

CR03: Associations with incongruence between patient and informal carer symptom reporting in advanced chronic obstructive pulmonary disease

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Aim: Informal carers provide valuable information on patients' symptom experiences to clinicians and researchers, and accurate carer assessment is critical for symptom management by carers themselves. However, few studies have investigated the validity of proxy reporting in COPD or the primary care setting. We aimed to assess agreement between patient and carer reports on symptoms, and identify factors associated with incongruence in a population-based sample of advanced COPD.

Method: A prospective, cross-sectional analysis of data from well-characterised patients with advanced COPD and their carers (119 patient-carer dyads), who separately rated patient symptoms on a 4-point scale. Wilcoxon signed-rank tests determined differences in mean patient and carer symptom scores, and weight-kappa assessed agreement on scores. Spearman's correlation and Mann-Whitney U tests identified characteristics associated with incongruence.

Results: There were no significant differences between mean patient and carer scores for any symptom, although carers more frequently underestimated symptoms (Table 1). Patient-carer agreement was only fair to moderate; higher agreement was found for physical symptoms (constipation, diarrhoea) than psychological (anxiety, depression) or those with emotional valence (dyspnoea, fatigue) (Table 1). Greater estimation by the carer was associated with non-spousal relationship, non-cohabitation, lower carer educational level, greater carer anxiety, more carer unmet support needs, and greater subjective caring burden, and by the patient was associated with younger age, longer duration of COPD, and greater patient anxiety.

Conclusion: Symptom underestimation by carers and poorer agreement on emotional symptoms may reflect patient concealment, long disease trajectories in COPD leading to carer compassion-fatigue and response shift, and lack of symptom awareness in the primary care setting. Incongruence was associated with less patient-carer interaction, greater disease and caring burden, and poorer patient and carer psychological health. Our findings suggest the need to encourage open communication within dyads and educate carers in assessing subjective symptoms.

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