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**Titolo tesi:** **Nursing care dependency in patients with cancer and nurses caring for them**

## **ABSTRACT**

**Introduction** Being dependent on the care of others is a natural and relational human condition. However, in contemporary Western societies dependency is often stigmatized and it could be lived negatively by patients. This social denigration impacts also on nurses' dependency work. Patients with chronic conditions such as advanced cancer can become increasingly dependent from nursing care. Caring for patients with cancer is emotionally burdensome for nurses. A meta-synthesis of international literature on care dependency revealed that the nurse-patient relationships might either help to accept this condition or increase patients' suffering. Given nurses' impact on the patients' experiences, it is crucial to explore nurses' perceptions about care dependency. Quantitative measures of care dependency are mostly used to plan nurse staffing and skill mix. Measure of dependency level and of the perceived burden of dependency in patients with cancer in Italy that would help to plan adequate and individualized care are lacking. Therefore, the aims of this thesis were: 1) to explore the experiences and perceptions regarding dependency on care of Italian nurses' taking care of patients with advanced cancer in palliative care; 2) to explore the experiences of care dependent patients with advanced cancer and of the nurses caring for them; 3) to test the psychometric properties of the CDS on cancer patients in Italy; 4) to develop a questionnaire able to assess the perception of care dependency in patients diagnosed with cancer, and to test its psychometric properties.

**Methods** The first study was a phenomenological exploration of perceptions of dependency of nurses in a palliative care service, following Giorgi's descriptive method. In the second study interviews of patients with cancer and focus groups with nurses were conducted and analysed using inductive content analysis. The third was a multicentre cross-sectional validation study of the Care Dependency Scale with patients with cancer. Confirmatory Factor Analyses were conducted on two subsamples and on the total sample to establish construct validity. The fourth was a multicentre cross-sectional development and validation study of the new Care DEeP Questionnaire aimed at assessing perceptions of care dependency in inpatients with cancer. Exploratory factor analysis (EFA) was conducted using Mplus.

**Results** From the first qualitative study, a general structure "*Nurses caring for dependent patient transcend the boundaries of dependence*" and 4 themes emerged: 1) *Care dependence is an experience of regression and powerlessness*; 2) *Care dependence exceeds the boundaries of life*; 3) *Nurses are required to go beyond their personal limits*; 4) *Care dependence is a relation of mutual growth*. In the second study three themes emerged: 1) *Within dependence, the relationship is a lifeline*; 2) *Dependence is influenced by internal and external factors*; 3) *Dependence generates changes*. In the cross-validation of CDS, CFAs performed on a first subsample (n = 258), on a second subsample (n = 259) and on the total sample (n = 517), yielded acceptable fit indexes. Two factors *Physical care*

*dependency* and *Psychosocial care dependency* with a second-order factor *Care Dependency* were confirmed. Reliability in terms of internal consistency and inter-rater reliability were satisfactory. In the fourth study, the Care DEeP Questionnaire was filled in by 208 patients admitted to two hospitals. The EFA found a two-factor model including a positive and a negative perception of care dependence. The hedonic balance score was also provided as synthetic indicator of subjective well-being.

**Conclusions** The qualitative studies revealed the importance of self-transcendence for building positive relationships that lead to the opportunity of finding meaning in life and make a maturing path. Striving to build positive relationships implies a change in nurses' and patients' lives. In this way they come to understand important aspects of life and to find meaning in difficult situations. The Italian version of the Care Dependency Scale was shown as valid and reliable to assess the level of care dependency in patients with cancer. It can distinguish between physical and psychosocial needs, creating a base for personalized patient care. The newly developed Care DEeP Questionnaire can be used by oncology nurses to assess positive and negative experiences of patients with care dependence, in order to personalize and improve their care.