
Health care needs in end-stage COPD: Views of patients, informal, and formal carers

Background: According to the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines palliative care for severe COPD needs to be planned through discussions with patients and their informal carers in order to explore wishes related to end-of-life decisions. Despite these recommendations, access to palliative care is still limited for patients with severe COPD and the specific needs of that patient group remain poorly explored, in particular in Germany. Insights into unmet and yet unknown care needs can contribute to better communication between the involved parties and to better care planning, which should be anticipatory and tailored to the needs of COPD patients and their informal carers.

Objective: To identify together with patients, their informal carers (e.g., spouses) and their formal carers (e.g. GPs) barriers to the access of health care services and needs (what is missing and why?) and treatment proposals (how can unmet needs be met in medical care?) for patients and relatives in order to develop recommendations for GPs and specialists and to thereby take a first step towards adequate palliative care for patients with severe COPD in Germany.

Methods: Study 1 will build on semi-structured interviews with patients and their formal carers as well as their informal carers. We will explore a) care needs of patients with severe COPD and of their informal carers, b) the potentially unmet needs and barriers to access as perceived by physicians and c) how those needs could be addressed and met (treatment proposals). In study 2, using the Delphi method, experts from various disciplines prioritize the treatment proposals and evaluate their feasibility (quantitative, multi-stage survey procedure). Based on an expert panel, we will derive recommendations, which will then be evaluated by patients and their informal carers (cognitive interviews, study 3). Our approach maximizes the likelihood that we will derive recommendations and solutions that are acceptable, relevant, practice-oriented, feasible and effective according to the views of patients with COPD, their informal and formal carers.

Relevance: We aim to improve our understanding of the (palliative) care needs of patients with severe COPD and of their informal carers. Based on those insights we will derive recommendations as to how those needs can be addressed by existing health care services. Overall, existing health care services could then be offered and utilized earlier and in close keeping with the actual care needs of patients with COPD.

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