

## Holistic needs of people with thoracic cancer identified by the Sheffield Profile for Assessment and Referral to Care (SPARC<sup>®</sup>) questionnaire

### ABSTRACT

*Background:* A holistic needs assessment is recommended in people with cancer at key stages, including soon after diagnosis. For people with thoracic cancer, there is a lack of data obtained routinely at this time point.

*Objective:* To identify the most common and/or distressing supportive and palliative needs present soon after diagnosis using a specifically developed questionnaire.

*Methods:* As part of a local rehabilitation service, patients within 3–6 weeks of a diagnosis of thoracic cancer were invited to complete the SPARC<sup>®</sup> questionnaire.

*Results:* Over a 26 month period, 738 patients completed the questionnaire, representing about 70% of all patients diagnosed with thoracic cancer during this time. Respondents had a median [IQR] of 15 [11–21] symptoms or issues, with 2 [0–5], 4 [2–7] and 7 [5–11] causing ‘very much’, ‘quite a bit’ and ‘a little’ distress or bother respectively. The top five most frequent needs causing any degree of distress or bother were physical, present in 68–80% of patients: feeling tired, shortness of breath, cough, feeling sleepy in the day, changes in weight. Two psychological issues followed: worrying about effects of the illness on others, feeling anxious, both present in 67%. Despite most patients reporting talking to health professionals about their condition, 20–30% wanted further information.

*Conclusions:* These findings represent the largest cohort of patients with thoracic cancer completing the SPARC<sup>®</sup> questionnaire soon after diagnosis, and provide detailed information on the high level of need that thoracic oncology services must be able to respond to.

Key words: lung cancer; mesothelioma; needs assessments; non-small cell lung cancer; small cell lung cancer

## **Introduction**

English cancer guidelines and strategy recommend a holistic needs assessment is undertaken in people with cancer at key stages, including within 31 days of diagnosis, with the findings used to inform a comprehensive, personalised care plan [1]. Self-assessment is considered a useful part of the process with several tools highlighted in a national report [2]. One, the Sheffield Profile for Assessment and Referral to Care (SPARC<sup>®</sup>) questionnaire, was developed for the purpose of screening for referral into palliative care services [2], and identifies holistic needs over the past month and the associated degree of distress or bother to the patient, in order to identify those who require early or immediate review [3]. Having found the SPARC<sup>®</sup> questionnaire acceptable to patients recently diagnosed with thoracic cancer [4], we adopted its routine use within a dedicated rehabilitation service, and here summarize our findings in a large cohort.

## **Participants and methods**

Patients residing within the rehabilitation service catchment area, related to the hospital's area of service, were invited to complete the SPARC<sup>®</sup> questionnaire. According to the needs identified, a dietitian, physiotherapist and/or occupational therapist visited within 3–6 weeks of diagnosis [5,6]. For example, reports of 'Loss of appetite' prompted dietetic input, 'Feeling weak' the physiotherapist, and 'Changes in your ability to carry out your usual daily activities' the occupational therapist. A copy of the completed questionnaire was also shared with the patient's community General Practitioner. As a clinical service undertaking assessments and providing

care in line with national recommendations, ethics approval was not required ([www.hra-decisiontools.org.uk/research/](http://www.hra-decisiontools.org.uk/research/)).

The SPARC<sup>®</sup> questionnaire contains an introductory paragraph outlining its purpose and instructions, including leaving questions blank if unsure; 45 questions cover seven areas of need with a free-text area for reporting others. Data are presented as mean (SD) or median [interquartile range, IQR] as appropriate. The median [IQR] number of symptoms or issues per patient causing any degree of distress or bother were calculated. Proportions with 95% confidence intervals were calculated for the most frequent responses. Calculations were performed using Statistical Package for the Social Sciences (version 20).

## **Results and discussion**

### ***Demographic data and questionnaire completion***

Over a 26 month period, 738 patients (60% male), mean (SD) age 70 (10), completed a questionnaire. Most were white British (92%) with non-small cell carcinoma (74%), awaiting/receiving palliative treatment (74%) (see online supplementary table 1). The cohort represented about 70% of all patients assigned a diagnosis of lung cancer during this period; the commonest known reasons for questionnaire non-completion were being too unwell/death (125, 17%) and residing outside of the rehabilitation service area (98, 9%). Completion rates were generally high (see online supplementary table 2); the highest proportion of blank responses occurred in the treatment section (~30%), mostly as patients had yet to commence treatment.

### ***Holistic needs***

For full results see online supplementary table 2.

### ***Symptoms or issues causing distress or bother***

The proportion of patients reporting at least one symptom or issue causing 'very much', 'quite a bit' or 'a little' distress or bother were 67%, 88% and 99% respectively. The median [IQR] number of symptoms or issues was 15 [11–21], ranging from 0 to 41; these could be divided into 2 [0–5], 4 [2–7] and 7 [5–11] that distressed or bothered patients 'very much', 'quite a bit' and 'a little', respectively.

Figure 1 summarizes the overall responses. Table 1 lists the ten most frequently reported symptoms or issues. These were present in 60–80% of patients for any degree of distress or bother and 33–50% of patients when limited to 'very much' or 'quite a bit' of distress or bother. In both instances, most were physical symptoms and although the order varied, only one issue differed ('Feeling weak?' replacing 'Feeling anxious?').

#### *Communication and information issues*

Most patients had been able to talk with their family (630, 85%) about their condition, followed by a hospital nurse (573, 78%), their doctor (520, 70%) and community nurse (140, 19%). Fifteen percent or less had talked with a social worker, religious advisor or others.

#### *Personal Issues*

Only 101 (14%) patients responded that they need help with personal affairs and 116 (16%) that they would like to talk to another professional about their condition or treatment. Nonetheless, overall 21–30% of patients wanted further information, e.g. about their condition, care or treatment.

#### *Other concerns*

Free text was provided by 143 (19%) patients and grouped into themes (see online supplementary table 3). Generally, this expanded on concerns already identified, with the most common themes: physical symptoms (40), financial issues (22),

wanting more information about diagnosis/investigations (21), treatment (19) and support at home (14). Overall, each represented  $\leq 5\%$  of total respondents.

### ***Discussion***

To our knowledge, this is the largest cohort of its kind involving the SPARC<sup>®</sup> questionnaire. No previous reports permit direct comparison, but the predominance of physical symptoms appears a consistent finding [7,8]. Strengths of our findings include the large sample size and relatively high completion rates. A weakness was the inability to include those patients who deteriorated and died rapidly, who arguably most need timely support. Our impression was that many of this group were diagnosed following an emergency admission, which is supported by a lower proportion of the cohort diagnosed via this route (27%) than expected (~40%). Subsequently, we explored the needs of this specific group and confirmed a higher symptom burden compared to those diagnosed electively (median of 21 vs. 15 symptoms or issues) [9]. A further weakness is that this was a single rather than longitudinal assessment; the SPARC<sup>®</sup> questionnaire was not developed as an outcome measure and more specific assessments were used to evaluate the rehabilitation service [5,6].

We used the SPARC<sup>®</sup> to tailor the input of our rehabilitation service, with annual user surveys indicating a high degree of patient/carer satisfaction with the service. However, others have reported the application of the SPARC<sup>®</sup> questionnaire without integration into a care plan as counterproductive, possibly by raising expectations that are not subsequently met [10]. Thus, we recommend that services incorporating an holistic needs assessment, must ensure they are able to respond to the needs identified in an integrated and timely manner.

### **Conclusions**

Patients with a recent diagnosis of thoracic cancer report a median of 15 symptoms or issues, of which six and two caused very much or quite a bit of distress or bother respectively. Physical symptoms occur most commonly, although worrying about the effects of the illness on others, and feeling anxious also rank highly. Despite most patients reporting talking to professionals about their condition, 20–30% want further information. These findings will be of interest to all working to improve the care of this group via, e.g. existing teams or early integration of specialist supportive/palliative care.

### **Acknowledgements**

The rehabilitation service, including AH, was funded by a Macmillan Cancer Support Project Grant. We thank Helena Alvey, Rachel Bentley and Cheryl Percival, and other members of the rehabilitation service, who co-ordinated the completion and collection of the SPARC<sup>®</sup> questionnaires. We thank Tricia McKeever for helpful comments on the manuscript.

### **Disclosure Statement**

The authors have nothing to disclose.

## References

- [1] National Cancer Transformation Programme. Achieving world-class cancer outcomes. A strategy for England 2015-2020. Progress report 2016-2017, 2017.
- [2] Richardson A, Sitzia J, Brown V, Medina J, Richardson A. Patients' Needs Assessment Tools in Cancer Care: Principles and Practice. London, King's College London, 2005.
- [3] Ahmed N, Bestall JC, Payne SA, Noble B, Ahmedzai SH. The use of cognitive interviewing methodology in the design and testing of a screening tool for supportive and palliative care needs. *Support Care Cancer* 2009;**17**:665–73.
- [4] Wilcock A, Klezlova R, Coombes S *et al.* Identifying supportive and palliative care needs in people with a recent diagnosis of thoracic cancer: acceptability of the SPARC questionnaire. *Thorax* 2010;**12**:937–938.
- [5] Percival C, Hussain A, Zadora-Chrzastowska S, *et al.* Providing nutritional support to patients with thoracic cancer: findings of a dedicated rehabilitation service. *Respir Med* 2013;**107**:753-61.
- [6] Bentley R, Hussain A, Maddocks M, Wilcock A. Occupational therapy needs of patients with thoracic cancer at the time of diagnosis: findings of a dedicated rehabilitation service. *Support Care Cancer* 2013;**21**:1519-24.
- [7] Ryan T, Ingelton C, Gardiner C *et al.* Symptom burden, palliative care need and predictors of physical and psychological discomfort in two UK hospitals. *BMC Palliat Care* 2013;**12**:11.
- [8] Boland EG, Boland JW, Ezaydi Y *et al.* Holistic needs assessment in advanced, intensely treated multiple myeloma patients. *Support Care Cancer* 2017;**22**:2615-2620.
- [9] Wilcock A, Crosby V, Hussain A, *et al.* Lung cancer diagnosed following an emergency admission: Mixed methods study of the management, outcomes and needs and experiences of patients and carers. *Respir Med* 2016;**114**:38-45.
- [10] Ahmed N, Hughes P, Winslow M, *et al.* A pilot randomized controlled trial of a holistic needs assessment questionnaire in a supportive and palliative care service. *J Pain Symptom Manage* 2015;**50**:587-598.