

Review Article

Experience of Advanced Chronic Obstructive Pulmonary Disease: Metasynthesis of Qualitative Research

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Abstract

Context. Chronic obstructive pulmonary disease (COPD) is a life-limiting illness. Despite best available treatments, individuals continue to experience symptom burden and have high health care utilization.

Objectives. To increase understanding of the experience and ongoing needs of individuals living with COPD.

Methods. Medline, PsycINFO, CINAHL, and Sociological Abstracts were searched for articles published between January 1990 and June 2013. Metasynthesis of qualitative data followed the principles of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. Metasyntheses are increasingly used to gain understandings of complex research questions through synthesizing data from individual qualitative studies. Descriptive and analytical themes were developed through thematic synthesis and expert panel discussion of extracted primary quotes, not the primary data themselves.

Results. Twenty-two studies were included. Four hundred twenty-two free codes were condensed into seven descriptive themes: better understanding of condition, breathlessness, fatigue, frailty, anxiety, social isolation, and loss of hope and maintaining meaning. These seven themes were condensed further into three analytical themes that described the experience and ongoing needs of individuals with COPD: the need for better understanding of condition, sustained symptom burden, and the unrelenting psychological impact of living with COPD.

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Conclusion. Combining discrete qualitative studies provided a useful perspective of the experience of living with COPD over the past two decades. Further studies into the ongoing needs of individuals with COPD are unlikely to add to this well-established picture. Future research should focus on solutions through the development of interventions that address patients' ongoing needs. *J Pain Symptom Manage* 2014;48:1182–1199. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Chronic obstructive pulmonary disease, advanced disease, ongoing needs, experience, qualitative, metasynthesis

Introduction

Chronic obstructive pulmonary disease (COPD) is a chronic life-limiting illness affecting more than 80 million people worldwide.^{1–3} Despite best available treatments, individuals with advanced COPD continue to experience symptom burden and have high rates of health care utilization.^{4–10} The fluctuating and episodic decline is characteristic of the COPD trajectory and makes it difficult to determine when death is likely.^{5,11–13} Life-limiting illness is defined as an illness where death will likely be a consequence of the specified illness and likely shorten an individual's life.^{14,15} The term "life-limiting illness" is inclusive of nonmalignant terminal diseases such as COPD.¹⁶ Although not synonymous with advanced COPD, "severe COPD" or "Stage 3" COPD is defined by the Global Initiative for Chronic Obstructive Lung Disease as "characterized by further worsening of airflow limitation ($FEV_1/FVC < 0.7$; $30\% < FEV_1 < 50\%$ predicted, where FEV_1 is defined as the "forced expiratory volume in one second" and FVC is defined as "forced vital capacity")."¹⁷ Advanced COPD also is characterized as "greater shortness of breath, reduced exercise capacity, fatigue and repeated exacerbations that almost always have an impact on patients' quality of life."^{17(p. 4)} Independent predictors of death from COPD include hospitalization, functional limitation, severe reduction in lung function, use of long-term oxygen therapy, depression, low nutritional state, and the presence of comorbidities.^{7,13,18,19} Additionally, a clinician's assessment that an individual is unlikely to survive two years also is seen as a useful prognostic tool.^{13,19}

Within the context of population aging and the increasing burden of chronic illness, there

is an emphasis on person-centered care and shared decision making.^{6,20–22} Individuals and their families increasingly accept responsibility for everyday care requirements, further adding to the burden of this illness, particularly in the advanced stages.²³ Understanding the ongoing needs of individuals with COPD is of central importance in the development of health services and systems that are flexible and responsive to the individual.^{23,24} This requires an understanding of not only the available therapies but also the likely experience of individuals; qualitative research elucidates the experience of individuals within the scientific discourse.^{25–28} A recent Canadian report commissioned by the Health System Strategy Division of the Ministry of Health and Long-Term Care has highlighted the complexity of patients' experience of COPD from diagnosis to end of life and the impact on individuals, their caregivers, health professionals, and the health system.²⁹ In spite of the clear benefit of this individual perspective, small sample sizes and inherent absence of generalizability limit the capacity to incorporate this information in policy, practice, and research.^{27–29}

Metasyntheses are increasingly used to gain understandings of complex research questions through synthesizing data from individual qualitative studies.^{27–30} The synthesis of qualitative data from several individual studies provides a useful perspective of and enriches "the understanding of complex and multifaceted health experiences and health care practices."^{27,28} Although previous discrete qualitative studies discuss symptom burden and experience,^{12,18,31,32} there has been no formal integrated synthesis of the lived experience of COPD. Metasynthesis is used as the methodological approach in this article and has followed

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