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ABSTRACT

Introduction. Nutrition is a basic human need and a fundamental of nursing care. During end-of-life, patients may experience difficulties in satisfying their need for nutrition, thus risking malnutrition syndrome, and requiring the positioning of artificial nutrition and hydration (ANH). Provision of ANH frequently concerns cancer patients. ANH for end-of-life patients is still a much debated and controversial topic. The decision-making process on ANH, including its initiation, withholding or withdrawal, is often complex, and nurses' involvement in this process is still undefined. Examining and clarifying their role is important to shed light on nurses' care activities in ANH. This thesis aims at an in-depth exploration of nurses' contribution to the care of patients on ANH at end-of-life, to gain a comprehensive understanding of it. In particular, it aims to explore nurses' involvement in the decision-making process, and to identify Italian nurses' knowledge and attitudes around this topic.

Methods. Firstly, a scoping review of nursing literature was conducted. It was carried out in accordance with the framework outlined by Arksey and O'Malley, and following the recommendations by Levac, Colquhoun, and O'Brien. An inductive qualitative content analysis process was conducted according to Elo and Kyngäs. Secondly, a validation study of the 58-item Questionnaire on the Knowledge, Attitudes, and Behavioural Intentions in Providing Artificial Nutrition and Hydration for Terminal Cancer Patients was conducted. The tool was cross-culturally adapted into Italian and was psychometrically tested. Thirdly, a descriptive cross-sectional study was conducted to ascertain the knowledge and attitudes of nurses belonging to Italian oncology and palliative care units.

Findings. In the scoping review 39 records were selected. The content analysis generated the main category 'nurses' role in the decision-making process' with two subcategories: 'mediator' and 'activator', and three generic categories: 'being', 'feeling' and 'knowing', each with two sub-subcategories. The generic category 'being' includes the 'relationships' and 'attitudes' subcategories; the category 'feeling' includes 'ethical and moral dilemmas' and 'emotional responses'; and the category 'knowing' includes 'clinical knowledge' and 'ethical knowledge'. The validation study resulted in a final questionnaire of 38 items. The overall content validity index was .85. Confirmatory factor analysis was conducted for the different sections of the questionnaire (knowledge and attitudes), while a preliminary analysis for the behavioural intentions section yielded non-acceptable results. The internal consistency for the knowledge and attitudes scales was adequate (ranging .64 - .93). The cross-sectional study found that a high percentage of oncology and palliative care nurses showed reasonable knowledge of ANH. More disagreement was evidenced about benefits and burdens of ANH, and lower importance was given to them.

Conclusion. The scoping review showed that nurses perform the role of activator and mediator. Their ability to establish good relationships and their attitudes enable the creation of teamwork and closeness to patients and family. Nurses have to create the right balance between personal-self and professional-self. The validation study provides evidence that the Italian version of the questionnaire has acceptable psychometric characteristics for the sections regarding Knowledge and Attitudes.

The cross-sectional study highlighted that some misconceptions and a low level of awareness still exist among nurses about ANH. This exploration of nurses' knowledge of and attitudes towards ANH in end-of-life cancer patients helps towards an understanding of how nurses can be involved in better meeting patients' nutritional needs. More nursing



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studies should be conducted and extended to different care settings. Moreover, guidelines should be amplified with a nursing perspective to better define nurses' role in the decision-making process on ANH.