

POST TREATMENT

Experiences and outcomes of lung cancer patients using electronic assessments

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Conflict of interest

The statistics in this article are the results of a self-evaluation carried out by local project staff, in collaboration with Edinburgh Napier University TCAT Evaluation Team. The views expressed in this article do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support

Peer review

This article has been subject to external double-blind peer review and checked for plagiarism using automated software

Abstract

The NHS Lanarkshire Lung Cancer Project is part of the Transforming Care after Treatment programme, a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities, to support a redesign of care following active treatment for cancer. More people are living with lung cancer, but it continues to have a poor prognosis, therefore follow-up care is vital and all patient needs, not just medical, must be addressed appropriately. This article outlines a two-year project that aims to influence changes in follow up for patients with lung cancer, through the testing of digital health technology. The article reports the interim results of the project, which suggest that using electronic patient reported outcome measures, combined with telephone consultations, are acceptable methods of identifying and supporting patients' needs.

Keywords

cancer nursing practice, holistic cancer needs assessment, lung cancer, patient reported outcome measures, Sheffield Profile of Assessment and Referral of Care, transforming care after treatment

Background

Lung cancer is the most common cancer in Lanarkshire, Scotland, accounting for 16% of all cancer diagnoses. Between 2008 and 2012, 2,398 people in Lanarkshire were diagnosed with the condition and this number is expected to rise, mainly due to an ageing population, earlier detection and developments in treatment (Aung and Clark 2011). Despite improvements in detection and treatment, lung cancer continues to be diagnosed at later stages and 46% of patients in Scotland are diagnosed at stage IV (Cancer Research UK (CRUK) 2017). Therefore, it has one of the lowest survival rates of any cancer, with only 31% of patients surviving more than a year after diagnosis (CRUK 2017). Follow-up care is concentrated in the first two years after treatment and it is vital that all patient needs, not just medical, are addressed appropriately.

Rowe et al (2014) suggest that one third of patients with cancer have unmet needs and for 60%, these needs are still a concern six months post treatment. The National Institute for Health and Care Excellence (2004) recommends that patients' needs are assessed at multiple points on their cancer journey, including after treatment. There are numerous patient-reported outcome measures available to support this. However, patients with lung cancer and lung cancer clinical nurse specialists consider that the

Sheffield Profile for Assessment and Referral for Care (SPARC) questionnaire is easy to complete (Maguire et al 2013). The SPARC questionnaire consists of 45 items within the following eight domains:

- » Communication and information issues.
- » Physical symptoms.
- » Psychological issues.
- » Religious and spiritual issues.
- » Independence and activity.
- » Family and social issues.
- » Treatment issues.
- » Personal issues.

It also includes a text box to enable patients to raise other concerns. Patients score each item as 0=not at all, 1=a little bit, 2= quite a bit, and 3=very much (Leppert et al 2011). Using the results in disclosure of patients' needs that they might not have raised during a consultation (Maguire et al 2013), the information gathered from the questionnaire and subsequent discussion between the patient and healthcare professional can be used to compile a care plan to address these needs (National Cancer Survivorship Initiative 2013).

The Scottish Cancer Patient Experience Survey reveals that only 24% of patients with lung cancer in Scotland have received such a care plan and 56% feel unsupported by their health and social care teams after treatment (Scottish Government 2016a).

These findings resulted in a two-year project, which started in March 2016, aimed at influencing changes in the way patients with lung cancer are followed up through to the testing of electronic health technology. As part of the project, patients complete an electronic SPARC (eSPARC) questionnaire, which is reviewed by a lung cancer nurse specialist and enables provision of self-management information, signposting and onward referral, to ensure patients' needs are identified and met.

Aim

The aim of the NHS Lanarkshire Lung Cancer project was to test the use of electronic patient-supported outcome measures to support patients with lung cancer following completion of primary treatment, and is part of the Transforming Care After Treatment (TCAT) partnership programme between NHS Scotland, the Scottish Government, local authorities and Macmillan Cancer Support (Scottish Government 2016b). Launched in June 2013, with five years funding from Macmillan Cancer Support, TCAT tests new ways of working to identify unmet needs and support patients' transition from acute to primary care on completion of treatment. The NHS Lanarkshire Lung Cancer project is one of 11 phase-one TCAT projects in Scotland (Scottish Government 2016b).

Method

Patients with lung cancer who live in Lanarkshire were invited to complete an eSPARC questionnaire monthly for six months, provided by telehealth company Docobo. Although patient-supported outcome measures have been successful in identifying unmet needs, there is a lack of evidence that they improve clinical outcomes or quality of life (Ahmed et al 2014). Therefore, patients were asked to complete three additional patient-supported outcome measures – the Functional Assessment of Cancer Therapy – Lung, the Memorial Symptom Assessment Scale and Supportive Care Needs Survey – before starting the project and after completing the third and sixth assessment to support evaluation. Patients were also asked to complete a patient experience survey following their last assessment.

Sampling

Eligibility criteria were NHS Lanarkshire patients with a diagnosis of lung cancer, who have completed surgery, radical radiotherapy, palliative radiotherapy or chemotherapy. The project focused on active treatment pathways. Patients receiving best supportive care were not included.

Procedure

A patient information leaflet was sent to all eligible patients, followed by a telephone call from the project manager. If they agreed to participate, consent was obtained with baseline patient-reported outcome measures data. They were then asked to select a preferred day on which to complete the eSPARC questionnaire and were sent an email on that day containing a link to the Docobo platform (Docoboweb), from which they could access the eSPARC questionnaire any time between 6am and 11am. A reminder text message was sent on the day of the assessment through NHS.net to encourage patients to check their email.

The concerns identified on completed eSPARC questionnaires were reviewed by the lung cancer clinical nurse specialist and patients were given the option of a face-to-face or telephone consultation to discuss these. The aim of the consultations was to explore concerns scored 2 (quite a bit) and 3 (very much), and patients and the lung cancer clinical nurse specialist agreed on a plan of care to manage each one, through a combination of self-management information, signposting and onward referral. The agreed plan of care was documented on a care plan shared with patients by email or post, depending on their preference. Using WinVoice technology, a copy of the care plan was uploaded onto patients' clinical portal records and sent electronically to their GPs.

For concerns scored 1 (a little bit) patients were directed to the self-management document, an evidence-based document written by the project team, providing self-management information and details about local services relevant to the 45 items on the SPARC questionnaire. A copy of the document was available on Docoboweb, which patients could log in to at any time and they were emailed a copy with their care plan.

Results

At this interim stage, 34 (22%) of the 158 patients invited to participate accepted. Reasons for declining include additional support not required, ill health due to non-cancerous conditions and lack of computer access. Complete data is available for 20 patients who have completed three eSPARC questionnaires and two Functional Assessment of Cancer Therapy – Lung, Memorial Symptom Assessment Scales and Supportive Care Needs Survey patient-reported outcome measures.

Participant characteristics

Table 1 summarises participants' characteristics, which reflect the general lung

cancer population in the UK, where the male-to-female ratio of new lung cancer diagnoses

TABLE 1. Participant characteristics

	Number	Percentage
Gender		
Female	10	50%
Male	10	50%
Age		
50-59 years	4	20%
60-69 years	6	30%
70-79 years	8	40%
80+ years	2	10%
Scottish Index of Multiple Deprivation		
1 (most deprived)	5	25%
2	5	25%
3	5	25%
4	2	10%
5 (least deprived)	3	15%
Economic activity		
Employed	1	5%
Unemployed	2	10%
Retired	14	70%
Long-term sick or disabled	3	15%
Diagnosis		
Non-small cell lung cancer	20	100%
Primary treatment		
Chemoradiation	2	10%
Chemotherapy	4	20%
Radiotherapy	3	15%
Surgery	11	55%
Co-morbidities		
1	8	40%
2	3	15%
3+	9	45%

is 11:10 (CRUK 2016) and most patients are diagnosed over the age of 65 (National Cancer Registration and Analysis Service 2017). A range of Scottish Index of Multiple Deprivation groups were involved in the project – 70% of participants are retired and 60% live with more than two co-morbidities.

eSPARC questionnaire

The average length of time to complete the first eSPARC questionnaire was 13 minutes and 15 seconds, which decreased slightly with each assessment, dropping to 11 minutes and 51 seconds by the third assessment. Most cancer nurse specialist consultations were carried out by telephone (71%); 13% were face-to-face reviews and no review was required for 15% of assessments. The average length of time of face-to-face consultations was 50 minutes – compared to 18 minutes for telephone consultations. The average length of time of cancer nurse specialist consultation fell by 11 minutes and 46 seconds by the third assessment.

A total of 832 concerns were identified from the 60 completed eSPARC questionnaires. The number of concerns decreased at each time point, from 15.40 to 12.55, and the number of high concerns fell by 73% between the first and third assessment (Figure 1). The top concerns – shortness of breath, pain, feeling tired and cough – were similar over the three time points.

Care planning

Self-management information was given in response to 668 (80.5%) concerns, which can be attributed to the 10% reduction in 1 (a little bit) concerns scored by the third assessment. The top six services to which patients were signposted and referred are summarised in Table 2. Between the first and third assessment, the number of signposting (*n*=74) and onward referrals (*n*=41) reduced by 25% and 57% respectively. No action was required for 46 concerns, as these were either resolved before the assessment or were due to a cancer- or long-term condition-related symptom, for which management was optimised.

Patient-reported outcome measures

The Functional Assessment of Cancer Therapy – Lung, the Memorial Symptom Assessment Scale and the Supportive Care Needs Survey were completed fully by 20 patients, and Edinburgh Napier University is supporting analysis of the data. At this interim stage, some questions have been selected for analysis. In the Supportive Care Needs Survey, there was a 20% increase between the first and third survey in patients reporting they were satisfied

they were 'being treated like a person and not just another case', and 'being informed about things you can do to help yourself get well'.

On the Functional Assessment of Cancer Therapy – Lung, there was a 25% increase in patients reporting they were 'very much content' with their quality of life, in response to: 'I am content with my quality of life right now', between the first and third assessment.

Although complete analysis of the Memorial Symptom Assessment Scale was not available at the interim stage, early analysis appears to demonstrate a reduction in symptom burden. However, further work is required to understand the significance of this.

Patient experience

A total of 18 patients completed the patient experience survey (Box 1), and feedback about the service was positive, with 89% of patients rating it as excellent. One commented: 'It was great to have a one-to-one consultation after the assessment. This enabled me to discuss any concerns I may have had' (Patient 13).

All patients agreed that the eSPARC was easy to schedule and access at a time convenient for them and one said they valued the flexibility to do it in stages rather than all at once: 'I liked the idea that you had a whole day to do it. It meant you could go back and forward to it and didn't have to do it all in one go' (Patient 13).

The psychological effects of cancer and its treatment, from alterations in appearance and physical ability to living with the fear of recurrence, can be life-changing (Macmillan Cancer Support 2013). Encouragingly, the

participants appeared to value the emotional support the project provided them with: 'The service has provided good practical help and emotional back up' (Patient 2); 'I had someone to advise me which stopped me worrying' (Patient 7); 'Although I have had no major concerns, the nurse always contacted me by phone to discuss my responses and ensured that I had all the help I needed. Just having a quick chat with a concerned person boosted my mood if I had been a little down' (Patient 20).

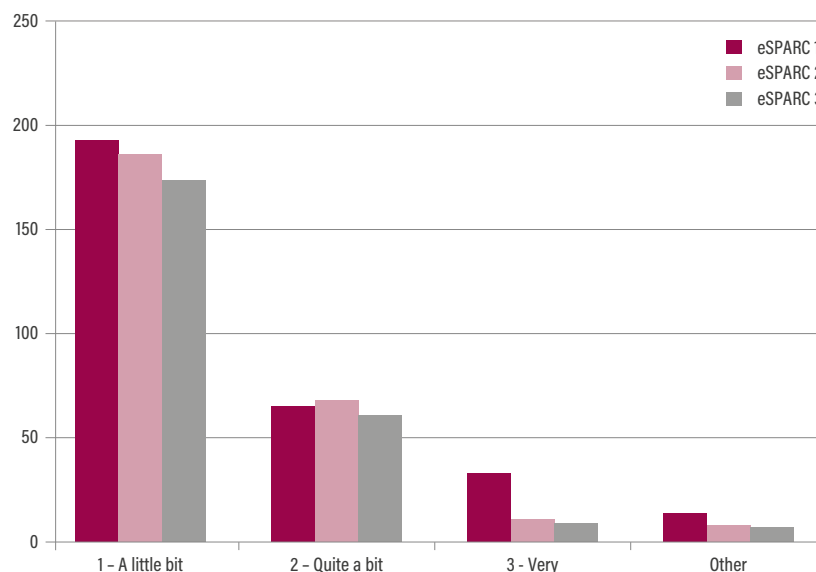
This feedback suggests that, from patients' perspectives, the process of undertaking an eSPARC questionnaire, followed by consultation with a cancer nurse specialist, is an acceptable model of care that helps them discuss and manage their concerns.

Discussion

The number of people living with cancer is set to increase, therefore more people will be

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Figure 1. Number of concerns



BOX 1. Patient experience survey

- Q1 Written instructions on how to access the eSPARC assessment were clear and easy to understand.
- Q2 It was easy to schedule in my assessment at a time that was convenient for me.
- Q3 The eSPARC assessment allowed me to raise all the concerns about the effects of my cancer and treatment on my quality of life me.
- Q4 The self-management information was clear and easy to understand.
- Q5 I used the self-management information to manage my concerns.
- Q6 The self-management information supported me to access local services.
- Q7 The project team was able to support me and signpost me to relevant services.
- Q8 Overall how would you rate the service?
- Q9 Have you contacted your GP, NHS 24 or attended the ED in the last six months?
- Q10 Do you have any further comments, questions, or concerns?

TABLE 2. Signposting and onward referrals

Signposting	Onward referral
Local pharmacist (14)	Macmillan Benefits Advice Service (7)
Kilbryde Hospice (10)	Kilbryde Hospice (5)
The Haven (6)	South Lanarkshire Leisure Active Health (5)
GP (6)	Lung cancer clinical nurse specialist (3)
The Maggie's Centre	Occupational therapist (3)
Get Walking Lanarkshire	South Lanarkshire Leisure Weigh to Go (3)

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living longer with the effects of the disease and its treatment. In response to this, the Scottish Government (2016c) set a challenge to health, social care and third sector staff to develop new ‘sustainable and innovative’ ways of working to meet this demand and better support patients.

At this interim stage of the NHS Lanarkshire Lung Cancer project, it appears that using technology to identify patients’ needs has several benefits. Attending clinic appointments can be time-consuming, costly and stressful for patients (Beaver et al 2009). However, these issues can be avoided by offering an online assessment and telephone consultation. This model of working appears to be acceptable to patients as 71% of participants opted for a telephone rather than a clinic-based consultation. There are also benefits from a nursing resource perspective as the telephone consultations took one third of the time of clinic appointments. However, more work is needed to explore other factors that might influence this, such as complexity of needs.

Beating Cancer: Ambition and Action (Scottish Government 2016c) suggests that to improve patients’ quality of life following treatment, they must have their needs assessed and be provided with an individual care plan. At present, only one quarter of patients have received this care plan. This project ensures that all patients with lung cancer living in Lanarkshire, apart from those receiving best supportive care, are offered an assessment and care plan.

Only one third of patients have unmet needs (Rowe et al 2014) so not all patients

were expected to accept the offer of an online assessment. Therefore, the uptake rate of 22% is not surprising. However, several patients declined to take part in the online assessment because it is electronic. We need to consider how to make the service available to those who cannot access this method of assessment.

Despite this, the model has successfully identified – and helped to manage – patients’ concerns and demonstrates a 75% reduction in high concerns. Contrary to findings of other studies, interim data from the Supportive Care Needs Survey suggests a 25% improvement in patient-reported quality of life. This data will be examined during full evaluation of the project to determine if the trend continues.

Conclusion

Early results of this project indicate that the eSPARC questionnaire is an effective tool for identifying the unmet needs of patients with lung cancer following completion of treatment. At this stage, it appears to be equitably accessible to patients, regardless of gender, age and the Scottish Index of Multiple Deprivation group. The data suggest that patients prefer telephone reviews, and that the model can help identify and reduce patients’ high concerns and improve their quality of life.

With support from Edinburgh Napier University, the project was fully evaluated in August 2017. This should lead to further work to test transferability of the model to other tumour groups. For the nursing profession, it could signify a new and effective way of supporting patients with cancer following completion of treatment.

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