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Using patient-reported outcome measures to deliver enhanced supportive care to people with lung cancer: Feasibility and acceptability of a nurse-led consultation model

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ABSTRACT

Purpose: Developing new supportive/palliative care services for lung cancer should encompass effective ways to promptly identify and address patients' healthcare needs. We examined whether an in-clinic, nurse-led consultation model, which was driven by use of a patient-reported outcomes (PRO) measure, was feasible and acceptable in the identification of unmet needs in patients with lung cancer.

Methods: A two-part, repeated-measures, mixed-methods study was conducted. Part 1 employed literature reviews and stakeholder focus group interviews to inform selection of a population-appropriate needs assessment PRO measure. In Part 2, lung cancer nurse specialists (CNS) conducted three consecutive monthly consultations with patients. Recruitment/retention data, PRO data, and exit interview data were analysed.

Results: The Sheffield Profile for Assessment and Referral to Care was the PRO measure selected based on Part 1 data. Twenty patients (response rate: 26%) participated in Part 2; 13 (65%) participated in all three consultations/assessments. The PRO measure helped patients to structure their thinking and prompted them to discuss previously underreported and/or sensitive issues, including such topics as family concerns, or death and dying. Lung CNS highlighted how PRO-measures-driven consultations differed from previous ones, in that their scope was broadened to allow nurses to offer personalised care. Small-to-moderate reductions in all domains of need were noted over time.

Conclusions: Nurse-led PRO-measures-driven consultations are acceptable and conditionally feasible to holistically identify and effectively manage patient needs in modern lung cancer care. PRO data should be systematically collected and audited to assist in the provision of supportive care to people with lung cancer.

Keywords: Lung cancer; Needs assessment; Unmet needs; Patient-reported outcome (PRO) measures; Nurse specialist; Supportive care

Background

Lung cancer remains the most common cause of cancer-related death, accounting for approximately 20% of the total cancer mortality [1]. In spite of recent treatment advances, survival rates remain poor [2]. The majority of patients still present with advanced disease, at a stage where use of treatment with curative intent is limited [3]. Not only people with lung cancer are physically challenged, but also they have unmet healthcare needs, in many cases significantly more when compared to people with other cancer types [4]. Early and effective supportive and palliative care is therefore paramount in this patient group [4–6]. Supportive and palliative care ‘helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease’ and should ‘be given equal priority with other aspects of care’ [7, 8].

The development and integration of new supportive/palliative care services should encompass innovative ways to promptly identify the healthcare needs of people with lung cancer. Using patient-reported outcome (PRO) measures in routine cancer care practice can be beneficial to this effect [9, 10]. PRO measures are defined as ‘measurements of an aspect of a patient’s health status that come directly from the patient’ [11]. Deriving data (referred to as ‘PRO data’) can be used to alert clinicians on emerging and priority needs and concerns, enable active clinician review of the patient’s health status towards prompt clinical intervention. There is now mounting research evidence that collection of PRO data that is followed by a tailored clinical response can lead to improved patient-clinician communication, better symptom control, increased use of supportive care measures, improvements in self-efficacy, patient satisfaction with cancer care, and survival [10, 12–14].

Despite positive evidence, implementation of PRO-measures-driven consultation models in routine clinical practice has been challenging and not fully realised [15]; lung cancer care is not an exception. One reason is that, for such a complex healthcare intervention to be successfully implemented, careful research planning and design is required to deploy key components, identify resultant effects of PRO data collection and use, and tackle any barriers to inform future policy and practice [10, 12, 16]. Drawing on this gap in current literature, we aimed to develop a nurse-led, PRO-measures-driven consultation model (intervention) to enhance the delivery of supportive/palliative care to people with lung cancer, and test its feasibility and acceptability in routine clinical practice. Secondly, we examined the prevalence, intensity and over-time change in reported supportive care needs in the study sample as a preliminary indication of intervention-related effects. We selected a nurse-led model because, among members of the multidisciplinary team, nurses are consistently seen as being the most appropriate practitioners to lead on PRO measure use [17]. Indeed, current evidence supports lung cancer nurse specialists (CNS) as providers of tailored care that is likely to improve patient symptom control, reduce unnecessary hospital admissions, and increase satisfaction with care [5, 18, 19].

Methods

This was a two-part, mixed-methods study, with each part designed to contribute to achieving the overall study aim. The study was informed by the Medical Research Council (MRC) complex interventions framework [20] referring to the feasibility/pilot and developmental elements of the framework. Ethical approval was granted by the local Research Ethics Committee.

Part 1: Intervention development stage

In Part 1, we generated research evidence to assist us on refining aspects of the intervention and selecting the most appropriate needs assessment PRO measure for use in Part 2. First, we reviewed the relevant literature. We conducted one systematic review on patients’ supportive care needs, and one on available needs assessment PRO measures. Methodological details of these reviews have been published elsewhere [21, 22]. We shortlisted PRO measures based on key parameters, including target population and setting; content, length, comprehensiveness and representativeness; scoring; psychometric properties (validity, reliability, responsiveness to change); feasibility (time, reading level); and respondent acceptability (length, wording). Subsequently, we scoped out the views and opinions of people with lung cancer and health professionals on important aspects of supportive care for this patient group. For this exercise, we conducted two focus group interviews, one with patients and one with health professionals, using a purposive sampling procedure at one NHS board in the UK. Eligible patients were (a) diagnosed with lung cancer; (b) at different phases of the cancer trajectory; (c) deemed physically and psychologically fit to participate; (d) able to read and write English; (e) able to provide written informed consent; (f) aged ≥ 18 years; and (g) able to provide consent for the researcher to access hospital case notes. Eligible health professionals were lung CNS registered within the

participating health board. During the focus group sessions, all participants were asked to provide basic demographic information on an author-developed form. Patient clinical data were collected from hospital case notes. At the end of each focus group, we involved participants in a 10-minute exercise, whereby shortlisted PRO measures were distributed to each group. Participants reviewed the PRO measures and selected the three 'most appropriate' for use in lung cancer care, in terms of overall presentation, length, wording, and comprehensiveness.

Part 2: Feasibility testing stage

In Part 2, we conducted a single-arm, repeated measures trial to test the feasibility and acceptability of the consultation model (intervention), whereby the lung CNS used the selected needs assessment PRO measure during clinical consultations to identify patients' priority healthcare needs and provide tailored care. As per guidance for early feasibility testing [23, 24], we aimed to recruit up to 30 patients with lung cancer from the same health board. None of the Part 1 patients was involved in Part 2. Patient eligibility criteria were as follows: (a) histologically confirmed diagnosis of lung cancer; (b) life expectancy ≥ 4 months; (c) deemed physically and psychologically fit to participate; (d) able to read and write English; (e) able to provide written informed consent; and (f) able to provide consent for the researcher to access hospital case notes. Lung CNS participants were the same individuals as in Part 1.

Three consecutive patient-clinician consultations took place at monthly intervals, i.e. baseline (T1); 1 month post-baseline (T2); and 2 months post-baseline (T3). This approach acknowledged the limited survival of this patient group [25], thus allowing sufficient time to pilot-test with reduced risk for death-related attrition. At each time-point, patients completed the selected PRO measure in a quiet room in the hospital immediately prior to their appointment with the lung CNS. Subsequently, the lung CNS met with the patient and used PRO data to identify unmet needs, direct discussions, and intervene accordingly. The lung CNS documented any identified needs and clinical interventions/advice in author-developed pro-formas. No specific clinical guidance was given to lung CNS as to how to respond to patient needs.

To assess intervention feasibility we analysed data on patient availability/recruitment, time and resource requirements, missing data, and patient retention. In terms of acceptability, we investigated patient adherence to the intervention, perceived burden, value and appropriateness of the timing of delivery. At the end of the study, we conducted exit interviews with a subset of patients ($n \leq 10$) and the lung CNS to explore their perceptions on the tested intervention in greater depth, and gather suggestions for improvement. Secondly, we analysed PRO measure data to explore the prevalence of supportive care needs in the study sample, and how and in what extent these needs changed from T1 to T3.

Data Analysis

All interviews (Parts 1 and 2) were aided by the use of topic guides that employed open-ended questions, and were audio recorded and transcribed verbatim. The software analysis package QSR NVivo© was used to aid organisation of the data that was classified into themed categories. Analysis of the data was thematic, focussing on whether and how participants agreed or disagreed about each issue [26]. For reliability and validity purposes, two researchers coded interviews separately and then cross-checked them.

Quantitative data (Part 2) were analysed using SPSS (IBM SPSS Inc.; Chicago, IL) descriptive statistics functionality and graphs. The dataset was checked for missing values, and these were approximated accordingly. Frequency counts for each item on the PRO measure were generated to describe response patterns. Individual items were also aggregated to yield scores on domains of need. To assess sensitivity to change, effect sizes were calculated for individual items, and effect sizes and standardised response means (SRM) for all of the domains of need [27, 28]. Effect sizes and SRM of 0.2, 0.5 and 0.8 were regarded as indicating small, moderate and large degrees of change, respectively [29]. Friedman tests with post hoc between groups comparisons (Mann-Whitney U) were used to test for significant over-time changes in the domain of need scores. All tests were two-sided; the level of significance was set at 0.05.

Results

Part 1

Our systematic reviews identified a wide range of unmet needs in people with lung cancer [22], and generated a pool of twenty-six validated, self-report PRO measures to assess these needs [21]. We

specifically targeted PRO measures that assessed the majority of identified domains of need, i.e. physical (loss of energy, breathlessness, pain, sleeplessness); psychological (anxiety, loss of control, sadness, feeling a burden); social (impact of illness on family members); daily living (not being able to work/do housework); practical (too much time wasted over diagnosis/treatment); communication (having a clinician to trust and available); information (things one could do to help get well); and spiritual needs (fear of the unknown) [22]. As such, we shortlisted eleven PRO measures, which we introduced to focus group participants. During the focus groups, patients (n=4; three men) confirmed their living with multiple needs, particularly stressing the importance of receiving help with their practical and daily living needs. The lung CNS (n=3; two women; all >6 years clinical experience in lung cancer care) noted how patients' needs are "...interlinked and of equal importance" (CNS1), but acknowledged that the complexity of lung cancer care often rendered needs assessments challenging. Based on these views, focus group participants agreed that the Sheffield Profile for Assessment and Referral to Care (SPARC) [30] was the most appropriate/suitable PRO measure, which was seen as "*brief, comprehensive, and to the point*" (CNS2). The SPARC consists of 45 items that concern communication and information issues, physical symptoms, psychological issues, religious and spiritual issues, independence and activity, family and social issues, treatment and person issues. Recent research supports its psychometric properties and acceptability among patients with thoracic cancer [31].

Part 2

Feasibility: Recruitment/refusal Rates

From February 2011 to April 2012, 76 eligible patients were identified; 56 refused for various reasons. These included starting treatment and wanting to focus on that (n=5); concurrent participation in another clinical trial (n=3); too unwell (n=7); just out of hospital (n=2); too much on at the moment (n=26); poor concentration (n=2); too many hospital visits (n=4); additional time factor (n=5); transportation and relocation issues (n=2). The final sample consisted of 20 patients (response rate 26.3%) who provided written informed consent. Patient demographic and clinical characteristics are shown in **Table 1**.

Feasibility: Patterns of Missing Data and Attrition Rates

Missing items due to non-response were scarce (<2%) irrespective of assessment point. No specific patterns of missing data were observed. From T1 to T2, five patients were lost to follow-up. Reasons included deterioration in condition (n=3), decision to withdraw after treatment had stopped due to toxicities (n=1), and difficulty to attend consultations (n=1). Two more patients dropped out between T2 and T3 due to deterioration in their health status. As a result, thirteen patients (attrition rate 35%) completed all three assessments.

Perceived acceptability and value of the intervention

Nine patients with lung cancer (6 men, 3 women) and three lung CNS (2 women, 1 man) took part in exit interviews. Two themes were generated, namely "Perceptions regarding the delivery of the intervention" and "Reflections on the change in clinical consultations" (**Table 3**).

- *Theme 1: Perceptions regarding the delivery of the intervention*

Patients found the SPARC easy to understand and complete, whilst its scoring system allowed them to self-assess how their symptoms and needs changed over time, instilling a sense of control (Q1). Patients felt that the SPARC prompted discussion on the full spectrum of their potential needs; yet, some suggested the inclusion of additional questions regarding psychological issues (Q2, Q3). Having a highly individualised one-to-one session with the lung CNS was positively viewed as it created a familiar and safe environment for discussion (Q4). Eight patients also agreed that 'once a month' was "*just right*" as this time frame allowed enough time for the nurse to implement an intervention and subsequently evaluate if it was working.

Lung CNS perceived that the questionnaire offered an easy format for them to assess patients' priority needs (Q5). It was however highlighted that more junior staff may have not been able to deal with the full spectrum of patient needs, especially those more sensitive issues, and that formal training in discussing these domains of need is required (Q6). Like patients, the CNS viewed the face-to-face aspect of the intervention an important part of the study (Q7). For one lung CNS, having PRO data available in advance of the actual consultation appointment was perceived to be helpful to give the CNS time to organize resources and appropriate methods of management. It was also suggested that for those patients who are unable to attend acute care, the SPARC be delivered in the community setting by primary care staff (e.g. District or Macmillan nurses) or via home visits by the CNS. The point of diagnosis, end of treatment and

follow-up were perceived to be key points of patient need; it was thus suggested that these crucial time points be considered in future assessments (Q8, Q9).

- *Theme 2: Reflections on the change in clinical consultations*

Patients felt that the intervention provided structure to their thinking, whilst enabled them to be active participants in their care. This gave them a sense of empowerment and control (Q10, Q11). Patients described how some long-term symptoms, such as breathlessness, had been re-assessed and subsequent interventions had led to significant improvements. It appeared that these symptoms had been bypassed in previous consultations due to their chronicity or to being attributed to other conditions (Q12). All participants commented on how having dedicated time with the CNS was unlike their experiences of previous consultations, which were predominantly rushed and only focusing on one area of care (Q13). The consistency of meeting with the same CNS each time was also viewed positively as it allowed for a rapport to be built, making it easier for patients to share their concerns.

Lung CNS highlighted how the consultations appeared to differ from previous ones, in that the patients were driving consultations, bringing up issues that were pertinent to them (Q14). This approach appeared to lead to a more holistic method of assessment that encompassed many domains of the patient experience. Sensitive issues, such as death and dying, concerns regarding family, the effects of treatment and sexuality were commonly raised, and these were issues that were rarely discussed previously. Reflecting on standard consultations, lung CNS acknowledged that previously consultations tended to mainly focus on physical needs. Use of the SPARC was perceived to provide patients with an 'open invitation' to report a wide array of needs; in turn, it provided CNS with a 'direct invitation' to even discuss sensitive issues (Q15). In addition, the dedicated consultations allowed CNS to spend time with the patient and understand the underlying cause of concerns, which in turn resulted in more appropriate management (Q16).

Prevalence and Over-Time Change in Reported Needs

Dealing with physical ailment (predominantly, shortness of breath, cough, fatigue and sleeplessness), feeling anxious and in a low mood, and feeling that everything was an effort were predominant sources of concern throughout Part 2 (**Suppl. Table**). Close to 40% reported having worrying thoughts about death and dying regardless of time-point. Eight in 10 also reported worrying about the effect their illness was having on their family and significant others.

In aggregated analyses (**Table 3**), a relative reduction in the magnitude of patients' needs was observed from T1 to T2 and from T1 to T3. Change-related effect sizes were predominantly small, except for the spiritual needs domain (T1-T2) and the family/social needs and treatment concerns domains (T1-T3). Moderate SRMs were also found for the physical and psychological domains of need.

Friedman tests revealed only trends towards reduction in spiritual/religious, family/social and treatment concerns across the three time-points ($0.10 \geq p > 0.05$). A significant reduction in the magnitude of psychological and spiritual needs was found from T1 to T2, whilst reductions in family/social and treatment concerns from T1 to T3 were also evident ($p < 0.05$). With the exception of the latter domains, relapse to baseline levels was observed at T3 for all other domains of need (**Figure 1**).

Discussion

Our findings suggest that this nurse-led, PRO-measures-driven consultation model is acceptable to both patients with lung cancer and lung CNS, and conditionally feasible in clinical practice to enhance delivery of supportive/palliative. Our study also highlights the potential for the model to lead to meaningful reductions in patients' unmet needs that could be associated with gains in quality of life. Hard evidence on the effects of the routine use of PRO measure feedback on the supportive care needs of patients with cancer is scarce [10]. However, the observed significant reduction in the psychological and spiritual domains of need (T1 to T2), and family/social and treatment concerns domains (T1 to T3) suggest that, despite the lack of a control group, these patient outcomes are amenable to improvement in clinical practice [32]. No significant overall change in the physical needs domain was found, thus supporting existing evidence suggesting persistent symptom distress for patients with lung cancer over time [33].

Whilst small, our study suggests that PRO-measure-driven consultations may act as facilitators to a comprehensive assessment that leads to prompt identification and tailored management of needs in this patient group. In exit interviews, patients highlighted how the selected PRO measure prompted them to think about their full spectrum of needs, resulting in them flagging needs and concerns that they would not have been identified previously. Relevant evidence purports the usefulness of PRO measures in identifying issues that are most bothersome to patients [34]. Our findings are of particular significance as people with lung cancer have been reported to be reluctant to ask for help with their needs [35]. Patients also commented positively on the opportunity to establish a close relationship with the CNS that contributed to their sense of being cared for. PRO-measures-driven consultations can help establish rapport during early palliative care for lung cancer that can act as a means of reassurance for patients that their needs and preferences are taken into account [6]. Lung CNS described how patients were 'driving' the consultations, using the PRO measure to highlight issues that were most important to them, and be in control of the flow of information. Often, such issues went beyond physical symptoms, i.e. issues about death and dying, or concerns about the family [32]. Evidence suggests that nurses perceive physical needs as easier to assess/manage than other needs [36, 37]. Such perceptions may lead clinicians to neglect important non-physical needs, unless clinical assessments directly involve the patient. PRO-measures-driven consultations serve this very notion. As part of a multidisciplinary team effort, referrals would be warranted where necessary (e.g. for patients with complex psychosocial needs), but dedicated training programs could be of particular help to increase confidence among lung CNS to address less salient (and more sensitive) needs that may be considered 'challenging' and potentially off-putting.

While attrition rate was kept to a moderate 35% considering a physically challenging illness like lung cancer, only about 3 in 10 eligible patients were enrolled in the study in the first place. Whether patient access rates would be the same should this model be a fully integrated healthcare service can only be assumed. However, patient accessibility to a potentially useful service could be questioned. This is particularly relevant for PRO-measures-driven consultation models that claim to promote patient-centredness and inclusivity in a highly systematic way [10, 38]. For instance, PRO-measures-driven consultation models could enhance patient accessibility to tailored care, particularly in light of reports that older patients with poorer performance status, earlier cancer stage, and more comorbidities may be less likely to be assessed by a lung CNS [39]. For this to be realised, there is a clear indication for further refinement of this service model before implementation takes place. In line with participants' suggestions, a number of steps can be taken to increase operationalisation of the delivery of PRO measures-driven needs assessments in this area. Patient self-assessments prior to consultation appointments could allow for adequate time for nurses to evaluate patient feedback and organise resources according to need priority. Harnessing technology to realise collection of PRO data is a crucial step to this direction [40], especially as it can help overcome patient participation barriers that can adversely impact on feasibility and deployment of this service. Moreover, ensuring availability of such services in the community rather than exclusively in acute care is important to ensure that patients cared for at home are not excluded from needs assessments. This is an important component of the future delivery of PRO-measures-driven consultation models in light of the advanced nature of lung cancer [25] and the shift of services to local settings [41, 42].

A number of limitations warrant commenting. First, representativeness of the study sample is limited to older male, married and well-educated patients, with good performance status and a limited number of additional co-morbidities. It thus may be argued that our patient group was not representative of the general lung cancer population. Second, delivery of in-clinic consultations may have excluded patients, who were unable to attend due to practical difficulties or health status. Third, the pre-requisite for patients to be able to read and write English may have acted as a barrier to recruitment of non-English speaking patients. Similarly, our sample of lung CNS included highly experienced health professionals, which questions whether similar findings would have been yielded with less experienced clinicians. Finally, the non-experimental nature of this feasibility study precludes safe conclusions on the effectiveness of this intervention model. In conjunction with the small sample size, poor response rate, and moderate attrition rate, findings should be interpreted with caution.

Conclusions

Nurse-led PRO-measures-driven consultations are acceptable and conditionally feasible to holistically identify and effectively manage patient needs in modern lung cancer care. Lung CNS are key professionals in the delivery of supportive care, and are receptive to and able to act upon information

gleaned from PRO measures in clinical practice. Pragmatic controlled trials are required to demonstrate the definitive impact of the delivery of PRO measures on lung cancer patient outcomes, at the same time taking into consideration the expectations of end users and the challenges of clinical practice. Whilst key time-points for PRO assessments in lung cancer care seem to be diagnosis and end of treatment/follow-up, systematic on-going needs assessments should be pursued throughout the illness experience.

Conflicts of Interest

The authors declare that there are no financial or other conflicts of interest with regard to this study.

Statement of Authorship

All authors have equally contributed to the preparation of this manuscript.

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FIGURE AND TABLE LEGENDS

Figure 1. Over-time changes in median scores of the six SPARC domains of need.

Table 1. Baseline demographic and clinical patient characteristics (n=20).

Table 2. Frequency distribution of individual needs and change-related effects sizes.

Table 3. Themes and quotes from exit interviews with patients and lung CNS.

Suppl. Table. Descriptive statistics and effect sizes of the six SPARC domains of need.

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TABLES

Table 1. Baseline demographic and clinical patient characteristics (*n*=20)

		Frequency	%
Age	Mean (SD)	67.1 (8.62)	
	Median	69.5	
	Range	32 (51-83)	
	IQR	13	
Time since diagnosis (days) ^a	Mean (SD)	284.6 (404.3)	
	Median	118.0	
	Range	1401 (20-1421)	
	IQR	267	
Gender	Male	13	65.0
Educational background	High school	18	90.0
	Some college	1	5.0
	University	1	5.0
Marital status	Married/partnered	13	65.0
	Single	2	10.0
	Divorced	3	15.0
	Widowed	2	10.0
Employment status	Employed	2	10.0
	Unemployed	4	20.0
	Retired	14	70.0
Type of disease	NSCLC	16	80.0
	SCLC	2	10.0
	Other (e.g. mesothelioma)	2	10.0
Disease stage ^b	Local	9	47.4
	Metastatic	10	52.6
Co-morbid illnesses	Yes	5	25.0

^a*n*=11

^b*n*=19

Abbreviations: IQR – Interquartile range; NSCLC – non-small cell lung cancer; SCLC – small cell lung cancer

Table 2. Descriptive statistics and effect sizes of the six SPARC domains of need

SPARC domain of need	T1 M±SD (range)	T1 Median (IQR)	ES T1-T2	ES T1-T3	SRM T1-T2	SRM T1-T3
Physical	17.00±8.83 (1-42)	15.00 (10)	-0.255	-0.187	-0.447	-0.263
Psychological/ emotional	4.15±4.57 (0-20)	3.00 (4)	-0.285	-0.142	-0.504	-0.272
Spiritual/religious	0.85±0.99 (0-3)	0.50 (2)	-0.455	0.0	-0.507	0.0
Independence	1.20±1.91 (0-7)	0.00 (3)	-0.236	-0.052	-0.306	-0.062
Family/social	1.65±1.27 (0-4)	1.00 (2)	-0.236	-0.513	-0.217	-0.549
Treatment concerns	1.85±1.63 (0-6)	2.00 (3)	-0.215	-0.521	-0.259	-0.484

Abbreviations: ES – effect size; SRM – standardised response mean; M – mean; SD – standard deviation; IQR – Interquartile range; SPARC – Sheffield Profile for Assessment and Referral to Care.

Notes: ES are calculated as the difference between a mid-point and baseline score divided by the standard deviation (SD) of the baseline scores. SRM are calculated as the ratio of individual change to the SD of that change, after change scores (T2 minus T1, T3 minus T1) were calculated. Expectation-maximisation imputation was used to replace missing values for domain-of-need scores at T2 and T3, following a separate analysis to examine the possibility of attrition bias. No significant demographic or clinical differences between study completers and non-completers ($p>0.05$) were found, except for disease stage where non-completers were at a more advanced stage compared to completers ($Z=-2.147$; $p=0.032$).

Key: Cohen's d benchmarks $d= 0.2$ (small effect), 0.5 (moderate effect) and 0.8 (large effect); Key 2: ES of -0.25 indicates decrease of 0.25 SD

Table 3. Themes and quotes from exit interviews with patients and lung CNS

	Emerging themes	
Respondent	#1 Perceptions regarding the delivery of the intervention	#2 Reflections on the change in clinical consultations
Patient quotes	<p>Q1: <i>"they [the questions] made you think, like I, I'm not as bad as I think I am, you know when you see the... the different categories and you're saying 'I'm a 1, or I'm a 2, or...'; whatever it's a, well it's really it's not that bad and it made me feel better"</i> P3.</p> <p>Q2: <i>"the only down thing I found that was lacking a bit was what's going on in your b-r-a-i-n"</i> P3.</p> <p>Q3: <i>"I think even if the questionnaire would say just plain simple terms, "how did you cope with it in your mind?"</i> P8.</p> <p>Q4: <i>"...the most useful thing I've found is actually the one to one..."</i> P9.</p>	<p>Q10: <i>"eh, the questions made you think about what was going on and how your body was reacting and made you think more about what you wanted"</i> P3.</p> <p>Q11: <i>"...It made me feel as if, yeah I was achieving something"</i> P1.</p> <p>Q12: <i>"...if I had'nae done this, the, I'd ah just been going on and on eh with it, and they think this is coming from the COPD that I have, rather than the cancer, so that's good"</i> P2.</p> <p>Q13: <i>"I think I would, now I would ask a lot more questions now... Before then I was just sitting and it was just... pffft! – right over my head, went over my head and it was my wife that was picking, picking it all up"</i> P1.</p>
Lung CNS quotes	<p>Q5: <i>"I suppose I thought it was very clear, I thought patients do like the tick box thing... and em I think there was a wide variety of areas that they could tick"</i> CNS2.</p> <p>Q6: <i>"I think a lot of patients like the fact that they've got the appointment and it's that physical contact that they like with you"</i> CNS2.</p> <p>Q7: <i>"I'm just talking about having a level of experience and eh... and almost I suppose some type of post graduate education or further education to underpin what they're being asked to do and experiential work as well I know that's absolutely like vital"</i> CNS3.</p> <p>Q8: <i>"there's no reason why this cannot be built into a patient pathway through the diagnostic pathway at the point of diagnosis this could be administered to patients and at whatever time frame people felt was appropriate and beyond that"</i> CNS3.</p> <p>Q9: <i>"...and then you know once disease progresses, I suppose they are on their next lot of treatment after that and then their moving towards end of life"</i> CNS2.</p>	<p>Q14: <i>"I think the tool has been a useful...in guiding consultations with patients and often guiding you to areas of concerns for patients that you might otherwise not of thought about or not have interrogated as rigorously without the tool"</i> CNS3.</p> <p>Q15: <i>"I suppose when you have these consultations with patients, you are often depending on the patient being prepared to verbalise what their concerns are or being articulate enough to eh express them whereas I think you know if say they have to sit and they've had the opportunity to fill the questionnaire in, em... it probably gives you a bit better insight into what's going on... in their head... ..for me I think for certainly the patients that participated it made them open up a wee bit, so in terms of it being a positive experience I think I probably got more out of the consultations..."</i> CNS3.</p> <p>Q16: <i>"I mean I just have to emphasise...I really liked it...and I thought it was really useful and I liked the structure [mmm] of the appointments and the fact that you could follow interventions through and it's good to see that you're making a difference..."</i> CNS2.</p>

Abbreviations: CNS – Cancer Nurse Specialist; COPD – Chronic obstructive pulmonary disease.

Suppl. Table. Frequency distribution of individual needs and change-related effects sizes

SPARC		T1 (n=20)			T2 (n=15)			T3 (n=13)			ES T1-T2	ES T1-T3
Domain of need	Item	0	1	2-3	0	1	2-3	0	1	2-3		
Physical	Pain	6 (30.0)	10 (50.0)	4 (20.0)	9 (60.0)	5 (33.3)	1 (6.7)	4 (30.8)	8 (61.5)	1 (7.7)	-0.577	-0.250
	Loss of memory	16 (80.0)	3 (15.0)	1 (5.0)	11 (73.3)	4 (26.7)	–	11 (84.6)	1 (7.7)	1 (7.7)	0.036	-0.036
	Headache	12 (60.0)	7 (35.0)	1 (5.0)	10 (66.7)	4 (26.7)	1 (6.7)	10 (76.9)	3 (23.1)	–	-0.082	-0.363
	Dry mouth	3 (15.0)	12 (60.0)	5 (25.0)	5 (33.3)	6 (40.0)	4 (26.7)	1 (7.7)	9 (69.2)	3 (23.1)	-0.265	0.078
	Sore mouth	9 (45.0)	5 (25.0)	6 (30.0)	9 (60.0)	5 (33.3)	1 (6.7)	6 (46.2)	4 (30.8)	3 (23.1)	-0.400	-0.095
	Shortness of breath	2 (10.0)	9 (45.0)	9 (45.0)	2 (13.3)	7 (46.7)	6 (40.0)	1 (7.7)	3 (23.1)	9 (69.2)	-0.201	0.321
	Cough	5 (25.0)	9 (45.0)	6 (30.0)	5 (33.3)	7 (46.7)	3 (20.0)	7 (53.8)	2 (15.4)	4 (30.8)	-0.328	-0.348
	Feeling sick (nausea)	10 (50.0)	7 (35.0)	3 (15.0)	9 (60.0)	3 (20.0)	3 (20.0)	9 (69.2)	4 (30.8)	–	-0.034	-0.451
	Being sick (vomiting)	15 (75.0)	4 (20.0)	1 (5.0)	12 (86.7)	1 (6.7)	1 (6.7)	8 (61.5)	4 (30.8)	1 (7.7)	-0.175	0.280
	Bowel problems	10 (50.0)	6 (30.0)	4 (20.0)	8 (53.3)	6 (40.0)	1 (6.7)	5 (38.5)	7 (53.8)	1 (7.7)	-0.212	-0.012
	Bladder problems	15 (75.0)	3 (15.0)	2 (10.0)	11 (73.3)	4 (26.7)	–	10 (76.9)	2 (15.4)	1 (7.7)	-0.190	-0.074
	Feeling weak	5 (25.0)	10 (50.0)	5 (25.0)	3 (20.0)	7 (46.7)	5 (33.3)	6 (46.2)	3 (23.1)	4 (30.8)	0.179	-0.110
	Feeling tired	2 (10.0)	8 (40.0)	10 (50.0)	1 (6.7)	6 (40.0)	8 (53.3)	1 (7.7)	7 (53.8)	5 (38.5)	0.036	-0.048
	Problems sleeping at night	7 (35.0)	5 (30.0)	7 (35.0)	5 (33.3)	5 (33.3)	5 (33.3)	6 (46.2)	3 (23.1)	4 (30.8)	0.029	-0.176
	Feeling sleepy during the day	3 (15.0)	12 (60.0)	5 (25.0)	1 (6.7)	10 (66.7)	4 (26.7)	3 (23.1)	7 (53.8)	3 (23.1)	0.067	-0.201
	Loss of appetite	7 (35.0)	7 (35.0)	6 (30.0)	6 (40.0)	6 (40.0)	3 (20.0)	5 (38.5)	6 (46.2)	2 (15.4)	-0.217	-0.250
	Changes in your weight	6 (30.0)	12 (60.0)	2 (10.0)	7 (46.7)	7 (46.7)	1 (6.7)	5 (38.5)	7 (53.8)	1 (7.7)	-0.242	-0.215
	Problems with swallowing	15 (75.0)	4 (20.0)	1 (5.0)	12 (80.0)	3 (20.0)	–	8 (61.5)	4 (30.8)	1 (7.7)	-0.201	0.255
	Concerned about changes in appearance	14 (70.0)	5 (25.0)	1 (5.0)	8 (53.3)	5 (33.3)	2 (13.3)	9 (69.2)	3 (23.1)	1 (7.7)	0.426	0.051
	Feeling restless and agitated	12 (60.0)	6 (30.0)	2 (10.0)	10 (66.7)	3 (20.0)	2 (13.3)	9 (69.2)	2 (15.4)	2 (15.4)	-0.024	-0.012
Feeling that symptoms are not controlled	14 (70.0)	4 (20.0)	2 (10.0)	11 (73.3)	3 (20.0)	1 (6.7)	9 (69.2)	2 (15.4)	2 (15.4)	-0.145	0.012	
Psychological	Feeling anxious	7 (35.0)	10 (50.0)	3 (15.0)	6 (40.0)	6 (40.0)	3 (20.0)	7 (53.8)	4 (30.8)	2 (15.4)	-0.061	-0.283
	Feeling in a low mood	6 (30.0)	9 (45.0)	5 (25.0)	6 (40.0)	5 (33.3)	4 (26.7)	7 (53.8)	4 (30.8)	2 (15.4)	-0.081	-0.443
	Feeling confused	17 (85.0)	2 (10.0)	1 (5.0)	14 (93.3)	–	1 (6.7)	11 (84.6)	1 (7.7)	1 (7.7)	-0.167	-0.028
	Feeling unable to concentrate	14 (70.0)	4 (20.0)	2 (10.0)	12 (80.0)	2 (13.3)	1 (6.7)	10 (76.9)	2 (15.4)	1 (7.7)	-0.218	-0.169
	Feeling lonely	15 (75.0)	3 (15.0)	2 (10.0)	10 (66.7)	5 (33.3)	–	7 (53.8)	4 (30.8)	1 (7.7)	-0.085	0.121
	Feeling that everything is an effort	9 (45.0)	10 (50.0)	1 (5.0)	9 (60.0)	5 (33.3)	1 (6.7)	5 (38.5)	6 (46.2)	2 (15.4)	-0.242	0.161
	Feeling that life is not worth living	17 (85.0)	2 (10.0)	1 (5.0)	14 (93.3)	1 (6.7)	–	10 (76.9)	2 (15.4)	1 (7.7)	-0.248	0.344
	Thoughts about ending it all	18 (90.0)	1 (5.0)	1 (5.0)	14 (93.3)	–	1 (6.7)	11 (84.6)	2 (15.4)	–	-0.040	0
	Effect of condition on sexual life	18 (90.0)	1 (5.0)	1 (5.0)	15 (100.0)	–	–	12 (92.3)	1 (7.7)	–	-0.040	0.164
	Worrying thoughts about death or dying	13 (65.0)	6 (30.0)	1 (5.0)	9 (60.0)	5 (33.3)	1 (6.7)	8 (61.5)	4 (30.8)	1 (7.7)	0.026	0.118
Religious/ spiritual	Religious or spiritual needs not being met	15 (75.0)	2 (10.0)	3 (15.0)	14 (93.3)	1 (6.7)	–	12 (92.3)	–	1 (7.7)	-0.437	-0.225
	Losing independence	14 (70.0)	4 (20.0)	2 (10.0)	11 (73.3)	4 (26.7)	–	11 (84.6)	1 (7.7)	1 (7.7)	-0.191	-0.249
Independence	Changes in ability to carry out daily activities	14 (70.0)	5 (25.0)	1 (5.0)	10 (66.7)	4 (26.7)	1 (6.7)	10 (76.9)	2 (15.4)	1 (7.7)	0.085	-0.068
	Changes in ability to carry out household tasks	13 (65.0)	6 (30.0)	1 (5.0)	10 (66.7)	5 (33.3)	–	8 (61.5)	2 (15.4)	3 (23.1)	-0.158	0.223
	Feeling that people do not understand what you want	17 (85.0)	3 (15.0)	–	11 (73.3)	4 (26.7)	–	12 (92.3)	1 (7.7)	–	0.327	-0.191
Family/social	Worrying about the effect illness is having on family/others	4 (20.0)	9 (45.0)	7 (35.0)	3 (20.0)	7 (46.7)	5 (33.3)	4 (30.8)	7 (53.8)	2 (15.4)	-0.174	-0.388
	Lack of support from family/others	18 (90.0)	1 (5.0)	1 (5.0)	14 (93.3)	1 (6.7)	–	13 (100.0)	–	–	-0.163	-0.306
	Needing more help than family/other can give	19 (95.0)	1 (5.0)	–	15 (100.0)	–	–	13 (100.0)	–	–	-0.223	-0.223

Suppl. Table. Frequency distribution of individual needs and change-related effects sizes

SPARC		T1 (n=20)			T2 (n=15)			T3 (n=13)			ES T1-T2	ES T1-T3
Domain of need	Item	0	1	2-3	0	1	2-3	0	1	2-3		
Treatment concerns	Side effects of treatment	8 (40.0)	7 (35.0)	5 (25.0)	5 (33.3)	9 (60.0)	1 (6.7)	8 (61.5)	4 (30.8)	1 (7.7)	-0.186	-0.394
	Worry about long term effects of treatment	8 (40.0)	6 (30.0)	6 (30.0)	8 (53.3)	5 (33.3)	2 (13.3)	8 (61.5)	4 (30.8)	1 (7.7)	-0.370	-0.518

Abbreviations: ES – Effect size; SPARC – Sheffield Profile for Assessment and Referral to Care.

Notes: Based on data after EM imputation; Key: Cohen's d benchmarks d= 0.2 (small effect), 0.5 (moderate effect) and 0.8 (large effect); Key 2: ES of -0.25 indicates decrease of 0.25 SD