Original Article

Considerations in Developing and Delivering a Nonpharmacological Intervention for Symptom Management in Lung Cancer: The Views of Patients and Informal Caregivers

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Abstract

Context. Few studies consider patient’s and caregiver’s preferences when developing nonpharmacological interventions. This is important to develop acceptable and accessible nonpharmacological interventions for patients with cancer.

Objectives. The objective of this study was to identify the views of patients with lung cancer and their informal caregivers on the desirable components of a novel nonpharmacological intervention for the management of the symptom cluster of cough, breathlessness, and fatigue, and their needs and preferences regarding uptake and delivery of the intervention.

Methods. This study was qualitative in orientation, using semistructured interviews and framework analysis to elicit the views of 37 patients with lung cancer and 23 caregivers regarding the issues that were perceived to be important regarding the development and delivery of a nonpharmacological intervention.

Results. A number of key issues were identified that carried important implications for patient’s participation and adherence to the intervention,
including the perceived relevance of potential techniques; appreciable benefits in the short term; convenience; variation in patient’s preferences; timing of the intervention; venue; caregiver’s involvement; the provider of the intervention, and contact with other patients.

**Conclusion.** The data from this study have provided insight into the key issues that are likely to influence the development, uptake, and delivery of a nonpharmacological intervention to help manage the respiratory symptom cluster of cough, breathlessness, and fatigue. It is crucial that these findings are considered when developing and modeling a nonpharmacological symptom management intervention. J Pain Symptom Manage 2012; – : – . © 2012 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

**Key Words**
Lung cancer, symptom management, relevance, breathlessness, cough, fatigue

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**Introduction**

Several studies have identified the presence of a respiratory symptom cluster in patients with lung cancer (LC) showing close associations among breathlessness, cough, and fatigue. Factor analysis of longitudinal data from 109 patients with various diagnoses, including LC, suggests that breathlessness, cough, and fatigue form a discrete cluster close to diagnosis that appears to gain complexity over time. This interacting symptom cluster was found to play a central role in patients’ symptom experiences within the LC population, but is inadequately relieved by pharmacological interventions alone.

Symptoms are a major detriment to patients’ quality of life and functional ability when not adequately relieved and have been shown to be a strong predictor in survival studies. Poor management of symptoms complicates patient’s care, potentially affects quality of life and hospital admissions, and contributes to the heavy burden that often falls on family caregivers, as patients often rely on these informal caregivers for many daily activities, especially toward the end of life when the illness burden increases. Also, a systematic review showed that informal caregivers did not feature in any self-care symptom management programs, receive little practical support, and require more practically focused information.

Lung cancer symptom management intervention research to date has focused almost exclusively on breathlessness to the exclusion of other common distressing symptoms such as cough, fatigue, anxiety, and depression. A Cochrane review on well-being and quality-of-life interventions in LC identified only one effective nonpharmacological intervention for managing breathlessness in this population. This program, the Corner Model, which incorporates breathing exercises with anxiety management and counseling, has shaped breathlessness care for LC in the U.K. Some criticism has been directed at the program’s reliance on specialist nurses, high costs, and an exclusive focus on single symptoms. More recently, a Cochrane review of cough management in LC found no documented approaches for the nonpharmacological management of cough. However, techniques showing some effect in other respiratory illnesses included speech pathology training and managing symptoms (and adjusting treatment) through SMS messaging. Fatigue, on the other hand, is often managed with nonpharmacological techniques, and mild exercise, energy conservation, cognitive-behavioral techniques, and acupuncture all have shown positive results.

An integrative review on breathlessness identified a plethora of potential nonpharmacological interventions that showed promise, but conclusions were limited by a lack of good quality evidence from randomized controlled trials, small sample sizes, and a lack of replication. Examples included acupuncture, diaphragmatic breathing, inspiratory muscle resistance training, psychoeducation, physical activity, or psychological interventions. Moreover, pharmacological treatments did not completely manage breathlessness and had the added burden of...
side effects.20 We have found no documentation of these nonpharmacological interventions having been tested with LC patients. Therefore, there is a need to develop appropriate nonpharmacological interventions for this population to help manage the often distressing and debilitating symptoms of breathlessness, cough, and fatigue.

This study forms part of a broader project aiming to develop a nonpharmacological intervention for the management of a respiratory distress cluster (breathlessness, cough, and fatigue) in LC, focusing on the theory development and modeling aspects of the Medical Research Council Framework for complex interventions.21 It is one of the first studies to focus on the management of a symptom cluster rather than on single symptoms. However, significant challenges have been experienced in previous trials with LC patients. These have been the result of patients’ poor performance status and high symptom burden with complex symptomatology, which can lead to difficulties in study recruitment and retention, and in implementation of nonpharmacological interventions.22,23 Hence, it is crucial to explore the views of all stakeholders on issues that might make a nonpharmacological intervention more appropriate, viable, and stand better chance of being integrated into practice, prior to testing any intervention, and also responding to policy drives for service users to be more involved in research and health service development, particularly when need is difficult to define.24

The aim of the study reported here was to explore perceptions of LC patients and their informal caregivers regarding the desirable components of a novel nonpharmacological intervention, and needs and preferences regarding uptake, delivery, and timing of an intervention to help manage the symptoms of cough, breathlessness, and fatigue.

Methods

In this qualitative study, semistructured interviews were carried out with patients and, when possible, their primary caregiver.25 Patients were all diagnosed with LC and were either in treatment or had completed treatment with either curative or palliative intent. Interviews were conducted by three experienced qualitative researchers in three different locations across England (including two specialist cancer hospitals and two district general hospitals in the northwest and south of England).

The study was approved by a multisite Research Ethics Committee, the ethics committee of the University of Manchester, and all participating hospitals. Participants were recruited in outpatient clinics during routine follow-up, initially by the clinicians who explored the patients’ willingness to participate and later by the researchers who provided more detailed information and obtained written consent. Patients and their caregivers were interviewed separately either in a private room in the hospital or their own home. When this was not possible interviews were conducted by telephone (n = 2).

The interviews aimed to explore patients’ and caregivers’ views and attitudes toward existing nonpharmacological interventions. Interventions were identified from previous systematic reviews9,17,18,20 and included: quick and simple exercises; cough suppression; vocal and sleep hygiene practices; diaphragmatic breathing, chest wall vibration, education, and advice; relaxation techniques; and anxiety management techniques. We were interested in how participants perceived their effectiveness, acceptability, importance, and feasibility, and their preferences for the delivery methods of an intervention, in accordance with the modeling component of the Medical Research Council Framework.21 To facilitate this process, an interview guide was constructed. Questions included:

- How useful do you think (this) technique would be?
- Has anyone talked to you about this technique; how important is it for you? Would you try it in the future? If so, why? If not, why not?
- How easy do you think it would be to use? Do you see any problems/obstacles to using it?
- Would you prefer to learn the technique at home, by yourself or with others helping you or in hospital?
- When would be the best time to deliver any intervention and who would you like to deliver it?
Where would be the best location for the intervention to be delivered?

To what degree would you like your caregiver to be involved in the delivery of the intervention?

The researchers who conducted the interviews were free to explore issues not identified in advance. Typically, each interview lasted 30–90 minutes and was recorded and transcribed verbatim. Transcripts were checked against the original audio recordings. Regular team meetings took place to discuss progress with the data collection, the data, and the issues arising from the study. Information relating to sociodemographic characteristics of the sample including age, gender, education, and marital status, and disease- and treatment-related information (treatment received and stage of LC) were collected from the patients or the patients’ records as appropriate.

Analysis of the interviews took place simultaneously with continued data collection and in accordance with the framework analysis method described by Richie and Spencer.26 This method of qualitative analysis involves charting and sorting data in a matrix to facilitate comparisons and interpretation of the key ideas and themes emerging from the data. To facilitate this process, four researchers each independently analyzed an early small set of interviews and discussed their findings with the research team to establish consistency in the data collected and the issues/themes identified. This process was maintained throughout the study with regular discussion meetings. The researchers who led the data analysis initially familiarized themselves with the data by reading the transcripts several times to enable the identification of important and recurrent themes. Following this, an index of themes was produced, which was then used to code each transcript. A comprehensive data chart was then constructed by extracting data segments from the original transcripts and arranging these in the matrix according to the emerging themes.

Results

Sample Sociodemographic and Clinical Data

A total of 37 patients and 23 caregivers were recruited to the study. The three recruitments sites contributed eight, 15, and 14 patients and six, eight, and nine caregivers, respectively. Sixteen interviews were carried out with both the patient and the caregiver together. Twenty-two of the patients were men and 15 women. Their ages ranged from 48 to 91 years (mean age = 69.5 years, standard deviation = 8.9); they were an average of 16 months postdiagnosis with approximately three-quarters being married and often cared for by their spouse/partner (66.7%) without a university/college education (76%). Two patients were diagnosed with mesothelioma, 16 with non-small-cell LC, and 19 with small-cell LC. All interviewed patients had preexisting comorbidities including asthma, emphysema, cardiovascular disease, diabetes, hyperthyroidism, arthritis, and osteoporosis. Detailed sociodemographic and clinical data are presented in Table 1.

Key Issues

The analysis focused on issues that were perceived by patients and caregivers to be important in the development and delivery of a nonpharmacological intervention for managing cough, breathless, and fatigue. A number of key issues were identified that carried implications for patient’s participation and adherence and are described below: the perceived relevance of techniques; appreciable short-term benefits; convenience; participant’s beliefs about the intervention; timing of the intervention; venue; caregiver’s involvement; the provider of the intervention; and contact with other patients (see indicative quotes in Table 2).

Perceived Relevance of the Intervention. Patients generally showed little inclination to use techniques they believed held little relevance to them at a specific time point, especially in cases where symptom control was not a priority.

Appreciable Benefits of the Intervention in the Short Term. Patients appeared to be more likely to adhere to those approaches/techniques that had appreciable benefits in the short term. Where this was not the case, patients often reported discontinuing techniques.

Convenience of the Intervention (Being Part of Daily Routine). Generally, patients reported greater adherence to techniques that were simple and easy to fit into daily routines, although
comorbidities and limited mobility could be issues for some patients. This was particularly important because patients were attempting to return to as normal (prediagnosis) a routine as possible.

Flexibility to Accommodate Variations in Patient’s Preferences of Intervention Components. Participants showed wide variation regarding both the components of potential interventions they had experienced and those they were interested in. Generally, patients were only given advice or were taught techniques regarding symptom management when they were referred to a specialist nurse in cases of extreme symptom experiences. In some regions, patients would be referred to breathlessness programs. Typically, however, patients received little or no advice regarding symptom management, which is supported by several quotes from patients. Patients generally were interested in those techniques that might relieve specific symptoms, that is, techniques to suppress cough, particularly in certain situations (when eating, taking medication, to prevent pain and vomiting, and when out in public), and to relieve sputum production, breathlessness, fatigue, anxiety, and panic. Patients also tended to be interested in those techniques that enabled them to better manage daily activities and help maintain independence.

Participant’s Beliefs About the Intervention. Beliefs of the patients appeared to influence the techniques they were interested in. Broadly speaking, those people who tended to be oriented to a more medical model of health were often reluctant to engage with relaxation techniques, massage, reflexology, and acupressure, as they tended to question their validity and worth. There were, however, others who were more accepting of nonpharmacological interventions. Generally, these patients fell into three broad groups: 1) those willing to try anything that might help relieve distressing symptoms (irrespective of whether they had used them in the past and benefited from them), especially patients with a high level of symptom burden; 2) those patients who had used these techniques in the past (or knew someone who had used them) and had benefited from them, and 3) those patients who wanted to be more informed before considering the use of new techniques.

Timing of the Intervention. Patients often reported being overwhelmed at the time of diagnosis as there were already great demands on their time, with too much information for them to absorb about, for example, disease prognosis. The treatment phase also was very demanding and time-consuming for patients and caregivers alike and was seen to coincide with increased patient’s symptomatology (e.g., from side effects). This

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Participant’s Sociodemographic and Treatment Characteristics</th>
</tr>
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<tbody>
<tr>
<td>Characteristics</td>
<td>n (%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>15 (40.5)</td>
</tr>
<tr>
<td>Male</td>
<td>22 (59.5)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>28 (75.7)</td>
</tr>
<tr>
<td>Single</td>
<td>3 (8.1)</td>
</tr>
<tr>
<td>Divorces/widowed</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Church of England</td>
<td>28 (75.7)</td>
</tr>
<tr>
<td>Catholic</td>
<td>7 (18.9)</td>
</tr>
<tr>
<td>None</td>
<td>2 (5.4)</td>
</tr>
<tr>
<td>Relationship with primary caregiver</td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>24 (66.7)</td>
</tr>
<tr>
<td>Children</td>
<td>5 (13.9)</td>
</tr>
<tr>
<td>Other family members</td>
<td>4 (11.2)</td>
</tr>
<tr>
<td>Friends</td>
<td>1 (2.8)</td>
</tr>
<tr>
<td>No carer</td>
<td>2 (5.6)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Secondary school (or part of)</td>
<td>28 (75.7)</td>
</tr>
<tr>
<td>College</td>
<td>5 (13.5)</td>
</tr>
<tr>
<td>University education</td>
<td>4 (10.8)</td>
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<tr>
<td>Employment status</td>
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</tr>
<tr>
<td>Retired</td>
<td>36 (97.3)</td>
</tr>
<tr>
<td>Sick listed</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White British/European</td>
<td>36 (97.3)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>Disease stage</td>
<td></td>
</tr>
<tr>
<td>Stage 1</td>
<td>1 (3.1)</td>
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<tr>
<td>Stage 2</td>
<td>7 (21.8)</td>
</tr>
<tr>
<td>Stage 3</td>
<td>10 (30.3)</td>
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<tr>
<td>Stage 4</td>
<td>12 (44.8)</td>
</tr>
<tr>
<td>Type of treatment</td>
<td></td>
</tr>
<tr>
<td>Chemoradiotherapy</td>
<td>17 (45.9)</td>
</tr>
<tr>
<td>Chemotherapy only</td>
<td>12 (32.4)</td>
</tr>
<tr>
<td>Radiotherapy only</td>
<td>6 (16.2)</td>
</tr>
<tr>
<td>Surgery only</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>Surgery and chemotherapy</td>
<td>1 (2.7)</td>
</tr>
<tr>
<td>Treatment intent</td>
<td></td>
</tr>
<tr>
<td>Radical</td>
<td>4 (11.8)</td>
</tr>
<tr>
<td>Palliative</td>
<td>30 (88.2)</td>
</tr>
</tbody>
</table>

*a Five missing cases.

*b Three missing cases.
Table 2
Issues Identified by Patients With Lung Cancer and Their Carers Affecting Participation and/or Adherence to a Symptom Management Intervention

<table>
<thead>
<tr>
<th>Key Issue</th>
<th>Examples of Patient’s or Carer’s Quotations</th>
</tr>
</thead>
</table>
| Perceived relevance of the intervention | ...suppose if the cancer goes worse I’ll most probably want all that, but at the moment I just don’t feel no need for it (LP7).  
She’s breathless, but we’ve got more important things to worry about now than breathlessness and breathing (LC1).  
I feel better when I’ve had a walk; you know... because it seems as though the actual walking is moving the congestion in my chest... (LP13a). |
| Appreciable benefits in the short term   | ...I feel better when I’ve had a walk, you know... because it seems as though the actual walking is moving the congestion in my chest... (LP13a).  
C: Yeah, when you first came in she gave you some [exercises] didn’t she...  
P: But they weren’t doing any good and we stopped them (SPC5). |
| Convenience (daily routine)              | I have a... quite a new routine around the house, whereby... I try and get all the little... household jobs and things done in the morning (SP14) |
| Variations in preferences of intervention components | You know... because your life is not simple... sometimes I find it difficult to stand upright or to stretch, sort of to get something out of the cupboard, and sort of different strategies that they can help me with... I’m independent and I like to do things myself (LP2b). |
| Participant’s beliefs about the intervention | “Oh you’ve got to go for reflexology,” I said. “Look, if I’ve got a puncture, changing the oil in the car isn’t going to solve the puncture, let’s address the issues (LP11).  
If there’s going to be an end to a problem yeah, why not. End of the day you get desperate and you just try anything don’t you? (SP5).  
Yes, I’d be open with [complimentary therapies], I’d want to move a lot more about them before I started. I don’t know much about them except that they are alternative medicines... so I’d want to move more (SP6).  
The treatments have been quite time consuming, and then you feel tired now I’ve started with the chemotherapy and the radiotherapy... There were so many tests and different things had to be done, you didn’t really have time to do a great deal in-between... I do intend to give it [exercise] a go once I’m over the worst of this lot. I think it would be the wrong time to start trying to do it until I’ve got over the worst of the radiotherapy and this bout of chemo, because your first week after the chemo is like you’re really tired and just want to sleep, and don’t really want to do very much at all. So it’d be silly to push yourself to actually try and do something like that [exercise] then, when your body’s at its weakest. But once I’m feeling a bit better, then yeah, I shall kick off! (LP3b).  
...It’s possibly about the timing. Because the nurse did talk to you about that (attending a breathlessness clinic) when you were first discharged from the other clinic but you weren’t well enough to go then (MPC3).  
...if I’ve got something on my mind and a worry, not much goes in... Sort of getting that timing right, because if that person is still worried or they’ve got... because like what, as I say the bowels was the main thing with me and now that’s over... it [information and advice] goes in better if I’m relaxed and comfortable (LP2a). |
| Timing of the intervention               | The treatments have been quite time consuming, and then you feel tired now I’ve started with the chemotherapy and the radiotherapy... There were so many tests and different things had to be done, you didn’t really have time to do a great deal in-between... I do intend to give it [exercise] a go once I’m over the worst of this lot. I think it would be the wrong time to start trying to do it until I’ve got over the worst of the radiotherapy and this bout of chemo, because your first week after the chemo is like you’re really tired and just want to sleep, and don’t really want to do very much at all. So it’d be silly to push yourself to actually try and do something like that [exercise] then, when your body’s at its weakest. But once I’m feeling a bit better, then yeah, I shall kick off! (LP3b).  
...It’s possibly about the timing. Because the nurse did talk to you about that (attending a breathlessness clinic) when you were first discharged from the other clinic but you weren’t well enough to go then (MPC3).  
...if I’ve got something on my mind and a worry, not much goes in... Sort of getting that timing right, because if that person is still worried or they’ve got... because like what, as I say the bowels was the main thing with me and now that’s over... it [information and advice] goes in better if I’m relaxed and comfortable (LP2a). |
| Venue for intervention                  | Well it is an effort when I have to go up to (name of town), because he has to have a hospital car to pick him up, and I go with him... That can be a pain because they might take us, they might come late and you’re getting all wound up... and the other night we got home here at seven o’clock, and that was from half past twelve we left here. So by the time he came in, he couldn’t stop shaking (SC2).  
I think if you’re in hospital like if my husband was sent to hospital, he hasn’t got anybody there to help him remember it. It goes in one ear and out the other (SC13).  
Possibly going to the hospital because, you know, it’s a more disciplined environment... Some people would be more comfortable in their home I know, but I think for me personally... I think there’s the discipline of actually getting yourself to the hospital and then going to the hospital you have a responsibility to other people when you go to a hospital, you know, a lot of people, the medical staff are going to put themselves out to help you. Whereas somebody at home it’s all terribly relaxed, I mean, [cough] it’s probably because I’ve led a disciplined life all my life you see really and personally I would prefer to go to hospital for it (SP14). |

(Continued)
added burden was often compounded by factors such as daily traveling back and forth to the radiology/chemotherapy clinics, finding appropriate car parking, and waiting for their appointment in the hospital. The data suggest that additional commitments during this period were unwelcome. Patients reported not being responsive to information given at what they perceived to be inappropriate time points (i.e., when not experiencing symptoms, when too ill to take information on board, when waiting for treatment/appointments, or when they were concerned about other issues). These factors were perceived to affect the extent to which they could absorb and retain information.

Venue for Intervention. Appropriate settings discussed by patients and caregivers included the patient’s home, general practitioner’s surgery, the hospice, and the hospital (including chemotherapy and radiotherapy clinics or at the follow-up clinics). Generally, however, patients and caregivers preferred the idea of an intervention being either home based or hospital based. Those people who preferred the idea of the intervention being home based saw it as more convenient and less burdensome as they would not have to deal with logistic issues, that is, parking, organizing transport, and travel. Others explained this choice saying the patient might be better supported at home, or that it was more personal. Some participants preferred the discipline of a hospital environment. There were, however, patients who preferred to keep medical appointments distinct and separate from their home lives and this appeared to be related to their coping strategy.

<table>
<thead>
<tr>
<th>Key Issue</th>
<th>Examples of Patient’s or Carer’s Quotations</th>
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<tbody>
<tr>
<td>Caregiver’s involvement</td>
<td>If it would save me going up the hospital, I’d have it here [home] because that hospital can be a bit of a horror with driving in there, parking and getting in and out of there, yeah (SP3). Well personally speaking I, I much prefer people to come to me than me to go to them [laughing] because I feel more comfortable … (SP6). C: I tried telling you, hadn’t I, on how to breathe and what-have-you… but we just land up… either getting stroppy with each other or laughing and… because I have tried to sort of tell you, haven’t I, how to breathe and that… he’d listen to somebody rather than me, yeah… But with me we just… no. Yeah. And it’s about sitting isn’t it? Like [makes noise], we’ve tried telling you to sit properly with your backside at the back of the chair and such like. P: I think she forgets I’m 68 (SPC5).</td>
</tr>
<tr>
<td>Provider of the intervention</td>
<td>I mean you’ve still got to do your cooking, your cleaning, your washing, your ironing, you’ve still got to do what you normally did whether you’re tired or what you are, it’s just a case of wanting, get on with it like, you know, so (LC13). …Because motivation is quite difficult I think, especially when you’re on your own all day (MP3).</td>
</tr>
<tr>
<td>Training format/contact with other patients</td>
<td>I would like to learn it with a professional and then once they have taught me how to do it, once I’ve got the experience. I always like to learn it from somebody if I can, because obviously they are the professionals and they’re, you know, or they can explain to me, and because I would prefer to do it that way (LP2b). If there’s any volunteers there (hospice) who would do it, it would be fine (LP15). One thing I think early on they said, “Well there’s groups like the Lung Cancer Survivors Group,” and I thought, oh I don’t really think I want to get involved with that particularly, you know (LPC11).</td>
</tr>
</tbody>
</table>

L/M/S in the participant code indicates the recruitment site; P = patient; C = carer; “…” indicates omitted words.

Caregiver’s Involvement in the Delivery of Intervention. Caregivers were often seen as an important source of motivation and encouragement with regard to adherence to medical advice, regulating levels of activity, and trying out different techniques. Patients also reported that they often relied heavily on caregivers to recall information and ask questions (or prompt them to do so) as there was much to absorb during consultations with health care professionals (HCPs). Caregiver’s involvement may
cause tensions within families and undermine levels of autonomy for the patient. For such reasons, some caregivers thought it more likely that patients would listen to and follow advice from others rather than from caregivers. There also were some concerns from patients and caregivers over increasing the demands placed on caregivers, particularly during the treatment phase and toward the end of life when symptom burden increases, especially for those with limited social support. It also was evident from the data that without the support of a caregiver’s motivation was more difficult.

**Provider of the Intervention.** Patients and caregivers reported that they received treatment and information from a wide variety of HCPs during their illness (e.g., general practitioner, consultant, specialist nurses, Macmillan nurses, occupational therapists, and physiotherapists). Patients also showed differing attitudes toward information depending on the source (e.g., type of HCP, other patients). Some patients appeared to be strongly inclined toward HCPs providing the intervention, particularly in the first instance. Others appeared to be happy to be taught by a non-health care professional. However, for some patients the important issue was not so much about who delivered the intervention but that they, as patients, were competent, and a health provider could assure their competence. There was a perception that sometimes HCPs, in general, were less concerned about specific symptoms. Some patients found that advice could sometimes be contradictory, or that it was difficult to know whom to speak to about a specific issue or symptom. This sometimes led to the perception that patient’s queries were being ignored or not being taken seriously, suggesting that HCPs were not getting engaged when they did not have anything to offer.

**Training Format of the Intervention/Contact With Other Patients.** Some patients reported that they had little opportunity to speak to other patients and discuss their illness and how to cope and viewed this as potentially valuable for them. Other patients reported that they definitely preferred not to meet with other patients.

**Discussion**

This study has shown that participation and/or uptake of a symptom management intervention in patients with LC is influenced by perceptions of relevance, short-term benefits, convenience, beliefs, timing and venue of intervention, caregiver’s involvement, the provider, and the training format of the intervention. An intervention, therefore, would have to offer a range of components to reflect the highly differing preferences and needs of patients in different situations. This issue relates to an identified need for a menu-based service that is adaptable and takes into account variations between patients but also within individual patients across time. Although this is a new concept for cancer symptom management, the findings echo similarities within the cardiac rehabilitation literature where flexibility and adaptability of the rehabilitation program is advocated, with individual program components tailored to the needs of the individual and reeducation and readjustment of the program takes place as time goes by. The need for flexibility in cardiac patients also arises from offering the rehabilitation program to a broad range of patients that may have considerable physical and functional impairments. Consideration also is given in cardiac rehabilitation to patients’ beliefs, involvement of the family and delivering the intervention in the community or at the patient’s home, further indicating that knowledge gained over the years from cardiac rehabilitation may be useful and transferable to the symptom management setting in LC care. This is particularly important as rehabilitating cancer patients with complex symptoms is currently limited and services are not necessarily proactively responsive to patient’s needs for improved quality of life and adaptation to changes in physical and psychosocial limitations.

The data suggest that patients generally showed little inclination toward potential techniques that they believed had little relevance to them at a particular time point. Therefore, it is important to ensure that patients understand the potential relevance of all intervention components to them personally to maximize uptake. This may indicate the need for repeating any education related to the intervention as time goes by. This also may
necessitate the “fine tuning” of the intervention components to meet individual needs and make an intervention more relevant to individuals. We also need to consider the health beliefs of patients (and caregivers), particularly those who were more inclined toward a medical model of health, as this was seen to influence the extent to which patients were willing to engage in techniques that they believed would not have a direct impact on the patient’s symptoms, such as relaxation.

Data suggest that patients would be more likely to adhere to techniques that have appreciable benefits in the short term. Thus, components that act over the short term to reduce symptoms seem more likely to produce higher patient’s adherence as patients reported previously discontinuing techniques that had no immediate effects. This is a particularly important point in a disease such as LC, where the goal is to relieve symptoms and to allow patients to function more fully in their daily life. It also was evident that patients were more likely to adhere to techniques that were simple and fit easily into their daily routines (e.g., exercise and taking the dog for a walk) and enabled them to maintain their independence. However, we need to bear in mind that some techniques might be problematic for patients with limited mobility and any intervention would need to be tailored accordingly. Also, participants were keen to maintain as normal a life as possible. Sahlin29 and Wikan30 explain that people attempt to create continuity after an unexpected disruption to life. The ongoing interpretation of the events and experiences enables people to make sense of their personal worlds, and a knowledgeable world provides a framework for understanding major events and everyday experiences. Biographical disruption is the focus of much work in the literature.31,32 Given the significance of disruptions, we need to consider when developing the intervention how the impact of any further disruption might be mediated.

The analysis suggests that the timing of the intervention is crucial for patient’s uptake and adherence. Diagnosis and treatment were seen to be very demanding and time-consuming for patients (and caregivers); the impact of that was often compounded by increased patient’s symptomaticity (e.g., side effects of treatment). Furthermore, some symptom improvement is expected during this time as a result of chemo/radiotherapy. Hence, it is suggested that an intervention be offered to patients once they complete first-line treatments, and provided that symptom onset does not make earlier intervention more appropriate. It is also acknowledged that patients may undergo second- or third-line treatments, but our data suggest that after the end of the first-line treatment is the most appropriate and acceptable time to introduce a nonpharmacological intervention. However, for many patients the priority was to get on with their lives once treatment was completed. In such cases, there was a tendency to avoid issues that emphasized their sick role. Therefore, implementing an intervention once the first line of treatment is completed would have to overcome this potential obstacle to patient’s attendance/adherence. When modeling the intervention, we also would need to consider how the timing of information affects the ability of the patient to retain the information they receive regarding any intervention. In view of this, training might need to be repeated at different time points and supplemented with written information.

Whereas there was a range of locations seen as appropriate for delivering the intervention, most participants tended to prefer the intervention to be delivered in their home or the hospital. For some, this choice appeared to be related to coping strategies or support needs, although there was a reoccurring preference for locations that were personally convenient or more personal. We also need to consider that it may be difficult to motivate patients to make further hospital visits, especially given the issue of affordable transport and that patients soon become too unwell for repeated visits to hospital.13,14 Also, asking someone who is fatigued to travel any distance to a venue to learn a technique might itself be stressful and may undermine any potential benefits. Delivering a service at home may be costly and unsustainable because of the resources required in providing such a service; however, learning again from the cardiac rehabilitation field, health care costs were not different in home- or hospital-based programs, and physical and quality-of-life outcomes were equal.33 The cost effectiveness of the proposed home-based (or community) intervention will need to be carefully measured in future trials.
The analysis further suggests that there are potential advantages for informal caregivers to be involved in the delivery of the intervention as they are generally more proactive and have a central role with regard to regulating levels of activity, patient's adherence, and retention of information. Indeed, recent research highlights that patients sometimes only attend management clinics at the urging of family members. Our findings also showed that patients often relied heavily on informal caregivers for many daily living activities. This level of support was seen to place an increased level of burden on many caregivers, particularly during treatment and toward the end of life when the symptom burden increases rapidly, especially where there was limited social support. This is something that is reflected in other studies and needs to be considered when developing the intervention. In addition, many caregivers feel both unprepared for this role and also have their own comorbidities to cope with, necessitating a more careful attention toward caregiver's training and support by HCPs on an ongoing basis. The intervention also may act as a form of support for informal caregivers in that they will have a direct point of contact to discuss issues/concerns and provide a degree of coaching. This might help to empower caregivers and reduce feelings of helplessness as they would have strategies to draw on to help with symptom management. We further need to consider that not all patients have caregivers and not all patients want their caregivers involved in the delivery of the intervention (either because they want to maintain their autonomy or former roles, or they want to protect their caregivers). Any involvement from caregivers in an intervention would have to be tailored to accommodate these concerns.

The data showed mixed views as to who should provide the intervention. For some patients, the issue was not so much who provided the intervention but the reassurance that they were performing the intervention correctly. For others, the issue was that they feel comfortable with the person providing the training. This is a matter that requires further consideration to determine patients' preferences in this regard.

It was evident from the analysis that there was also a great deal of scope with regard to patient's education and advice as patients tended to learn techniques through "trial and error" rather than being taught specific techniques. It also became clear that some patients misunderstood what was involved in certain techniques. In addition, there was often a reluctance to use techniques that patients and caregivers had previously found to be beneficial, for fear of any adverse effects on patient's outcomes. There was also little awareness of vocal and sleep hygiene practices, breathing techniques, and cough and anxiety management, and generally much practice communicated was considered inappropriate from a professional perspective.

The format for the intervention was not well articulated. Although some participants were clearly opposed to any group format (particularly those who tended to use denial as a coping strategy), others appeared to value the opportunity to be involved with other patients. Therefore, to gain a clearer understanding, this area will require further investigation.

Previous research has demonstrated the potential importance of patient's preferences for participating in health care decision making. As stated in the literature, we support the view that patient-centered care should strive to respond to individual patient's needs and preferences when possible. However, providing this level of support may be particularly challenging given the present economic climate, as this may well affect the level of available resources. In light of this, critical decisions may have to be made regarding the preferences we can afford to meet and those we cannot. This issue is of central importance and we will need to consider it when developing the intervention.

The findings from this study need to be seen in light of its limitations. Although we have identified a number of key issues from the interviews that need to be considered when developing a nonpharmacological intervention, some areas were less well articulated. These require further clarification and include the venue of the intervention, the extent of caregiver's involvement, the provider of the intervention, and the format of the intervention, which we are currently testing using a best-worst scaling methodology. We also recognize that decision making may not be stable over time and patient's preferences for treatment may vary over the course of treatment/illness. The interviews in this study were conducted across variety of stages of treatment and illness trajectories, and the stage of illness/treatment was shown to be important for
many of these issues. More clarity regarding these issues may be gained through piloting the intervention.

**Conclusions**

The data from this study have provided insight into the key issues that are likely to influence the development, delivery, and uptake of a nonpharmacological intervention to help manage the respiratory symptom cluster of cough, breathlessness, and fatigue. It is crucial that the identified attributes are considered when developing and modeling the proposed nonpharmacological symptom management intervention prior to testing it. This will ensure the intervention is person centered and reflects the diverse needs and preferences of this particular population in appropriate and sensitive ways. The information provided is generic enough to be applicable to the development of other nonpharmacological interventions in LC patients. Our next step is to pilot test an intervention based on the preferences and delivery suggestions communicated by patients and caregivers in this study.

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