



A qualitative exploration of distress associated with episodic breathlessness in advanced lung cancer



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ABSTRACT

Purpose: Breathlessness is a distressing symptom, particularly common in those with advanced lung cancer. Previous research has identified the symptom occurrence of episodic breathlessness, identifying average frequency, duration and severity of episodes, but has not explored the distress specifically associated with these episodes. This study explored the distress associated with episodic breathlessness for adults with advanced cancer and the relative impact of three elements; frequency, duration or severity.

Methods: Semi-structured interviews were conducted with four participants with advanced lung cancer. Analysis adopted an interpretative phenomenological approach.

Results: A complex relationship existed between distress caused by episodic breathlessness and its frequency, duration and severity for study participants. Episodic breathlessness had a significant impact on participant's perceptions of self and previous experience effected how distressed they were by their breathlessness. The emotional work created by the symptom was considerable for individuals.

Conclusion: The study highlights the importance of recognizing symptoms as a combination of different experiences that may each cause different levels of distress. Initial evidence is provided that the emotional work involved for patients to self-manage each separate element of breathlessness should be considered in its treatment.

1. Introduction

The prevalence of breathlessness in patients with lung cancer has been reported as 70.5% with a range of 50–87% (Kathiresan et al., 2010). It is a symptom which has a significant impact both on quality of life (Mohan et al., 2007; Habraken et al., 2009) and on costs associated with healthcare (Chin and Booth, 2016), as well as having impact not only on those experiencing the symptom but also on their carers (Booth et al., 2003). In studies looking at breathlessness as a whole, those experiencing it frequently use metaphors and narratives to describe their symptoms (Nicholls, 2003; O'Driscoll et al., 1999), using terms such as “unpleasant”, “frightening”, “anxiety” and “troublesome” (Booth et al., 2003; Gysels and Higginson, 2011; Henoeh et al., 2008; Kathiresan et al., 2010; Maguire et al., 2014). Patients with lung cancer appear to be more distressed by their breathlessness than those with other life limiting diseases, describing episodes of breathlessness with faster onset and less predictability (Booth et al., 2003; Gysels and Higginson, 2011).

The term “episodic breathlessness” was defined by Simon et al. (2014) as a “severe worsening of breathlessness intensity or

unpleasantness beyond usual fluctuations” and has been described in patients with a range of conditions. It can be described in terms of its different elements, including frequency, duration and severity and its prevalence in patients with lung cancer has been reported as 40.5% (Mercadante et al., 2016). Weingartner et al. (2013) described the typical characteristics of episodic breathlessness and found the average frequency was 1–10 episodes per day, duration was 1–5 min and the mean peak severity of episodes was 6.5 on a 0–10 scale.

In previous qualitative research, the distress associated with breathlessness has looked at the symptom as a whole, rather than that associated specifically with episodic breathlessness. There is therefore no specific definition of distress associated with episodic breathlessness. Whilst episodic breathlessness has been identified as a common and severe symptom, previous research has demonstrated the lack of equivalence between symptom intensity and symptom distress (Tishelman et al., 2005). The symptom experience for an individual consists of a relationship between symptom occurrence and symptom distress, and patients with similar intensities of breathlessness may nevertheless experience it quite differently from each other (McDaniel and Rhodes, 1995). Therefore it is important to understand the distress

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Table 1
Sample of questions from interview guide.

Topic	Possible Questions
Overall Experience of Breathlessness	<ul style="list-style-type: none"> • Can you tell me about your experience of breathlessness? • What do your episodes of breathlessness mean to you?
Frequency	<ul style="list-style-type: none"> • How does the frequency of episodes affect your quality of life? • What does this mean to you?
Duration	<ul style="list-style-type: none"> • How does the length of episodes affect your quality of life? • What does this mean to you?
Severity	<ul style="list-style-type: none"> • How does the severity of episodes affect your quality of life? • What does this mean to you?
Comparative distress	<ul style="list-style-type: none"> • How do each of these aspects of breathlessness affect your quality of life? • Which aspect of breathlessness distresses you most? • If we could improve one aspect of your breathlessness, which would have the biggest impact on your quality of life? Why?
Exploratory Questions to explore concepts/themes further	<ul style="list-style-type: none"> • Is there anything else you would like to tell me about your breathlessness?

associated with a symptom to be able to fully recognise its impact on an individual.

Significant strides have been made in research into both the pharmacological and non-pharmacological management of breathlessness in recent years (Chin and Booth, 2016), with a number of studies highlighting the importance of multidisciplinary management for patients with breathlessness (Farquhar et al., 2014; Higginson et al., 2014). An improved understanding of the distress associated with the different elements of symptom occurrence of episodic breathlessness would enable clinicians to better understand the symptom experience. This could improve outcomes by identifying patient-relevant therapeutic targets and ensuring clinicians can focus their management strategies appropriately.

The aims of this study were to explore the nature of the distress associated with episodic breathlessness and the degree to which each element (frequency, duration and severity of episodes) of breathlessness contributed to the distress of the participants.

2. Methods

2.1. Study design

The study adopted a phenomenological approach using in-depth, semi structured, face to face interviews. Heidegger's double hermeneutic approach to Interpretative Phenomenological Analysis (IPA) methodology was used, acknowledging both the participants' and the researchers' interpretative process (Reiners, 2012). IPA methodology was chosen for this study as it is concerned with exploring individual significant experiences, rather than trying to "fit" people's experiences into predetermined categories (Smith et al., 2009). As no previously published research has investigated distress in episodic breathlessness, this exploratory, open approach supported the research team to analyse the data without preconceived concepts. A process of "bracketing" preconceived assumptions, throughout the research process, is required in IPA to ensure that the phenomenon in question is examined with "relative openness" (Finlay, 2009). Therefore, the authors put aside previous scientific theory and personal experience around episodic breathlessness, aiming to focus on participants' individual experiences. To facilitate this process, a reflexive diary was used by the lead researcher to document thoughts, feelings and preconceptions and raise awareness of possible bias that might affect the research process, whilst acknowledging that it is impossible to completely remove one's own preconceptions during the research process. An ideographic approach was taken, examining the individual perspectives of study participants before looking for more general group themes (Smith et al., 2009).

2.2. Participants and recruitment

Participants were recruited from a hospice in Essex between

September 2015 and October 2016. Patients were eligible if they were aged 18 years or over, had stage III or IV lung cancer or mesothelioma, were experiencing breathlessness (scoring greater than 4 on an Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991)) and were able to communicate in English. ESAS was routinely assessed at this hospice at the time and was screened by the clinical team initiating contact for the research. Patients were excluded if they did not have capacity to consent, had a psychotic disorder or a clinical history of anxiety or depression, a reversible cause of breathlessness, were too unwell to take part or had a prognosis of less than one month. Inclusion criteria were broad to elicit a range of experiences of breathlessness. A self reported scale was used to identify patients with breathlessness due to the subjective and experiential nature of breathlessness (Chin and Booth, 2016). A target sample size of four participants was identified to enable in-depth analysis of each individual's data. Smith et al. (2009) suggest that, as the primary concern of IPA is to recount detail of individual experiences, a smaller sample size is appropriate to enable a focus on quality of data rather than quantity.

The clinical team in the hospice initiated first contact with potential eligible participants, either face-to-face or by telephone, to introduce the study and elicit willingness to participate. Potential participants were contacted by the research team by telephone to ensure eligibility, to provide information about the study and answer any questions. Informed consent was secured before the interviews were conducted.

2.3. Procedure

Demographic and clinical data for patients were obtained prior to the interviews. The duration of interviews was approximately 30–45 min and were conducted at the participant's home by the first author (ES) (a physiotherapist with a clinical background) using an exploratory approach. An interview guide was available to be used if individual participants needed prompting, however a conversational style of interview, with an initial question of "can you tell me about your experience of breathlessness" was used to try and elicit participants' individual experiences. Particular focus was given to questions exploring the meaning and distress associated with episodic breathlessness to elicit information about the illness experience. Table 1 contains a sample of questions from the interview guide. All but one interview occurred with the participant and researcher alone, in the one exception the participant requested their spouse to be present. All interviews were audio-recorded and transcribed verbatim, with field notes added to the transcription.

2.4. Ethics

Ethical approval was obtained from NRES Committee London - Hampstead (15/LO/1423) and South Essex Partnership University NHS Foundation Trust Research Governance Group.

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