

*Review Article*

# What Are the Key Elements of Educational Interventions for Lay Carers of Patients With Advanced Disease? A Systematic Literature Search and Narrative Review of Structural Components, Processes and Modes of Delivery

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**Abstract**

**Context.** Educating carers about symptom management may help meet patient and carer needs in relation to distressing symptoms in advanced disease. Reviews of the effectiveness of carer interventions exist, but few have focused on educational interventions and none on the key elements that comprise them but which could inform evidence-based design.

**Objectives.** To identify the key elements (structural components, processes, and delivery modes) of educational interventions for carers of patients with advanced disease.

**Methods.** We systematically searched seven databases, applied inclusion and exclusion criteria, conducted quality appraisal, extracted data, and performed a narrative analysis.

**Results.** We included 62 articles related to 49 interventions. Two main delivery modes were identified: personnel-delivered interventions and stand-alone resources. Personnel-delivered interventions targeted individuals or groups, the former conducted at single or multiple time points, and the latter delivered as series. Just more than half targeted carers rather than patient-carer dyads. Most were developed for cancer; few focused purely on symptom management. Stand-alone resources were rare. Methods to evaluate interventions ranged from postintervention evaluations to fully powered randomized controlled trials but of variable quality.

**Conclusion.** Published evaluations of educational interventions for carers in advanced disease are limited, particularly for non-cancer conditions. Key elements for consideration in developing such interventions were identified; however, lack of reporting of reasons for nonparticipation or dropout from interventions limits understanding of the contribution of these elements to interventions' effectiveness. When developing personnel-delivered interventions for carers in advanced disease, consideration of the disease (and, therefore, caring) trajectory, intervention accessibility (timing, location, and transport), and respite provision may be helpful. *J Pain Symptom Manage* 2016;■:■-■. Crown Copyright © 2016 Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. All rights reserved.

**Key Words**

*Informal carers, education, intervention, symptom management, advanced disease, narrative review*

**Introduction**

Despite a substantial and growing literature on lay carer experiences and needs in advanced disease,<sup>1</sup>

the evidence base for carer interventions remains limited, and few existing carer interventions are supported by rigorous research.<sup>2,3</sup>

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*Accepted for publication:* December 24, 2015.

The systematic review by Bee et al.<sup>4</sup> of carers' needs in providing home-based end-of-life care to people with cancer suggested that home-based palliative care services have been insufficiently focused on assisting carers acquire information and practical skills. The review highlighted the lack of practical support, often related to inadequate information exchange, which resulted typically in carers adopting a trial and error approach to caring. The authors concluded that health providers could better assist carers by providing the information and skills training necessary to facilitate increasing the confidence of carers in their ability to undertake practical aspects of care.<sup>4</sup> Although a number of reviews have focused on the effectiveness of various types of carer interventions in chronic disease and cancer,<sup>5–9</sup> few have focused on educational interventions.<sup>10,11</sup>

Educating carers about symptoms, and in particular about evidence-based nonpharmacologic interventions for symptom management (e.g., what patients can be expected to do, what to do in an acute symptom episode), may be an effective approach to meeting both patient and carer needs in relation to distressing symptoms in advanced disease such as breathlessness.

Breathlessness is a distressing and disabling symptom of advanced disease;<sup>12–15</sup> it is a frequent symptom of advanced cancer and cardiorespiratory disease, such as chronic obstructive pulmonary disease and heart failure, and complicates neurologic and neuromuscular conditions. It is a difficult and frightening symptom for both patients and their carers.<sup>16</sup> Carers of patients with breathlessness experience anxiety and emotional distress,<sup>16–21</sup> isolation,<sup>16,22</sup> and restrictions;<sup>16–18,20–23</sup> they lack support and assistance,<sup>16,21,23</sup> knowledge, and strategies, and they experience helplessness and powerlessness.<sup>16,21,22</sup> The development of evidence-based interventions to support carers of patients with breathlessness is, therefore, warranted.

This review forms part of a program of work to develop an evidence-based educational intervention for lay carers on the symptom of breathlessness in advanced disease. In the absence of an existing systematic review on the key elements that comprise such interventions, we sought to establish the key elements of educational interventions for lay carers of adult patients with advanced disease, for example, the structural components of the intervention, the processes of the intervention, or its mode of delivery. However, scoping work suggested that the literature on educational interventions for carers of patients with breathlessness in advanced disease would be scant. For example, the review by Caress et al.<sup>24</sup> of the

information and support needs of family carers of patients with chronic obstructive pulmonary disease found no studies that described or evaluated interventions designed to enhance caregiving capacity. Thus, despite our ultimate goal of developing an evidence-based educational intervention for carers on breathlessness in advanced disease, we chose not to limit our review to this symptom but to include educational interventions for a range of advanced and chronic cancer and non-cancer conditions.

We anticipated differences in the key elements of educational interventions for carers of patients with cancer compared with those with non-cancer disease because of the differing disease (and, therefore, caregiving) trajectories; the temporal context of the cancer caregiving role differs from that in non-cancer diseases in that it is usually shorter and the trajectory steeper. Thus, we sought to structure the review findings by broad disease group.

The objective of our review, therefore, was not confined to the symptom of breathlessness but sought to understand the structural components, processes, and modes of delivery of such interventions that could usefully inform the development and format of an educational intervention for carers on breathlessness in advanced disease.

## Methods

We conducted a systematic search and narrative review. The five authors brought a range of perspectives to the review, including health services research (M. F., C. P., F. M. W., and J. B.), nursing (M. F.), general practice (F. M. W. and J. B.), information specialism (I. K.), and education (J. B.).

### Inclusion Criteria

The inclusion criteria are outlined in [Table 1](#) and described later.

*Types of Intervention.* For their meta-analysis of the effectiveness of interventions for carers of older adults, Sørensen et al.<sup>25</sup> developed a useful classification of seven carer intervention types: 1) psychoeducational, 2) supportive, 3) respite/adult day care, 4) psychotherapy, 5) interventions to improve care-receiver competence, 6) multicomponent interventions, and 7) miscellaneous interventions. The review of the cancer literature by Pasacreta and McCorkle<sup>26</sup> used a simpler framework categorizing interventions into three types: 1) educational, 2) support, counseling, and psychotherapy, and 3) hospice and palliative home care services.

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