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Titolo tesi: Self-care of patient and family caregiver dyads in Chronic Obstructive Pulmonary Disease

ABSTRACT

Introduction. Chronic obstructive pulmonary disease (COPD) is an invalidating chronic disease that seriously affects the lives of the sick person and those of family members or other informal caregivers. Most care for COPD, as with other chronic diseases, is performed by the patients themselves, and by their caregivers at home, in collaboration with health care professionals in the acute phases of the disease. Little is known about the self-care behaviors that people with COPD actually carry out, and even less about the contribution of their caregivers to self-care. This doctoral work intends to fill these knowledge gaps, analyzing the self-care dynamics between patients with COPD and their caregivers, using the patient/caregiver dyad as the unit of analysis. We aim to: 1) explore the self-care experiences and the unmet needs of persons with COPD and their caregivers, and 2) investigate the contribution of specific factors in dyadic self-care, such as knowledge about the disease, the dyadic effects of anxiety and depression on QoL, and typologies of dyadic care in COPD.

Methods. This doctoral work was based on three theories: the middle-range theory of self-care in chronic illness (Riegel et al., 2012), interdependence theory (Kelley & Thibaut, 1978), and the theory of dyadic illness management (Lyons & Lee, 2018). Three qualitative systematic reviews and an integrative review were undertaken to synthesize evidence about the self-care experiences and unmet needs of people affected by COPD, and their caregivers. Based on the three theories and the results of these reviews, we then developed a protocol of a longitudinal quantitative study, called the RESPYRO study, aimed at understanding the dependent relationship between patient and caregiver self-care, and at identifying the dyadic predictors and outcomes of self-care. The dyad enrollment started on November 2016 and it will continue until the enrollment of 300 dyads is complete. A set of questionnaires was administered to patients and caregivers. Cross-sectional, time zero results were analyzed using descriptive and correlational analysis, dyadic analysis through actor partner interdependence model (APIM), univariate analysis of variance, and multinomial logistic regressions analysis.

Results. A total of 124 dyads were enrolled by December 2017. The results showed that patients and caregivers possess limited knowledge of COPD. In caregivers, overall knowledge was correlated with education, whereas in patients only knowledge on specific topics was correlated with education and disease severity. Psychological distress showed to influence dyads' quality of life (QoL). In particular, anxiety and depression symptoms of caregivers negatively affect patient QoL. Dyadic care typologies were explored and specific characteristics for each type were recognized. In one every four dyads, patients and caregivers acknowledged different dyadic care typologies demonstrating a lack of agreement about responsibility for COPD care. **Conclusions.** The results presented in this doctoral work are innovative in COPD dyadic research. We are the first to document dyadic care typologies in COPD and the psychological distress effects on dyad QoL. The research increases knowledge about dyadic dynamics of self-care in COPD and identifies specific challenges that healthcare professionals should address when caring for patients with COPD and their caregivers. The analysis of longitudinal data will further advance the science of COPD dyads and will provide useful information for clinical practice.