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Title: *Patient views of routine quality of life assessment following a diagnosis of early stage non-small cell lung cancer*

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Visual Abstract

- What are patients' views on the collection of quality of life data during treatment for early-stage lung cancer?
- Technology literacy may limit the online data capture. Patients prefer treatment-specific questionnaires
- Quality of life data collection is important for patients and may help facilitating discussions in clinical consultation

Keywords: Quality of life (QoL), Shared decision making, informed decision making, VATS, SABR, lung cancer.

Abstract

There is increasing interest in quality of life evaluation following Video-Assisted Thoracoscopic anatomical lung resection or Stereotactic Ablative Body Radiation Therapy for early-stage non-small cell lung cancer. A qualitative interview study was conducted to gain insight into the optimal methods of assessing and discussing quality of life in clinical practice.

Methods

A prospective observational longitudinal study of early stage non-small cell lung cancer patients was conducted where repeated quality of life measures were administered either online or on paper.

A subset of participants were invited for qualitative interviews after the 6-month assessment or at the end of the study. The semi-structured interviews were transcribed verbatim and thematically analysed.

Results

Twenty-three patients were interviewed. Generally, patients were content with recruitment and data collection procedures. Most opted to complete the assessments on paper instead of online, this choice was influenced by level of technology literacy. Some found the questionnaires too generic to reflect their experiences. Barriers to questionnaire completion were mostly practical, and many acknowledged benefits of quality of life assessment including allowing them to express problems and health issues, and following changes over time. Generally, participants would like to discuss quality of life results during clinical consultations, but reported this rarely happened.

Conclusion:

Lung cancer patient interviews confirm the acceptability of repeated quality of life assessments, but online data capture is limited. Patients highlight the importance of discussing quality of life aspects with their clinical team. Future strategies are needed to optimize the routine collection of patient-reported outcomes in clinical practice.

Abbreviations

NSCLC: Non-small cell lung cancer

SABR: Stereotactic ablative radiotherapy

VATS: Video-Assisted Thoracoscopic Surgery

QoL: Quality of Life

COREQ: Consolidated Criteria for Reporting Qualitative Research

Lilac: Life after Lung Cancer Study

NHS: National Health Service

IT: Information Technology

EORTC: European Organization for Research and Treatment

QLQ C-30: Quality of Life Questionnaire

GP: General Practitioner

PROMs: Patient-reported Outcomes Measures

1 Introduction

Lung cancer is the third most common cancer in the UK, accounting for 13% of all new cancer cases (2015)[1]. If identified at an early-stage (Stage I-II), surgical resection of Non-Small Cell Lung Cancer (NSCLC) offers a favourable prognosis, with five-year survival rates from 90% for Stage IA to 65% for Stage IIA[2]. Although treatment guidelines recommend objective thresholds to estimate the surgical risk of lung resection[3], the main concern for patients is not the immediate mortality or complications, but rather the permanent disability and loss of independence post treatment which impacts greatly on patients' quality of life (QoL). A survey among European thoracic surgeons revealed a lack of standardised QoL collection among this community with only 12% of all surgeons currently incorporating these outcomes into their clinical practices [4].

The advent of Stereotactic Ablative Radiotherapy (SABR) for peripherally located NSCLC, as a non-surgical radical treatment for patients medically unfit for surgery, has further highlighted the need for more patient-centred data to inform treatment decision-making [5, 6]. SABR is a relatively recent technique implemented in lung cancer care but more QoL data are becoming available to allow comparison with surgical cohorts [7, 8].

Psychological wellbeing is very important to early-stage lung cancer patients, who have highlighted the need to incorporate this aspect of QoL into the pre- and postsurgical discussions[9]. Lung cancer patients rate independence and QoL as more important compared to survival or cancer recurrence when discussing treatment options [10]. Participants were willing to accept high periprocedural mortality, but not severe deficits in QoL when considering treatment.

Focusing on patients' values and preferences regarding treatment decisions is essential, but at present we do not know the best way to discuss and routinely assess QoL in this patient group throughout the diagnosis, treatment and follow-up care trajectory.

With longitudinal assessments of QoL, attrition is a common issue that can affect generalizability of findings [11]. The reported attrition rates in lung cancer studies vary considerably and only few studies to date document the pattern of, and reasons for dropout [12]. A recent review on QoL assessment in early stage NSCLC patients revealed particular difficulties with the pre-treatment assessment, hampering effectiveness analysis [13].

It has been also argued that the existing tools may not be sensitive enough to be useful in the clinical non-research setting[14].

Electronic reporting of QoL and symptoms had the potential to significantly improve data collection in lung cancer patients. It could reduce burden for patients (travel time and costs), and lead to more complete data capture at a lower cost to hospitals [15].

In our prospective observational study of patients undergoing treatments for early stage NSCLC, we aimed to determine the feasibility and patient acceptability of online self-reporting of patient-reported outcomes (Lilac study-Yorkshire Cancer Research Grant L399[16]). A subset of participants took part in qualitative interviews to explore opinions on routine assessment of QoL in the study and wider views of QoL discussions in clinical practice. In particular, our interviews aimed to explore patients' views on the practical aspects of taking part in the study and on how this participation influenced the clinical experience.

Here we report the findings from these interviews, which provide insight into the optimal methods of assessing and discussing QoL in clinical practice.

2 Material and Methods:

2.1 Sample and procedure

This qualitative study was embedded within the Life after Lung Cancer (Lilac) project, a prospective observational longitudinal study utilising repeated QoL measures. Patients undergoing treatments for early stage NSCLC (Video-assisted Thoracoscopic-VATS anatomical lung resection or Stereotactic Ablative Body Radiation Therapy-SABR) who were not involved in other QoL studies were consecutively recruited from the Leeds Teaching Hospitals NHS Trust. All participants signed a written consent form and the study received ethical approval from The National Research Ethics Service Yorkshire and the Humber-Leeds East Committee (REC Ref: 16/YH/0407). Recruitment took place between February 2016 and March 2017. QoL data were collected through the administration of the European Organization for Research and Treatment (EORTC) Quality of Life Questionnaire (QLQ C-30)[17] and its Lung Cancer specific Module (LC-13)[18] at baseline, 6 weeks, 3, 6 and 12 months follow-up. Participants had the option of completing questionnaires on paper or online. Full details of the study protocol have been published previously[16]. A subset of patients was invited for qualitative interviews after the 6-month assessment (interim interviews, performed to guide potential adjustments to the project methodology) or at the end of the study. For interim interviews we used consecutive sampling with an aim to interview three patients from each treatment group with representation from both online and paper completers. For end of study interviews we used purposive sampling for sex, age, and mode of questionnaire completion. Interviews were semi-structured and lasted approximately 40-60 minutes, taking place either in the hospital over the phone or at a location of the participant's preference. When interviews were performed face-to-face, participants were presented with the QoL questionnaires to facilitate the interview.

Interviews were performed until data saturation occurred [19]. Interviews were audio recorded, and transcribed verbatim by an external professional company.

2.2 Interviews

The full semi-structured interview schedule is presented in the Supplementary Table1. Patients were asked to comment on two main topics: Lilac study procedures and the impact of the QoL collection on their clinical experience. Detailed questions about recruitment procedures were added in response to initial recruitment issues in the pre-surgical setting. Patients were asked for views on their choice of either paper-based, or online questionnaire completion and their IT literacy. Interviews were performed by three members of the research team, none of whom were involved in the clinical care of participants (CP, Thoracic surgeon and research fellow on the study; BC research nurse and ES research assistant).

2.3 Data analysis and reporting

We used the framework approach to thematic analysis [20, 21]. The coders (CP and FWB) independently read transcripts several times to familiarize themselves with the content, and highlighted sections related to the research aims.

These were independently coded into key issues and themes, forming an initial basic coding framework. Following coding of the first three interviews, the framework was reviewed and amendments made in accordance with the content of the interviews (i.e., to allow further themes and subthemes to emerge from the data). Thus, an iterative approach was adopted so that changes could be made to the framework as new themes and relationships between themes emerged. Regular meetings were scheduled to discuss any queries or discrepancies, and these were resolved by discussion to reach a consensus. Finally, one coder (CP) examined all transcripts again to ensure robustness of the analytical process. The consolidated criteria for reporting qualitative research (COREQ)[22] were used in this report. All quotes provided were de-identified.

3 Results

3.1 Participants

For the interim interviews, six patients were approached consecutively after being on study for at least six months. As distribution of participants' questionnaire completion mode was skewed (less than 10% of the initial participants completed the questionnaire online), we interviewed three patients face-to-face at this stage (one online and two paper completers). Three patients declined (dealing with post-surgical issues (N=1), no reason provided (N=2). For the end of study interviews, 37 patients were approached of whom six declined (feeling overwhelmed (N=2), lack of time (N=2), or no reason provided (N=2)). Eleven patients could not be reached over the phone after three attempts. Within the end-of study interview samples, data saturation started after 18 interviews with no further additional themes being identified. Two additional interviews were conducted to ensure we had reached data saturation. A final sample of 20 patients took part in end of study interviews, seven were interviewed in person and the remaining over the phone. More than half of participants were female (N=12), mean age 74 years, range 42-84. Eight patients received SABR treatment and 12 received surgical resection, reflecting the proportion of treatment groups recruited for the full study.

3.2 Interim Interviews

Interim interview analysis highlighted that the schedule was primarily directed towards exploring experiences with electronic completion of questionnaires, which precluded capturing patients' wider experiences related to repeated collection of QoL data. Appropriate changes to the schedule, including additional questions about the reasons for preferred completion mode, were made before continuing with further interviews. Questions were added to capture patients’ views of clinician’s use of the QoL data linked to the electronic medical records in consultations, which emerged as an important factor from interim interviews.

3.3 End-of-study interviews

Four main themes were identified in relation to patient engagement with routine completion of patient-reported outcomes and the benefits of the QoL data collection in clinical practice (Table 1).

3.3.1 Recruitment and consent process.

Patients were generally very satisfied with the face-to-face Lilac consent process.

“I preferred it that it was personal rather than through a letter or something like that.” (Female +70Y SABR)

Five patients were happy for a doctor to first introduce the research study, feeling reassured that they were aware of what was happening at that moment in time. However, patients could not recall in too much detail what was initially discussed though they did feel that they were appropriately invited to participate and that the study was explained well.

“I’m glad he did ask because he knew what he was talking about.” (Female +70Y Surgery)

“You know the day you see the surgeon and discuss all about what they’re going to do, and then asked if you’d do the survey, I think it’s the only way you can do it.” (Female +70Y surgery)

The timing of recruitment, shortly after the patient had received their diagnosis, presented some difficulties. Five patients indicated that they had received traumatic news and that it was difficult to concentrate on other things.

“*when somebody tells you that you, 'we're treating you for cancer of the lung' you don't think about research... You're thinking about yourself a little bit and no, I mean I just went along with whatever they approached me with*” (*Male, +70Y surgery*)

This was particularly emphasised by surgical patients. One patient however, indicated that the study was perceived as a welcome distraction from this difficult moment.

3.3.2 Barriers and facilitators of completion methods

Patients completing questionnaires on paper, frequently mentioned that their choice was driven by the fact that they found it easier to access, and that it allowed them time to sit down, have the piece of paper in front of them, and reflect.

“At my age, I think I find it easier to do things on paper where I can actually see and then if you go wrong when you’re doing it online, it kicks you back to the beginning or it won’t let you carry on” (Female +70Y SABR)

Patients choosing the online completion method reported they generally found this method easier. One patient explained their handwriting is difficult to read, others reported choosing the online method for ecological reasons. One participant who tried the online method found it irritating to not have the possibility to skip questions and come back to them later.

Thirteen out of twenty patients interviewed did not consider themselves to have a good level of Information Technology (IT) literacy. Either they did not have access to internet or, if they did, they did not frequently use it. One patient reported being apprehensive about using online medical advice or websites. Another patient reported that because of her age she didn’t feel skilled enough to complete the questionnaire on the computer.

“I’ve got a mobile phone but I don’t, I just use it for calls and I don’t ever use the Internet really” (*Female <70Y Surgery*)

“Because the only line I've got, love, is a washing line” (Male +70Y SABR)

One online participant described how his granddaughter supported him to complete the questionnaires. Three others however, said they were not keen to ask family for help in completing the questionnaires although they were aware their family members do have access to internet. Despite this limited level of IT literacy overall, five patients reported using the internet to access their General Practitioners (GP) practice’s online services.

3.3.3 Engagement with the QoL Study (Lilac)

Almost all patients (19/20, 95%) considered that receiving reminders to complete the questionnaires helped them remember to complete the questionnaires. Preferred methods for reminders varied from person to person and included phone calls, text message or emails.

“I'm happy online but I think you have to do both because some older people are not very happy using the internet. So, for me, you can send me an email, I'm quite happy to go that way…I'm sort of technologically minded...but a lot of people are not” (*Female +70Y SABR*)

One patient highlighted the fear of phishing calls, having lost trust in people ringing for commercial reasons.

In general, patients were happy with the frequency of the questionnaires. Two patients mentioned the difficulty in completing the first one, six weeks after treatment. They explained that this was a busy period where most of the post-treatment complications occurred. One patient suggested having another questionnaire at 18 months after treatment, and another participant preferred more frequent assessments in general to better discriminate symptoms over time.

“I was just getting over the operation because my heart played up a little bit, so I had a few complications and the district nurse was coming, and then when that first

questionnaire come through, it took me, I think it were three or four days before I could actually figure out, that I felt like I could do it" (Female +70Y Surgery)

Patients identified several barriers in completing the questionnaires: three patients reported they did not receive some surveys, two acknowledged they had lost it, and two patients identified their health issues were a barrier to completion.

Facilitators to completing the questionnaires included that answering the questions allowed them to express problems and health issues. They also highlighted the importance of completing these measures to capture QoL changes over time.

Patients especially indicated that it helped them to feel reassured that someone was looking after them. One patient even stressed that it was way to share the burden and psychological issues.

"Because like in-between these questionnaires I've spoken to other people as well, you know, and I liked see how far I've come and that. Yeah, when I've filled one questionnaire in and then I filled another one at three months, I felt "oh I'm getting better here" (Female <70Y Surgery)

"I think it was a good way, sort of like you are sharing your, you know, sorrows and your pain with, you know, through paper" (Female <70Y Surgery)

"But just I think it would reassure people that somebody's actually interested" (Female +70Y Surgery)

Patients were satisfied with the content of the questionnaires in general, but four responders indicated that not all questions applied to them, or were too generic. Suggestions included adding free text space so they could indicate whether the symptom was related to the lung cancer treatment, for surgery-related notes, medications, and other health conditions. Patients under 50 years also suggested including specific questions about family life.

3.3.4 Perceived influence of quality of life assessment on clinical care

Most patients (14/20, 70%) indicated they did not discuss QoL with the clinical team. They thought doctors' busy schedules was one reason behind this. A patient explained that in clinic, questions are largely focused on health issues rather than overall wellbeing. However, one patient expressed that they would have probably had fewer clinic appointments if QoL was discussed in the consultation.

"it won't take 10 minutes or something like that because I appreciate people are very, very busy. But I think a lot of, after telephone, visits and things, could be avoided if a few caring questions could be asked" (Female +70Y Surgery)

"No, I didn't, I just discussed about walking and that" (Female +70Y Surgery)

All the patients but one said that the QoL data collected during the study, was not mentioned during their doctors' consultations.

4 Discussion

The aim of this work was to explore patients’views and experiences with our research study which focussed on the collection of QoL data, and its impact on patients’ experiences of care. On the whole, the study setup and procedures were accepted by patients, with positive feedback provided on the recruitment and consent process. Generally, patients preferred a face-to-face invitation to take part in the study with reminders sent through the post or via text.

Online data capture proved difficult due to the low level of IT literacy and older age of patients. While some patients had access to support from family members, many reported not wanting to burden their families for help with online questionnaires. This may explain contrasting findings in our sample compared to other studies conducted by our wider research team involving patients with breast, ovarian and colorectal cancers [23, 24].Our participants supported keeping the paper-modality as an option for older people in future studies in lung cancer. Other studies among e.g., colorectal cancer patients and women undergoing screening mammography have similarly concluded that paper-based questionnaire completion still seems preferred by older groups [25, 26].

Although the questionnaires used in the study (EORTC QOL C-30 and LC-13) were carefully selected as cancer specific and internationally validated measures, they were not able to capture specific issues related to surgery or SABR. Patients were concerned about questions being too generic, calling for additional notes to explain their answers. The updated version of the LC-13 questionnaire, where tailored treatment-related questions will be included, may help in overcoming these issues [27].

While the majority of patients perceived the completion of the questionnaires as improving self-awareness of their QoL and providing valuable additional information to share with their clinical team, the results of QoL data were rarely discussed during clinic consultation by patients or clinicians. These results are in line with the work of Powel and colleagues where early stage lung cancer surgical patients reportedly deferred decisions about treatment to their medical team [28]. Of note, the Lilac study was not designed to study the clinician's use of the QoL data in clinical practice. Instead, we tried to gain insight from patients on how the QoL discussion would have helped to understand better how the patient was recovering after treatment. Although clinicians were introduced to using the QoL data real time in clinics, more efforts and studies are needed to improve uptake and integration of Patient-Reported Outcomes Measures (PROMs) within electronic patient records.

Limitations

Our study has several limitations. Purposive sampling for qualitative research captures the diversity of the population to sufficiently describe the phenomenon of interest [29]. We acknowledge that the views of our participants may differ from those who declined to take part. Our study has also been characterized by limited participation of the electronic completers, possibly limiting the generalizability of the results.

Recruitment was based on a sample of lung cancer patients participating in the Lilac study. Demographic data collected did not include race/ethnicity or sociodemographic status of participants. We included patients from one regional hospital, so the results may not be widely applicable to other settings, regions or patient groups. A range of other variables such as cultural differences, travel distance, clinic wait times, interactions with non-clinical staff, may also influence participant recall and responses.

We did not directly observe patient–clinician interactions, so our findings may not reflect actual practice. As is the case for many qualitative studies, our results are subject to participant recall, social desirability and moderator acceptance bias[30].

Conclusions

In conclusion, this study suggests that our study population of lung cancer patients have a relatively low level of IT literacy, limiting the potential of online QoL data capture. This is something we can expect to change in coming years, with increasing use of technology in older populations, and availability of accessible technological platforms. To increase the uptake and use of QoL data by clinicians, more effort should be directed towards providing training to doctors and nurses in utilising patients' QoL data in practice. Most importantly, these qualitative interviews have highlighted the importance for patients to discuss QoL aspects with their clinical team – not just when issues are present, but also when things are going well. This underscores the need for more efforts in collecting and using quality of life data in clinical practice.

Conflict of Interest: KF reports participation to advisory boards and/or received fees for speaking for AstraZeneca, Boerhinger-Ingelheim, British-Meyers-Squibb, Lilly and Roche. GV reports personal fees from Roche, personal fees from Eisai, personal fees from Novartis. All the other authors have no financial conflicts of interest to declare.

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Table Legend:

Table 1: Themes and subthemes

Table 1

Consent process	**Introduction to the study**
	Timing of invitation
	Psychological situation
	Member of the staff
Completion methods: barriers and facilitators	Perceived facilitators for paper completion
	Perceived facilitators for online completion
	Perceived barriers for paper completion
	Perceived barriers for online completion
	Computer/Internet use
	Family support for Lilac participation
Patients engagement with Lilac	Reminder preferences
	Frequency of assessment
	Barriers to complete questionnaires
	Questionnaire role in expressing symptoms/issues
	Comments on questions and suggestions
Perceived influence on clinical care	Involvement of clinicians in quality of life discussion
	Clinician and staff perceived engagement with Lilac

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