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Developing a relevant and acceptable educational intervention for carers of patients with breathlessness in advanced disease: the Learning about Breathlessness Study

Executive Summary – August 2016

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This study received ethics approval from the National Research Ethics Service (NRES) Committee East of England – Cambridge Central (Reference number 14/EE/0009).

Background

Breathlessness is a common devastating symptom of advanced cancer and non-malignant diseases such as chronic obstructive pulmonary disease (COPD). It is a frightening symptom that places a huge burden on patients, health systems, and on informal carers (family members and friends providing daily help and support) causing distress and isolation. Carers play a crucial role in providing supportive care.

There is a need and desire amongst carers to increase their knowledge of breathlessness. Educating carers about breathlessness, evidence-based non-pharmacological interventions for breathlessness and aspects of breathlessness management (e.g. what patients can be expected to do, what a carer can do in a breathlessness episode) may be an effective approach to meeting both patient and carer needs. Yet we lack robustly developed and tested evidence-based interventions for carers: there is insufficient focus on assisting carers to acquire information and practical skills.

The Learning about Breathlessness Study sought to develop a relevant and acceptable educational intervention for carers of patients with breathlessness in advanced disease.

Design & methods

An MRC Phase I four stage mixed method study, using predominantly qualitative methods, mapped to the four study objectives.

Stage 1 - Identifying carers' educational needs and preferences: qualitative interviews with 25 patients and their carers living with breathlessness due to advanced cancer or COPD to identify carers' educational needs and intervention preferences, synthesised with findings from a systematic review of educational interventions for carers.

Stage 2 - Identifying evidence-based intervention content with clinical experts: one day workshop with 13 clinical experts to review Stage 1 findings and develop evidence-based intervention content and potential delivery-modes.

Stage 3 - Intervention co-development with informal carers: two half-day workshops with carers and patients (n=17) to co-develop the intervention based on Stages 1-2 findings to ensure relevance and accessibility.

Stage 4 - Identification of referrer-relevant outcomes: online survey of potential intervention referrers (clinicians; n=365) to identify current practice in educating carers about breathlessness and outcomes to measure in a future evaluation of the intervention.

Key findings

Why do carers want to learn?

Carers expressed a strong desire for an educational intervention on breathlessness: existing interventions were for patients. They wanted formalised advice which strengthened their supportive role or reassured them that what they were already doing was correct: affirmation to build their

confidence. They wanted information and knowledge to put them in a better position to help the patient and allay their concerns. They wanted strategies, 'work arounds', tips and tricks.

They also wanted to be included in discussions of breathlessness management to enable them to support the patient to manage their breathlessness day to day, but were rarely involved in advice-giving to patients or knew what the patient had been taught in terms of management strategies. They sought acknowledgement of their role in supporting the patient and contributing to managing their breathlessness.

What do carers want to learn?

Six key interrelated topics emerged as salient for carers:

- 1) understanding breathlessness
- 2) managing anxiety, panic and breathlessness
- 3) managing infections
- 4) keeping active
- 5) living positively
- 6) knowing what to expect in the future

1) Understanding breathlessness: carers wanted to learn about the causes of breathlessness and the experience of breathlessness. They felt this would help them have more patience with the person they supported and cope better with their own emotions around the condition.

2) Managing anxiety, panic and breathlessness: carers wanted to know how to recognise panic and how to respond to anxiety and panic confidently in order to manage breathlessness. They acknowledged that their response was often unhelpful, for example asking the patient what they could do when the patient was unable to respond due to their breathlessness. They themselves could feel anxious and panicked witnessing a breathlessness attack. Some had good strategies already but lacked confidence. They wanted practical tools and advice – tips on how to calm the patient and their breathing.

3) Managing infections: carers wanted to know how to avoid and respond to infections. Unexpectedly this topic was relevant to those living with cancer as well as those living with COPD. Avoiding contacts came at the cost of compounding an already restricted and isolated life: carers wanted help to manage this. They also wanted a better understanding of when to start emergency medication and when to seek additional help, even when emergency plans were already in place: they wanted clear usable guidance.

4) Keeping active: carers wanted practical guidance on how to help the patient be active, including armchair exercises, but this was accompanied by the challenge of getting the balance right – knowing the appropriate amount of activity and rest. There was a mismatch in expectations between carers and patients and this was a major cause of tension in the dyads: patients felt frustrated, with some feeling they wanted to do more but weren't being allowed, while others felt carers did not understand how they felt and had unrealistic expectations.

5) Living positively: carers wanted to know how to maintain a reasonable quality of life, overcoming isolation and restrictions. They wanted strategies to encourage the patient and ideas for appropriate

activities they could do together, especially within couples. They wanted help to plan, pace and problem solve. There was again a mismatch in expectations within dyads around what was possible and what was not. Also, some patients were reticent about getting help in the home or garden or about using wheelchairs or mobility scooters leading to frustration for carers; strategies carers can use to encourage patients to accept external help or use mobility aids would be valued, as would information on accessing support or equipment.

6) Knowing what to expect in the future: this topic was about carers wanting to feel prepared as illness progressed. It was not so much about prognostication, which is challenging in COPD in particular. Carers wanted information and education around possible trajectories or progression of breathlessness: not knowing was a source of worry. They wanted to anticipate future changes so they could be proactive in responding rather than simply reacting as they went along. However there was a tension for most carers relating to their desire to know more about this but not wanting to upset the patient.

Disease group differences

There were some differences in learning needs by disease group, with a greater interest among cancer carers in gaining knowledge for their role in supporting the patient whereas for COPD carers their desire related also to their own needs as carers. These differing of aspects of the caring role have been referred to by others as direct care needs and enabling needs and reflect the dual role carers have as both co-workers and clients. These different learning needs may relate to the shorter duration of the caring role in cancer, such that cancer carers appeared less ground down by the caring experience and the impact of restrictions and isolation than those caring for patients with advanced COPD.

How do carers want to learn?

There was wide variation in how carers wanted to learn:

- Simple, concise leaflets or booklets were viewed useful as a back-up to face-to-face learning but patients and carers described leaflet overload: especially among those with a cancer diagnosis. The proposed intervention should not, therefore, be a standalone leaflet.
- More popular were face-to-face, group, video or web-based learning, but there were concerns about the trustworthiness of some websites. One-to-one learning was less popular.
 - Some carers were very keen to learn in a group setting with other carers, but this was definitely not a preference of everyone.
 - Among cancer carers there were concerns about other group members, privacy about the disease, and the group dynamic.
 - Group learning was impractical for some: there were lots of practical considerations if accessing the intervention outside the home either with or without the patient.
- There was a strong desire for visual information.
- Carers wanted to learn from both clinical experts and from peer-carer experience: they were keen to learn tried and tested 'work arounds' and tips from those who had lived with the symptom.
- Unexpectedly there was a preference for learning with the patient, but this was not true for everyone, and not for every topic: carers thought it would be better to learn about "knowing

what to expect in the future” separately from the patient. There was a tension for carers in relation to their desire to know what to expect but not wanting to upset or burden the patient with this knowledge.

- Carers wanted an intervention that was personalised, or individualised, in terms of its content, its delivery mode and its timing.
- Carers did not want to be taught everything: they were prepared for the intervention to signpost them to more detailed resources should they want it.

Given this wide variation in intervention delivery mode preferences there was a need for flexibility in the intervention design: a striking need for multiple delivery modes.

Meeting the need for multiple delivery modes

Our solution to the need for flexibility in the intervention delivery mode is to enable multiple modes of access to a core of educational content relating to the six topics carers wanted to learn about. We therefore propose a web-based educational platform which will hold the educational content, developed by clinical experts and carers, but which will be accessible via four primary delivery modes:

- 1) Self-Accessed: accessed by carers (and patients) themselves or “prescribed” for self-access by a health care professional;
- 2) Peer-led Support Groups: reviewed with established peer-led support group e.g. British Lung Foundation Breathe Easy groups;
- 3) Clinician-led Established Groups: delivered by clinicians at clinician-led established groups e.g. pulmonary rehabilitation, or mesothelioma support groups; or,
- 4) Clinician One-to-Ones: delivered by clinicians in one-to-one sessions with individual carers (and patients).

We found near-universal access to internet among carers taking part in the study, in particular via tablets. Further, the Office for National Statistics reports 86% of the UK population has internet access: a rising figure, particularly amongst more socially deprived groups. However enabling access to the web-based educational platform through these four suggested modes could overcome access issues for non-web users as well as addressing the identified variation in delivery mode preferences.

The website would be menu-driven (to address carers’ preference for personalised content), include both text and pictures, include short film-clips with clinical experts and peer carers, include downloadable topic pages, and be badged or endorsed (e.g. by the University, NHS and patient and carer charities) to address concerns about the trustworthiness of some online information.

Using a web-based educational platform to hold the educational content would enable control of content, content fidelity and ease maintenance given its potential to be updatable.

Developing the intervention with clinical experts

Expert clinicians participating in the Stage 2 workshop validated and endorsed the six topics identified in Stage 1, recognising them as salient to carers as well as to patients. They suggested content in relation to each topic drawing on examples and guidance from their clinical practice in relation to educating both carers and patients. They noted the underlying theme of supporting

relationships within carer-patient dyads within several of the topic areas. They broadly endorsed the proposed format and delivery-modes developed in response to our findings on carers' preferences.

Developing the intervention with carers and patients

Mock-ups of webpages for five of the six topics were developed for review by carers and patients in the Stage 3 workshops. Given its sensitivity, a mock-up webpage was not developed for the sixth topic, "knowing what to expect in the future", but the topic was taken forward for further discussion in the Stage 3 workshops to identify potential content.

Carers and patients participating in the Stage 3 workshops validated and endorsed the six topics, recognising them as salient to both carers and patients, and suggested clarifications and amendments to the draft content shown to them on the five mocked-up webpages. They also endorsed the proposed modes of access to the intervention.

Their discussion of potential content for the final topic, "knowing what to expect in the future", revealed disease group differences and differences from our Stage 1 findings that will require further work before this topic's content can be developed. Those living with COPD had a preference for maintaining the positive, "can do", message of the other five topics, whereas those living with cancer seemed more at ease with the concept of including end of life care within this topic. This may reflect lack of awareness or acceptance of the life-limiting nature of COPD, as well as its less predictable trajectory.

Inclusion of this topic was grounded in Stage 1 findings, was endorsed by Stage 2 clinical experts and clinical experts on the MAWG. Stage 1 carers were usually interviewed separately from the patient, whereas the Stage 3 workshops included both carers and patients discussing this topic together: this may explain the different findings. Subject to funding, the planned follow on study (LaB2) will explore this topic further through focus groups with bereaved carers of breathlessness patients (one for COPD, one for cancer): the focus groups will explore what carers with the benefit of hindsight, would have wanted to learn about "the future" and how this might be appropriately achieved with potentially co-present patients.

Clinicians' current practice and views on outcomes for a future evaluation

Despite a broad evidence base of carers' needs in relation to breathlessness (affirmed by Stage 1 of this study), the Stage 4 clinician survey confirmed the lack of robustly developed and evaluated educational interventions for carers. Most clinicians reported educating carers indirectly by educating patients, but many endorsed the importance of educating carers about breathlessness. To help carers learn about breathlessness, they suggested joint education with the patient, practical advice and strategies on how to help patients, and advised that no single delivery mode was suitable for all carers. These findings thus supported the findings of Stages 1-3. 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.

Concluding comments

The Learning about Breathlessness study is the first to describe in detail the unmet educational needs of carers of patients with breathlessness in advanced disease. It identified the need and desire for an educational intervention for carers. As a MRC Phase I study, it has produced new knowledge relating to:

- six topics carers want to learn about to help them support someone with breathlessness in advanced disease
- the ways carers want to learn (intervention delivery modes)
- expert clinician-derived intervention content for the six topics, and views on the feasibility of the proposed intervention design and delivery modes
- carer and patient views on the intervention content (language and format) and feasibility of the proposed intervention design and delivery modes
- stakeholder current practice in educating carers about breathlessness and views on relevant outcomes for future testing of the intervention

Meeting the educational needs of carers requires robustly developed and evaluated interventions. This study provides the evidence-base for the content of an educational intervention for carers of patients with breathlessness in advanced disease.

Further, 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: a potentially key factor in ultimate intervention adoption. It has also provided crucial understandings to underpin pilot implementation work and future evaluative work (e.g. 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.

As such it forms the foundation for a Learning about Breathlessness (LaB) Study Programme and has become known as LaB1. LaB2, the proposed follow on study, will build on LaB1, producing specific new knowledge on what carers want to learn about the LaB1-identified topic "the future" (including end of life care), and how they could sensitively learn this with a potentially co-present patient. LaB2 will add this to LaB1's findings and iteratively develop the prototype evidence-based educational intervention for carers of patients with breathlessness due to advanced disease, ready for testing in appropriately designed study.

Dissemination

A range of study dissemination activities has included a flagship end of study Dissemination Event, oral and poster presentations locally (University, NHS Trusts, respiratory/cancer networks), nationally and internationally and peer-reviewed journal publications.

Dissemination Event

This free end of study dissemination session was held in Cambridge on 14th July 2016. Named individuals were invited via EventBrite (e.g. key clinicians, researchers and Stage 2 expert clinician participants) or personal letter (i.e. Stage 3 carer and patient participants). Local and national organisations were targeted to cascade the booking link internally and externally (including cancer, respiratory, and palliative care professional and provider organisations, researchers, and carer- and other representatives). The event was further promoted via Twitter by the study team and by some of the organisations.

Attendees included a range of clinicians from oncology, respiratory and palliative care services from primary, community and secondary care as well as a range of researchers (including palliative and cancer care), representatives from local networks, service users (including study participants) and service managers. Members of the MAWG attended, including our PPI advisor. The session included a presentation of the study findings and discussion session with members of the research team. There were accompanying poster presentations on the six key interrelated topics carers wanted to learn about, a study handout and certificate of attendance.

Oral presentations

- Primary Care Unit Qualitative Research Forum (QRF)
– University of Cambridge, 7th October 2014
Title: Identifying patient and carer preferences for an educational intervention for carers on breathlessness in advanced disease
- PCRS UK – National Primary Care Respiratory Conference
– Northampton, 16th -17th October 2015
Title: Developing an educational intervention on breathlessness in advanced disease for informal carers
- Primary Care Unit Research Seminar
– University of Cambridge, 5th April 2016.
Title: Developing an educational intervention on breathlessness in advanced disease for informal carers
- The 11th Palliative Care Congress
– Glasgow, 9th-11th March 2016
Title: Developing an educational intervention on breathlessness in advanced disease
- Royal College of Nursing International Research Conference
– Edinburgh, 6th-8th April 2016
Title: Developing an educational intervention on breathlessness in advanced disease
- Learning about Breathlessness Study – Dissemination Event
– University of Cambridge, 14th July 2016
Title: Learning about Breathlessness Study – Dissemination Event

Poster presentations

- Penfold C, Ewing G, Gilligan D, Mahadeva R, Booth S, Benson J, Burkin J, Lovick R, Todd CJ, Farquhar M. What do informal carers want to learn about breathlessness in advanced disease and how do they want to learn it? Marie Curie Cancer Care / Royal Society of Medicine joint meeting 'The future of palliative care' - 27th March 2015
- Penfold C, Ewing G, Gilligan D, Mahadeva R, Booth S, Benson J, Burkin J, Lovick R, Todd CJ, Farquhar M. What do informal carers want to learn about breathlessness in advanced disease and how do they want to learn it? Cambridge Institute of Public Health 2015 research conference: "Why public health research matters" – 8th October 2015

Invited presentations

- Penfold C. "Developing an educational intervention on breathlessness in advanced disease for informal carers – the Learning about Breathlessness study"
Breathlessness Research Interest Group (BRIG) 2014 meeting
– University of Cambridge, 7th November 2014
- Workshop: Farquhar M, Nauss D. "Enabling support for carers of patients with COPD" at INSPIRED approaches to COPD: Improving Care and Creating Value Collaborative Workshop,
– Vancouver, Canada, 9th-11th February 2015
[cited Learning about Breathlessness Study]
- Penfold C. "Developing an educational intervention on breathlessness in advanced disease for informal carers".
– NIHR CRN Eastern - Cambridge and Peterborough General Practice Forum, 26th February 2015
- Farquhar M. "Breathlessness and the family"
International Breathlessness Meeting
– Copenhagen, 7th May 2015
[cited Learning about Breathlessness Study]
- Farquhar M, Nauss D. "Supporting carers of patients living with chronic disease"
Canadian Foundation for Health Improvement (CFHI) webinar
– Canada, 3rd June 2015.
<http://www.cfhi-fcass.ca/Elearning/OnCall/shifting-culture-shifting-care/supporting-carers-of-patients-living-with-chronic-disease>
[cited Learning about Breathlessness Study]

Publications

- Chin C, Butcher HH, Spathis A, Ryan R, Johnson M, Pattinson K, Currow D, Banzett R, Yorke J, Clayson H, Macnaughton J, Penfold C, Farquhar M, Booth S. What's Trending in Breathlessness Research? Proceedings of the 8th Annual Meeting of the Breathlessness Research Interest Group. *Progress in Palliative Care* 2015; 23(6): 326-30
- Penfold C, Ewing G, Gilligan D, Mahadeva R, Booth S, Benson J, Burkin J, Lovick R, Todd CJ, Farquhar M. What do informal carers want to learn about breathlessness in advanced disease and how do they want to learn it? (Marie Curie Cancer Care 2015 abstract). *BMJ Supportive & Palliative Care* 2015; 5(1): 107
<http://spcare.bmj.com/content/5/1/107.1.abstract>

- Penfold C, Ewing G, Gilligan D, Mahadeva R, Booth S, Benson J, Burkin J, Lovick R, Todd CJ, Farquhar M. Developing an educational intervention on breathlessness in advanced disease for informal carers (Primary Care Respiratory Society 2015 abstract) *npj Primary Care Respiratory Medicine* 2015;25(15060):11
- Penfold C, Ewing G, Mahadeva R, Benson J, Burkin J, Howson S, Lovick R, Farquhar M. Developing an educational intervention on breathlessness in advanced disease (PCC 2016 abstract). *Palliative Medicine* 2016;30(4):S15
- Farquhar M, Penfold C, Ewing G, Lovick R, Howson S, Burkin J, Booth S, Mahadeva R, Benson J, Gilligan D, Todd C. Developing an educational intervention on breathlessness in advanced disease (RCN 2016 abstract). *RCN International Nursing Research Conference 2016: Book of Abstracts*. Royal College of Nursing, 2016.
- Farquhar M, Penfold C, Ewing G, Lovick R, Howson S, Burkin J, Booth S, Mahadeva R, Benson J, Gilligan D, Todd C. Developing an educational intervention on breathlessness in advanced disease (EAPC 2016 abstract). *Abstracts of the 9th World Research Congress of the European Association for Palliative Care (EAPC)*. *Palliat Med* 2016: NP153

Papers in press

- Farquhar M. Supporting Informal Carers. *European Respiratory Society (ERS) Monograph 73: Palliative Care*
[cites Learning about Breathlessness Study]

A further two papers have been submitted to journals (one relating to the six key topics carers want to learn about and one to the Stage 4 Clinician Survey findings) and two are in preparation (one relating to how carers want to learn and describing the development of the intervention, and one reporting our recruitment data to facilitate study planning by other research teams and to provide a citable evidence-base).

For further information about this study please contact the PI:

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