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Patients' attitudes to risk in lung cancer surgery: A qualitative study

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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.

1. 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.

2. Methods

2.1. 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,

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- 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. 1. Initial discussion guide.

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 h 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).

2.2. Data collection

Participants provided written informed consent before the interview. Face-to-face, semi-structured interviews, lasting approximately 60 min (range 27–73 min) 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 (Fig. 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.

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.

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*
Treatment plan	Surgery	14	*93*
	Radiotherapy	1	*7*

[a] These patients saw both an oncologist and a surgeon prior to interview.

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

2.3. 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.

3. 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 Fig. 2 and patient demographics are given in Table 1.

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

3.1. Treatment options

3.1.1. 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

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