

Original Article

“I Can Breathe Again!” Patients’ Self-Management Strategies for Episodic Breathlessness in Advanced Disease, Derived From Qualitative Interviews

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Abstract

Context. Episodic breathlessness causes additional distress to breathless patients with advanced disease, but management is still insufficient and there is a lack of knowledge on effective coping strategies.

Objectives. The aim was to explore patients’ self-management strategies for episodic breathlessness.

Methods. In-depth interviews with patients suffering from episodic breathlessness as a result of chronic heart failure, chronic obstructive pulmonary disease, lung cancer, or motor neuron disease were conducted. Interviews were transcribed verbatim and analyzed guided by the analytic hierarchy of Framework analysis.

Results. A total of 51 participants were interviewed (15 chronic heart failure, 14 chronic obstructive pulmonary disease, 13 lung cancer, and nine motor neuron disease; age, mean [SD], 68 [12], 41% women, median Karnofsky index 60%). They described six main strategies for coping with episodes of breathlessness: reduction of physical exertion, cognitive and psychological strategies, breathing techniques and positions, air and oxygen, drugs and medical devices, and environmental and other strategies. Some strategies were used in an opposing way, e.g., concentrating on the breathing vs. distraction from any thoughts of breathlessness or laying down flat vs. standing up and raising hands.

Conclusion. Patients used a number of different strategies to cope with episodic breathlessness, adding more detailed understanding of existing strategies for breathlessness. The findings, therefore, may provide a valuable aid for health care providers, affected patients, and their relatives. *J Pain Symptom Manage* 2016;52:228–234. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Coping, dyspnea, episodic breathlessness, palliative care, respiratory symptoms, self-management

Introduction

Episodic breathlessness causes additional distress to breathless patients with advanced, life-limiting disease, such as chronic obstructive pulmonary disease

(COPD) or cancer.^{1–3} Prevalence has been reported to be up to 81% in advanced cancer patients.² In 2014, an international consensus definition and categorization have been established for episodic

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breathlessness as “one form of breathlessness characterized by a severe worsening of breathlessness intensity or unpleasantness beyond usual fluctuations in the patient’s perception of breathlessness. Episodes are time limited (seconds to hours) and occur intermittently, with or without underlying continuous breathlessness. Episodes may be predictable or unpredictable, depending on whether any trigger(s) can be identified (...).”⁴

Although research on episodic breathlessness has increased over recent years and experiences and characteristics have been described, there is a lack of knowledge on specific management strategies to relieve the symptom effectively.^{2,3,5–7} Previous studies have investigated self-management and coping strategies for breathlessness in general in patients with COPD, asthma, or lung cancer (LC).^{8–12} However, as we now have a clearer understanding of different features of breathlessness, e.g., continuous and episodic breathlessness, more specific management strategies should be developed for episodic breathlessness.

Therefore, we aimed to explore patients’ experience of breathlessness episodes, their impact on patients’ lives, and the patients’ individual coping strategies. The data on the experience, types, patterns, and characteristics of episodic breathlessness have been reported elsewhere.^{5,6,13} This article reports on self-management and coping strategies that are used by patients to relieve episodic breathlessness.

Methods

Study details have been reported previously.^{5,13} This section provides a concise summary of the methods applied. Because the consensus definition of episodic breathlessness was not available at the time of this study, a working definition suggested by Reddy was applied: Episodic breathlessness is a “clinically significant aggravation of dyspnea in patients with continuous dyspnea or occurring intermittently.”²

Study Design and Ethics

We conducted a qualitative study using in-depth face-to-face interviews. The study followed the Consolidated Criteria for Reporting Qualitative Research guideline for reporting qualitative research.¹⁴ Ethics board approval has been obtained from the Joint University College London/University College London Hospitals Committees on the Ethics of Human Research Alpha (09/H0715/81).

Participants and Setting

A purposive sample was recruited in five outpatient clinics of two university hospitals in south London from January to May 2010.^{5,13} Patients suffering from

breathlessness resulting from one of the following diseases were eligible: COPD (Global Initiative for Obstructive Lung Disease classification stages III–IV), chronic heart failure (CHF) (New York Heart Association classification stages II–IV), primary or secondary LC (all stages), or motor neuron disease (MND) (all stages). Participants could be on any treatment for the underlying disease or for breathlessness.

Data Collection

Before the interview started, consent was obtained, and demographic and clinical data were documented. The semi-structured, in-depth, face-to-face interviews were conducted with an exploratory approach by two trained interviewers (S.T.S. and H.B.), usually at participants’ homes. The topic guide focused on experiences with episodic breathlessness, characteristics and triggers for such episodes, impact on daily living, and management strategies for episodic breathlessness. Patients were asked to specifically describe their experiences with coping strategies of episodic breathlessness in detail with regard to strategies used, how these strategies worked, how effective they were, and which dimension of breathlessness were changed (e.g., sensory sensation, emotion, or impact). The interviews were tape recorded and transcribed verbatim.

Data Analysis

Themes were derived from the data. The interview transcripts were read twice to familiarize with the content. We used the matrix-based Framework analysis method, guided by the analytic hierarchy of data management (identifying initial themes and coding), descriptive accounts (sorting, summarizing, identifying dimensions, and categories), and explanatory accounts (detecting patterns, identifying clusters, developing explanations, and a theory),¹⁵ using the computer program NVivo 8 (devised by QSR International in 2008).

Results

Participants

Fifty-one participants were interviewed and provided data on self-management or coping strategies for episodic breathlessness (Table 1). The median duration of the interviews was 55 minutes (range 17–89 minutes), and 45 of 51 interviews were conducted in the participants’ home. During 18 interviews, other (nonparticipating) people were present (e.g., wife, granddaughter).

All but two patients suffered from episodic breathlessness because of physical exertion. In addition, most patients experienced episodic breathlessness as a result of other triggers, such as emotions or

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