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Brief Report

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ABSTRACT

Context

Carers' needs in advanced disease, and specifically in relation to breathlessness, are well evidenced. Publications on educational interventions for carers of patients with advanced disease which focus on symptoms are scarce and absent for breathlessness.

Objectives

To establish current education provided by clinicians for carers of patients with breathlessness in advanced disease, views about educating carers about breathlessness and relevant outcomes for a future randomised controlled trial (RCT) of an educational intervention for carers.

Methods

Online survey completed by 365 clinicians: medical, nursing and allied health professionals from primary care, hospital and hospice. Descriptive statistics summarised respondent characteristics and survey responses, and the chi square test applied. Content analysis of free text comments.

Results

Most clinicians reported educating carers by educating patients at clinical contacts with patients. Carer involvement was largely an 'add-on'; an 'active' carer education strategy, where all carers were invited to attend, was not currently apparent. Clinicians endorsed the importance of educating carers about breathlessness through increasing carer confidence/control, helping patients' better self-manage breathlessness and potentially reducing admissions. Joint education with patients, giving practical advice and strategies for helping patients were advised. To inform a future trial, clinicians identified improvement in patient outcomes, particularly patient quality of life, as very important in enhancing clinician adoption of an educational intervention for carers.

Conclusion

This survey revealed an appetite amongst clinicians for an educational intervention for carers of patients with breathlessness in advanced disease and provided important insights to underpin a future Phase II RCT.

Keywords

breathlessness; intervention; carers; advanced disease; survey; palliative care; clinician views

Running title

Survey: educating carers about breathlessness

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INTRODUCTION

Breathlessness is a distressing, disabling symptom of advanced disease¹⁻⁴. It is a frequent symptom of advanced cancer and cardio-respiratory disease, such as chronic obstructive pulmonary disease (COPD) and heart failure. Breathlessness causes distress and isolation to patients and to informal carers (family members/friends).⁵ Their caregiving role in relation to breathlessness is multi-faceted, including managing symptoms and medications, assisting with personal care, and providing practical and emotional support.

There is a broad evidence-base for carers' experiences and needs in advanced disease⁶⁻⁷, and specifically in relation to breathlessness. The latter identifies carers' anxiety/emotional distress^{5,8-12}, isolation^{5,13}, restrictions^{5,8,9,11-14}, lack of support/assistance^{5,12,14}, lack of knowledge/strategies, helplessness and powerlessness.^{5,12,13} However, the evidence-base for interventions to meet these needs remains limited¹⁵⁻¹⁸. Bee et al's systematic review of carers' needs in providing home-based end-of-life care to people with cancer suggests that home-based palliative care services have insufficiently focussed on assisting carers to acquire information and practical skills¹⁹, whilst Caress et al's review found no studies describing or evaluating interventions to enhance caregiving-capacity for family-carers of COPD patients²⁰. Most recently, Farquhar et al's review found that educational interventions for carers of patients with advanced or chronic disease which focused on symptoms are rare and none focus on breathlessness²¹.

The study reported here forms part of the Learning about Breathlessness (LAB) Study programme which uses the MRC framework for developing and evaluating complex interventions²² and the principles of educational planning²³ to develop an evidence based educational intervention for carers of patients with breathlessness in advanced disease. This study, which is one component of the MRC Phase I of the LAB programme, aimed to establish current education provided for carers, views about educating carers about breathlessness and relevant outcomes for a future randomised controlled trial (RCT) of the developed intervention.

METHODS

Design

An anonymous online self-complete survey for clinicians delivered via professional associations.

Ethics

Approval from the NRES Committee East of England – Cambridge Central on 17th January 2014. REC reference number: 14/EE/0009

Recruitment of participants

Clinicians working with patients with breathlessness in advanced disease were recruited via eight professional associations and clinical networks (Box 1) identified through consultation with the study's Monitoring and Advisory Working Group (MAWG). Clinicians were sent an invitation letter

(Box 1) and a link to the online survey using different (often multiple) methods: direct email to the membership (six organisations); e-newsletter item (n=2); website item on the organisations' homepage (n=2); twitter (n=2) and Facebook (n=2). One organisation (APM) sent a follow up reminder email to their membership two weeks after first contact.

Insert Box 1 about here

Survey design and piloting

A short online survey comprising six questions and two free-text boxes was hosted in Qualtrics (Box 2). This survey of current practice and views on educating carers was designed to minimise participant burden and facilitate completion. Abernethy's approach²⁴ was used to also identify clinician-relevant outcomes for a future RCT in order to facilitate ultimate intervention adoption. The survey was piloted with clinician members of the MAWG which included specialties of respiratory medicine, general practice, nursing, palliative medicine, occupational therapy and oncology across primary, secondary and community care settings.

Insert Box 2 about here

Analysis

Descriptive statistics summarised respondent characteristics and frequency of responses. Frequency counts were cross-tabulated by professional group, work setting and specialty (including specialist interest) and the chi square test applied. Content analysis of free text comments was conducted independently by two authors (GE/MF), then compared, agreed and summarised. Quote identifiers (e.g. R7) relate to the response, not respondent.

RESULTS

(1) Survey participants

In total, 365 participants completed the survey: 155 (42%) medical practitioners, 129 (35%) Allied Health Professionals (AHPs) and 80 (22%) nurses; one other identified as an unspecified specialist palliative care professional. Table 1 shows their specialty or main specialist interest.

Insert Table 1 about here

Most respondents were based in hospices (specialist palliative care units) or secondary care/hospitals (Table 2). The remaining 22 respondents (6%) worked across settings the majority split between hospital/hospice and community.

Insert Table 2 about here

(2) Current methods of helping informal carers learn about breathlessness

Respondents were asked what they currently did to help informal carers learn about breathlessness (multiple responses: Table 3).

Insert Table 3 about here

Most reported educating carers by educating patients. In an accompanying free text box, 31 respondents provided additional comments, which were grouped in analysis using the Table 3 categories. From written responses it was possible to differentiate jointly delivered approaches where carers were actively invited/encouraged to attend with the patient (n=13) e.g. *"Carers are invited to and included in the sessions, but these are primarily targeted at the patients"* (nurse). Carers could also be included in sessions set up for patients, but not specifically invited (n=7) e.g. carers were *"welcome to stay and listen"* (AHP). Others described more direct delivery to carers, but mostly through using booklets/leaflets on breathlessness management as well as more *ad hoc* informal but direct contacts with carers. A small number reported providing carer education through referral to other members of their multi-disciplinary team (MDT).

Current methods of educating carers about breathlessness were tabulated by professional group, work setting and clinician specialty/specialist interest to identify any differences in education delivery. There were no differences between professional groups, across settings or specialties regarding reporting educating carers by educating patients. However, AHPs were more likely to deliver education directly to carers whereas this was reported less by doctors ($p < 0.007$) or oncology specialists ($p = 0.019$). AHPs and healthcare professionals who were hospice-based were less likely to refer carers for education by other services ($p < 0.001$ for both). Nurses and healthcare professionals in secondary care were more likely to signpost carers to education elsewhere ($p < 0.001$ for both). However those whose speciality was palliative care were less likely to either refer or signpost carers to other services ($p < 0.001$ for both).

(3) Additional clinician comments on educating carers about breathlessness

Of the 365 responding clinicians, 89 (24%) provided additional free text comments at the end of the survey. Comments were grouped into two main themes: (i) the importance of educating carers about breathlessness and (ii) potential methods of helping carers learn about breathlessness.

(i) Importance of educating carers about breathlessness

These additional comments fully endorsed the importance of educating carers about breathlessness: this was regarded as an important topic, often overlooked. Breathlessness was described as a distressing symptom which carers have a huge role in managing but often feel powerless to do so: *“they find it difficult to watch someone so breathless and fighting for breath”* (R7). It was frightening, resulting in feelings of helplessness and anxiety which impacted on the carer’s own health. Some clinicians acknowledged that they did little with carers and that the availability of a specific educational resource for carers would be very valuable.

Clinicians identified three ways in which an educational intervention would be beneficial: increasing carer confidence and control, helping patients better self-manage and potentially reducing admissions.

- Increasing carer confidence and control

Clinicians felt it important to enhance carers’ confidence in coping with patients’ panic attacks and breathlessness episodes. They felt that giving carers practical techniques to use when patients were breathless would empowering them, involve them in care and reduce anxiety: giving carers some control at frightening, difficult times. One clinician went further, commenting: *“In isolation breathlessness management may not impact the carers’ wellbeing, but extension of the skills, awareness and confidence will reap rewards”* (R39).

- Helping patients better self-manage

Clinicians felt that improved carer understanding of breathlessness would help patients self-manage: *“We have found that when a carer is aware of the techniques used to manage breathlessness they encourage the patient to use the techniques”* (R15). Being with patients 24/7 meant carers were well-placed to reinforce strategies taught to patients: this was particularly useful when patients started to panic.

- Reducing admissions

Clinicians commented on hospital admissions for people with breathlessness being more likely where carers or family were unable to cope. It was felt that empowering carers to manage breathlessness could reduce admissions and enable patients to remain at home. *“Breathlessness is a disabling symptom which results in unplanned admissions to hospital and distress for everyone. Admissions result in painful testing and investigations which cost the NHS as those reviewing the*

patient look for something treatable. If we can find ways of managing this symptom and supporting patients and carers, this will improve outcomes and reduce costs” (R38).

(ii) Potential methods of helping carers learn about breathlessness

Many of the clinicians suggested that educating carers about breathlessness was best done with the patient, where both could benefit from learning, sharing and problem-solving. It was felt this approach would enable better symptom management and reduced anxiety, while also improving carer confidence and reducing feelings of helplessness when faced with severe breathlessness.

Clinicians favoured provision of *“short practical techniques”* (R22) and strategies for coping with breathlessness and panic so as not to overwhelm the carer: *“simple tips on how to help”* (R21) to enable carers to positively offer support whilst diminishing their own anxiety/helplessness. *“Carers make such a difference if they can help support patients with breathlessness by providing coping strategies, visualisation, counting, fans etc.”* (R10).

No single mode of delivery was seen as suitable for all carers. Some clinicians had found that patients and carers are not always able to attend hospital-based educational sessions, preferring input nearer home. They also noted that people learn in different ways and so for some a one-to-one or joint patient/carer session with health care professionals may be preferred, although they may later join a group for peer education and support. Value was seen in having ‘top tips’ on a range of mediums, including web-based. Written information was also considered helpful, including illustrations, reinforcing clinician delivered information, particularly where time was limited.

(4) Clinician relevant outcomes to enhance intervention adoption

To inform a future RCT, respondents were asked to rate different carer and patient outcomes which might encourage them to use/refer to an educational intervention on breathlessness for carers.

Insert Table 4 about here

Clinicians rated outcomes for patients higher than outcomes for carers in encouraging them to use or refer to an educational intervention for carers. Further regarding carer outcomes, practical measures related to the carers’ role in caring for the patient, such as increased carer coping/problem solving or increased carer competence for caregiving, were rated more important than outcomes related to the impact of caring on carers themselves i.e. improved carer psychological health, quality of life or general health.

DISCUSSION

Despite a broad evidence base of carers' needs in relation to breathlessness, there is a dearth of robustly developed and evaluated educational interventions for carers. Most clinicians participating in the survey reported educating carers by educating patients at clinical contacts primarily aimed at patients. About a quarter provided additional comments endorsing the importance of educating carers about breathlessness through increasing carer confidence and control, helping patients better self-manage breathlessness and potentially reducing admissions. To help carers learn about breathlessness, they further suggested joint education with the patient, the usefulness of practical advice and strategies on how to help patients, and advised that no single delivery mode was suitable for all carers. To inform a future trial, clinicians identified improvement in outcomes for patients, particularly patient quality of life, as very important in enhancing clinician adoption of an educational intervention for carers of patients with breathlessness.

Although clinicians reported educating carers by educating patients, additional comments revealed that they rarely educated carers directly: carer involvement in sessions designed for patients were largely 'add-ons'. An 'active' carer education strategy, where all carers were invited by clinicians to attend with the patient, was not currently apparent. Thus it was perhaps not surprising that survey respondents identified educating carers about breathlessness as an important topic, often overlooked, and valued the idea of a specific educational resource for carers. The research literature too reveals a substantial gap in terms of such interventions. To date there have been no studies of carer educational interventions on breathlessness in advanced disease²¹ and an earlier review²⁰ also identified a lack of well-defined interventions to enhance the physical and practical skills of carers.

The survey results also suggested clinicians well placed to deliver an intervention. AHPs may be an appropriate group as they currently report more delivery of interventions directly to carers compared to medical/oncology colleagues. Similarly, hospice-based clinicians were less likely to report referring or signposting carers to other services for support and so may also be future providers. Clinicians' views of potential methods for the intervention included joint delivery with the patient and a focus on simple, practical techniques, although there was no consensus on a single mode of delivery. These views echo findings from carers themselves within the wider study²⁷ and provide helpful insights into the likely acceptability of the developed intervention to clinicians.

Clinicians identified outcomes that would enhance their adoption of an educational intervention, favouring patient outcomes of improved quality of life: an important understanding for future trial work. Measures of increased carer coping/problem solving or increased carer competence (i.e. those most likely to impact directly on the patient) were also prioritised over improved carer wellbeing: psychological health, quality of life or general health. Although the intervention is intended for carers, what appears to be important to clinicians is that it enhances the patient experience and the carer's ability to care for the patient, rather than one which seeks address the carer experience or impact of the caring role. However, not all carers situate themselves in this role²⁵ and furthermore have distinct needs in their own right. This is an important consideration in intervention development: carers also need to engage with the intervention and thus it must meet their needs as well as those of clinicians. A recent study²⁶ examining interactions between carers and healthcare professionals identified high levels of dissatisfaction in relation to attention to carers' well-being or information needs.

Potential explanations for the particularly poor response in non pall care should be explored (eg few clinicians addressing breathlessness in anybody under their care let alone carers...? Not seen as a clinical priority?) as this has implications for implementation in non pall care settings.

However, it must be borne in mind that these findings are from a brief online survey. We know that the majority of responses were from palliative care clinicians, but we recognise the limitation of not being able to determine a response rate. This was due to absence of information on the total number of clinicians alerted to the survey (the denominator) given the variety of methods of delivery, including via email lists and newsletters. Nevertheless interest in the topic was demonstrated by the higher than anticipated number of respondents and number and extent of additional qualitative comments provided. It may be the case that the strategy of a very brief survey was successful: previous work by the authors (GE/MF) found clinical staff responsive to brief focused data collection methods.²⁸

CONCLUSION

This brief survey provided important insights for future implementation work. It revealed an appetite amongst a significant group of clinicians with a likely interest in breathlessness management for an educational intervention for carers of patients with breathlessness in advanced disease, in itself a potential key factor in intervention adoption. It has also provided crucial understandings to underpin a Phase II pilot RCT of the developed intervention and Phase III definitive RCT, in terms of clinician-endorsed intervention methods and outcomes likely to enhance intervention adoption.

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Table 1. Specialty or main specialist interest of responding clinicians

Specialty/special interest	Medical	Allied Health Professional	Nursing	Other	Total (%)
Palliative Care	146	85	7	1	239 (66%)
Respiratory Medicine	3	23	31	0	57 (16%)
Oncology	4	16	32	0	52 (14%)
Other (includes clinicians who worked in more than one of the above specialties, or in lung transplantation, health psychology or pulmonary maintenance)	2	5	9	0	16 (4%)
Total	155	129	79*	1	364

* In total 80 respondents were nurses. However one nurse respondent did not answer the question on specialty/special interest and so is not included in this table.

Table 2. Clinical setting of respondents

Setting	N = 364	Percent
Hospice (specialist palliative care unit)	145	40
Secondary care / hospitals	135	37
Primary care	62	17
Other	22	6

Table 3. Current methods of educating informal carers about breathlessness (multiple responses)

Methods reported	N = 364	Percent
Educate carers by educating patients	304	84
Provide / deliver education directly to carers	231	63
Signpost carers to other resources	162	45
Refer carers on to other services eg breathlessness clinics or pulmonary rehabilitation	159	44
Other - please specify	32	9

Table 4 Clinician rating of carer and patient outcomes

Carer outcomes	Very important	Slightly/moderately important	Not at all important	Total Responses
Increased carer coping/problem solving	322 88.7%	41 11.3%	0	363
Increased carer competence for caregiving	308 84.6%	56 15.4%	0	364
Improved carer psychological health	290 80.1%	72 19.9%	0	362
Improved carer quality of life	282 77.5%	82 22.5%	0	364
Improved carer general health	230 63.7%	131 36.3%	0	361
Patient outcomes	Very important	Slightly/moderately important	Not at all important	Total Responses
Improved patient quality of life	347 95.3%	17 4.7%	0	364
Improved patient psychological health	337 92.8%	26 7.2%	0	363

Box 1: Clinician recruitment

Professional organisations and clinical networks which facilitated survey recruitment

- British Thoracic Oncology Group (BTOG)
- National Lung Cancer Forum for Nurses (NLCFN)
- Association of Respiratory Nurse Specialists (NLCFN)
- British Association of Occupational Therapists and College of Occupational Therapists - Specialist Section - HIV, Oncology and Palliative Care (COT SS HOPC)
- Association for Palliative Medicine (APM)
- Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC)
- Association of Chartered Physiotherapists in Respiratory Care (ACPRC)
- Contact, Help, Advice and Information Network (CHAIN)

Letter of introduction about the survey

Our research has been finding out what informal carers (family members and friends) of people who are breathless due to advanced cancer or COPD would like to learn about breathlessness in order to help them support the person they care for. As a clinician working with patients with breathlessness in advanced disease, we would like to invite you to participate in this brief online survey which will inform the development and evaluation of an educational intervention on breathlessness for informal carers.

The aim of the survey is to find out how clinicians help informal carers learn about breathlessness, and what outcomes would encourage them to use or refer to an educational intervention on breathlessness for informal carers. The survey is very short (just 6 questions) and will take less than 5 minutes to complete.

By completing the survey, you consent to take part in this study. The study is funded by Dimbleby Cancer Care and has been approved by NRES (National Research Ethics Service). For further information please email LAB@medschl.cam.ac.uk

Box 2: Clinician survey: 6 questions and 2 free text comment boxes

1 What is your occupational group?
2 What do you currently do to help informal carers learn about breathlessness? (Multiple responses invited) <ul style="list-style-type: none"> • Provide / deliver education directly to carers; Refer carers on to other services; • Signpost carers to other resources; • Educate carers by educating patients; • Other - please specify
Free text comments on current methods used to help carers learn about breathlessness
3 Please indicate how important each of the following carer outcomes would be in encouraging you to use, or refer to, an educational intervention on breathlessness for informal carers? (4 point rating scale) <ul style="list-style-type: none"> • Increased carer competence for caregiving • Improved carer quality of life • Improved carer general health • Improved carer psychological health • Increased carer coping / problem solving
4 Please indicate how important each of the following patient outcomes would be in encouraging you to use, or refer to, an educational intervention on breathlessness for informal carers? (4 point rating scale) <ul style="list-style-type: none"> • Improved patient quality of life • Improved patient psychological health
5 In which setting are you mainly based?
6 Please indicate your main specialty or special interest?
Free text comments on helping informal carers learn about breathlessness