

Original Article

Definition, Categorization, and Terminology of Episodic Breathlessness: Consensus by an International Delphi Survey

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Abstract

Context. Episodic breathlessness is a common and distressing symptom in patients with advanced disease. Still, it is not yet clearly defined.

Objectives. The aim of this work was to develop an international definition, categorization, and terminology of episodic breathlessness.

Methods. An online Delphi survey was conducted with international breathlessness experts. We used a structured questionnaire to identify specific aspects and reach agreement on a definition, categorization, and terminology (five-point Likert scale). Consensus was defined in advance as $\geq 70\%$ agreement.

Results. Thirty-one of 68 (45.6%), 29 of 67 (43.3%), and 33 of 67 (49.3%) experts responded in the first, second, and third rounds, respectively. Participants were 20–79 years old, about 60% male, and more than 75% rated their own breathlessness expertise as moderate to high. After three rounds, consensus was reached on a definition, categorization, and terminology (84.4%, 96.3%, and 92.9% agreement). The final definition includes general and qualitative aspects of the symptom, for example, time-limited severe worsening of intensity or unpleasantness of breathlessness in the patient's perception. Categories are predictable or unpredictable, depending on whether any triggers can be identified.

Conclusion. There is high agreement on clinical and operational aspects of episodic breathlessness in advanced disease among international experts. The consented definition and categorization may serve as a catalyst for clinical and basic research to improve symptom control and patients' quality of life. *J Pain Symptom Manage* 2014;47:828–838. © 2014 U.S. Cancer Pain Relief Committee.

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Key Words

Delphi method, dyspnea, episodic breathlessness, palliative medicine, respiratory symptoms

Introduction

Breathlessness was defined by the American Thoracic Society in 1999 and confirmed recently as “a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity.”¹ Recent studies suggest a distinction between continuous and episodic breathlessness.^{2,3} Episodic breathlessness is a common and distressing symptom in patients with advanced disease. Still, it is not yet clearly defined, and there is no universal terminology of episodic breathlessness. A recent systematic review found 27 studies (of 7584 hits) that addressed episodes of breathlessness as a primary or secondary outcome.⁴ A multitude of terms were used in the literature concurrently with episode, for example, attack,^{5,6} incident,⁷ acute,⁸ or breakthrough dyspnea.^{2,9} Only one observational study defined, specifically, breakthrough dyspnea as “a clinically significant aggravation of dyspnea in patients with continuous dyspnea or occurring intermittently.”²

The lack of a universal definition for breathlessness episodes leads to an inconsistent use of different terms in the literature, research, and clinical practice. This variability impedes advancement in both, clinical trials and symptom understanding in practice.¹⁰ For this reason, an internationally developed and consented definition, categorization, and terminology of episodic breathlessness are needed to improve symptom understanding for better assessment and management in clinical practice and foster research. The aim of this study, therefore, was to reach consensus on a definition, categorization, and terminology of episodic breathlessness.

Methods

Study Design and Setting

An online Delphi survey process was used to systematically collect and synthesize expert opinion on statements for the definition, categorization, and terminology of episodic breathlessness. The Delphi method is a formal

consensus technique, with the main purpose to “... obtain the most reliable consensus of opinion of a group of experts.”¹¹ The method has widely and effectively been used in medical and nursing research.^{12–14}

This study was conducted by the Department of Palliative Medicine at the University Hospital of Cologne on behalf of the international research group on breathlessness, the National Cancer Research Institute Palliative Care Breathlessness Subgroup (NCRI-PCBS).¹⁰ Ethical approval was obtained by the Ethics Commission of Cologne University's Faculty of Medicine (12-128).

Expert Panel

To obtain broad expertise in the field of breathlessness, panel members were recruited based on the following criteria: 1) recognized scientific expertise in breathlessness research or clinical experience, demonstrated by publication or activity in the clinical context, for example, participation in guideline development/dissemination; 2) multiprofessionality to facilitate diversity of views and expertise;¹⁵ and 3) international context to facilitate a global representation and exchange of state-of-the-art knowledge. Only experts familiar with the English language were included. Resources for recruitment were first authors of all publications on episodic breathlessness included in the recent systematic review about episodic breathlessness⁴ and of all Cochrane systematic reviews on the management of breathlessness; all members of the NCRI-PCBS; and experts proposed by the NCRI-PCBS members.

Seventy-one experts were contacted by e-mail to ensure at least 30 responses for each round because response rates vary greatly, and 60% has been recognized as a threshold of acceptability.¹⁶ Experts were invited by an individual e-mail, providing a statement on privacy policy and the aim and methods of the Delphi process.

Preliminary Draft of a Definition, Categorization, and Terminology

A preliminary draft of a definition, categorization, and terminology was developed based

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