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An Interpretative Phenomenological Analysis of the lived experience of multiple concurrent symptoms in patients with lung cancer: A contribution to the study of symptom clusters

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A B S T R A C T

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Purpose of the research: To explore the lived experience of multiple concurrent symptoms in people with advanced lung cancer to contribute to the understanding of the experience of symptom clusters.

Methods and sample: Purposive sampling recruited ten people with advanced lung cancer who were experiencing three or more concurrent symptoms, were at least 18 years of age and were able to provide written informed consent. The participants took part in two consecutive, in-depth interviews, 3–5 weeks apart. Interpretative Phenomenological Analysis was used to analyse the data.

Findings: Participants experienced 4–11 concurrent symptoms with fatigue, cough, pain and breathlessness featuring prominently in their interviews. The participants commonly identified associations between the symptoms that they experienced, with the occurrence of one symptom often used to explain the occurrence of another. Reductions in physical and social functioning were often associated with the experience of multiple concurrent symptoms, particularly at times of high symptom severity. The participants' highlighted breathlessness and cough as being of particular salience, due to the association of these symptoms with fear of death and visibility and embarrassment in public.

Conclusions: People with lung cancer experience multiple concurrent symptoms and perceive relationships between the symptoms experienced. Within the experience of multiple symptoms, people with lung cancer highlight individual symptoms that are of particular importance, based on their concomitant meanings. Such findings provide vital information for the future development of meaning-based symptom cluster interventions.

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Introduction

The symptom experience of people with cancer has been the focus of a significant body of research both theoretically and empirically for the past four decades. Using the biomedical perspective, a symptom is viewed as being representative of a pathological pathway for diagnosis and cure. In contrast, within medical anthropology symptoms are viewed not as being a 'reflection of the disease', but as representing the meaning that the

illness holds for the individual. Whilst the symptom experience has attracted much debate in the literature (Corner and Bailey, 2001; Krishnasamy, 2000; Tishelman et al., 1991), irrespective of the approach employed, all recognise the central role that symptoms play in the identification and management of disease and the negative impact that poorly controlled symptoms have on patient outcomes (Cleeland, 2007; Lipscomb et al., 2007; Mansson et al., 2007; Trotti et al., 2007).

Historically, research in the area of cancer symptom management has focused on the incidence and severity of individual symptoms such as pain, fatigue and depression (Ferrell and Dean, 1995; Ream and Richardson, 1997; Richardson and Ream, 1996). However, this focus has been criticised in that it does not address the experience of multiple concurrent symptoms and the fact that people with cancer rarely experience symptoms in isolation (Dodd et al., 2001a, 2001b). In response to the criticisms relative to the

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study of individual symptoms, the concept of symptom clusters was introduced into the literature (Dodd et al., 2001a, 2001b). This concept suggests that co-occurring symptoms do not exist independently but interact with each other via common underlying mechanisms, that have a synergistic effect on patient outcomes (Atkas et al., 2010; Barsevick, 2007). It has been suggested that the study of symptom clusters can advance cancer symptom management and open up new avenues for the management of multiple symptoms.

To date, the majority of studies on symptom clusters have adopted a predominately quantitative approach, identifying symptom clusters using an array of questionnaires and statistical approaches. Whilst the results of these studies have advanced knowledge in the field of symptom cluster research, the predominance of this quantitative approach has been criticised on the grounds of the inconsistency in methodological approaches used therein a lack of standardisation. The use of varying definitions, different data collection tools and approaches to data analysis, has resulted in a data set that is hard to interpret (Atkas et al., 2010). It has also been highlighted that current research reflects clusters that have been defined using statistical relationships between symptoms, as opposed to those derived from clinical or patient experience (Atkas et al., 2010; Hensch et al., 2009).

An alternative methodology for the identification of symptom clusters is provided by qualitative studies of the symptom experience. Such studies provide powerful and contextual insights into the patients' perspective of the experience of multiple symptoms, using experiential data to identify associations between concurrent symptoms. To date, few studies have identified symptom clusters using such data. Molassiotis et al. (Molassiotis et al., 2008) explored the experience of chemotherapy related nausea in patients with cancer and, using content analysis, reported that participants' narratives of the symptom often concurred with other symptoms, suggesting that such findings provide preliminary evidence to support a cluster of symptoms consisting of nausea, loss of appetite, taste disturbance, vomiting and 'possibly' intolerance of smells. A subsequent study published by the same authors (Molassiotis et al., 2010), identified a respiratory cluster of symptoms (cough, breathlessness, and fatigue) in patients with lung cancer, and reported that this cluster of symptoms persisted throughout the participants' experiences up to a year following diagnosis. The most recent study published (Lopez et al., 2011) was conducted in women with gynaecological cancer using qualitative longitudinal interviews, and identified an array of physical and psychological symptom clusters. These qualitative studies, whilst not identifying causal relationships between symptoms, have been argued to provide a 'stronger conceptual base' for the identification of symptom clusters in patients with cancer (Atkas et al., 2010) and as a result there has been a call for more studies to explore the patient experience of this phenomenon (Atkas et al., 2010) to advance the scientific based underpinning this important area of cancer symptom research.

It may be postulated that people with advanced lung cancer are a population that are particularly suited to the exploration of the patient experience of co-occurring symptoms. This group of patients commonly experience multiple concurrent symptoms (Cleeland, 2007; Cooley et al., 2003; Cooley et al., 2002; Cooley, 2000; Sarna and Brecht, 1997; Sarna, 1993) and experience significant distress due to their symptoms (Molassiotis et al., 2010; Cooley et al., 2003; Cooley et al., 2002; Cooley, 2000; Tishelman et al., 2000; Degner and Sloan, 1995). Furthermore, several studies to date have identified symptom clusters using quantitative and qualitative approaches in this patient group (Gift et al., 2003; Hensch et al., 2009; Molassiotis et al., 2010). The aim of this study was therefore to explore the lived experience of multiple

concurrent symptoms of people with advanced lung cancer. It was anticipated that the information gleaned from this study would contribute to our understanding of the experience of symptom clusters in patients with lung cancer.

Methods

Design, setting and sample

The study adopted a prospective, qualitative, study design using Interpretative Phenomenological Analysis (IPA) methodology (Smith et al., 2009). IPA is an established methodology in clinical, health and social psychology, which provides a stance and protocol for the analysis of experiential qualitative data (Flowers et al., 2006; Smith et al., 2009). Participants were recruited from a District General Hospital in Scotland that specialised in the care of people with lung cancer.

The lead lung cancer nurse at the participating clinical site identified participants at the outpatient clinic. A purposive sample of 10 people with advanced lung cancer was recruited to the study. All participants had to be 18 years of age or over, diagnosed with lung cancer, able to read and write English, able to provide written informed consent and to be experiencing three or more concurrent symptoms on recruitment to the study.

Procedure

Approval for the study was obtained from the NHS ethics committee. Taking into consideration the health status of the patient group and participant burden, participants took part in two iterative interviews 3–5 weeks apart either in their local hospital or home setting. As stated by Flowers (Flowers, 2008) the use of multiple interviews within IPA research 'may relate to "pragmatic" concerns. These may include, for example, participant characteristics such as their availability, health (e.g. people with respiratory conditions), or "attentional capacity" (e.g. children). Moreover multiple interviews also facilitate in-depth and considered reflection for both participant and researcher across the data collection process.

Interview process

Consistent with IPA, one lead question informed data collection using unstructured interviews. The question 'what does cancer mean to you' was used to drive a meaning centred approach. This approach was selected to take into consideration the core role that meaning plays in the illness experience with particular relevance to the symptom experience. (Frankl, 1959; Good and Good, 1980; Kleinman, 1988; Mishler, 1979; O'Connor et al., 1990; Taylor, 1995; Thorne, 1999).

The participants' experiences of symptoms were explored fully in the interviews, with any mention they made about multiple symptoms explored in greater depth. Any perceptions (or not) of the characteristics of symptom clustering within participants' narratives were noted. Following each interview, field notes and reflexive accounts were maintained to assist in any subsequent interviews and data analysis. The interviews were audio taped and transcribed verbatim.

Data analysis

'The essence of IPA lies in its analytic focus' which is to direct 'our attention towards our participants attempt to make sense of their experiences' (Smith et al., 2009). The step-by-step approach to analysis advocated by Smith and Osborn (Smith and Osborn, 2003)

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