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**Titolo tesi:** Self-care and social support in patient-caregiver dyad with multiple chronic conditions

### **ABSTRACT**

*Introduction.* Multiple chronic conditions (MCCs) represent a very common condition in older people. In the United States, 70% of the population over 65 years presents two or more chronic conditions. In Europe, the percentage of older people with MCCs ranges from 24.7% to 51%. Most of the treatment of chronic diseases is carried out in the home environment by patients themselves and their families; health professionals intervene only in case of exacerbations and for health education. An adequate self-care in chronic disease has been shown to improve quality of life and reduce hospitalizations and mortality. Little is known about the self-care of people with MMCs, and even less about the contribution of informal caregivers to the patient's self-care. Therefore, the present doctoral work considered not only the patient and caregiver as a unit of analysis but also the patient-caregiver dyad. The objectives were to: 1) develop a study protocol to identify self-care predictors and outcomes of self-care in patients with MMCs and their caregivers; 2) validate an instrument to measure the self-care behaviors of patients affected by MCCs; 3) validate an instrument to measure perceived social support in patients affected by MCCs; and 4) explore the dyadic effects of perception of social support on the quality of life at dyadic level.

*Methods.* The main theories that guided the doctoral work were: the Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012), the Theory of Interdependence (Kelley and Thibaut, 1978) and the Theory of Dyadic Illness Management (Lyons and Lee 2018). A literature review led to the identification of self-care predictors and outcomes at the patients and caregiver level in the chronic illness context. The literature and the theories led to the elaboration of a longitudinal quantitative study protocol, named SODALITY, of which this doctoral project forms part, whose intention is to analyze the interdependence between patients and their informal caregivers, called dyads, and identify predictors and outcomes of self-care in the patients and caregivers and in the dyads. Enrollment began in March 2017 and will continue until the inclusion of 1000 dyads. A series of instruments are used to collect data in patients and their informal caregivers. A recently developed instrument by Riegel et colleague and based on the Middle-Range Theory of Self-care of Chronic Illness was used to describe patient self-care behaviors. An analysis of the data collected at Time 0 was carried out using descriptive and correlational statistics, structural analysis, dyadic analysis with the Actor-

Partner Interdependence Model (APIM) and measurement invariance with multi-group structural equation modeling.

*Findings.* A total of 345 dyads were enrolled by June 2018. The results showed that the Multidimensional scale of perceived social support (MSPSS) is a valid and reliable instrument for measuring the perception of social support in the older Italian population affected by MCCs. The perception of social support of the patient and of his/her informal caregiver influences the quality of life of the dyad; in particular, a poor perception of family support by the caregiver negatively affects the quality of life of the patient, while a poor perception of friend support by patient influences the quality of life of the caregiver. The Self-Care Scale of Chronic Illness Inventory (SC-CII) is able to describe self-care behaviors in both the Italian and American populations despite the cultural differences between the two countries.

*Conclusions.* The results presented in this doctoral work are innovative in many aspects. They are the first to document the validity and reliability of instruments measuring the perception of social support and self-care in older patient affected by MCCs, and are the first to demonstrate how the perception of social support can influence the quality of life of an MCCs patient-caregiver dyad. They provide useful knowledge to healthcare professionals that could be applied in the care of patients with MCCs and their caregivers. Analysis of the longitudinal data will further advance the science of dyads with MCCs and provide useful information for clinical practice.