all that" 024 70F	
"...he's telling me all the percentages, pneumonia and the bleeding and if they open up again, air leak on the lung, what would happen, just going through the scenario of the operation." 026 66M	
"He said the risks of someone dying on the operating table was virtually negligible but there was a risk area and a couple of days after the operation, post-surgery and the things he pinpointed was either a serious infection or blood clotting" 010 64M	
<i>Reasons given by patients for taking high surgical mortality risks:</i>	
<u>Getting rid of cancer</u>	
"Radiotherapy yes, [friend]'s having that. But if this will clear it, I'd sooner take that chance..... I know it could come back, but I want this removing now, I want it now removing as soon as possible" 028 81M	
"I think the quick and easy way, the quick and clean way, is get it cut out and be gone" 002 81F	
<u>No alternative</u>	
"I wouldn't like that but on the other hand, if I die if I don't have the operation, what choice do I get?" 013 76F	
"Obviously it's not very comfortable is it [high mortality risk], but as regards that again, I haven't got much choice, it's got to be done". 021 71M	
<u>It won't happen to me</u>	
"Them two there could have something wrong with them....they could have something else wrong with them, like some other disease or something like that which the surgeon didn't know about or nobody's told him about it" 003 79M	
"Well, I would think in my own case, I'm reasonably fit so I wouldn't expect it to happen to me, on some people that ... don't listen to advice then I would expect them to die as it were" 005 82M	

Table 1: Participant demographics

		N = 15	(%)
Age (years)	Median	76	(Range 58–87)
Sex	Male	10	67
	Female	5	33
Stage	1a or 1b	8	53
	2a or 2b	4	27
	3a	3	20
Clinicians seen prior to interview	Respiratory physician	15	100
	Thoracic surgeon	13	93
	Clinical oncologist	2 ^a	13
	Lung cancer nurse specialist	14	93

		<i>N</i> = 15 (%)	
Treatment plan	Surgery	14	93
	Radiotherapy	1	7

^aThese patients saw both an oncologist and a surgeon prior to interview.