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Titolo tesi: End-of-life communication in nursing homes

ABSTRACT

Background. A growing number of elders spend the end-of-life (EOL) in nursing homes (NHs), which means that healthcare professionals (HCPs) increasingly encounter residents who are close to death and may benefit from less invasive and intensive care. Literature suggests that family carers are more satisfied with EOL care when the quality of their relative's remaining life is maximized without unnecessarily extending suffering. Although open and thorough EOL communication about goals of care and treatment decisions was suggested to promote better quality of care in NH, knowledge about what family carers perceive as good EOL care is fragmented and data about to what extent and how EOL communication may improve EOL care outcomes lack.

Objective. The aim of this doctoral research program was to (1) identify the elements that NH residents' family carers perceive as good EOL care and develop a conceptual model of good EOL care according to the family perspective; (2) evaluate the association between HCPs-family carers EOL communication and EOL care outcomes; (3) explore how EOL communication impacts on the goal of EOL care; (4) explore contributors to the shift in the care goal at the EOL in NH; (5) elaborate and confirm a first theory of EOL communication contribution in promoting palliative-oriented care in NH; and (6) identify and summarise the challenges encountered in designing and conducting qualitative research when exploring HCPs-family carers EOL communication in NH.

Methods. Firstly, a systematic review of qualitative findings according to the Joanna Briggs Institute meta-aggregation method was performed to identify what contributes to family carers' experience of good EOL care in NH. Secondly, a systematic review with meta-analysis was conducted to evaluate the association between HCPs-family carers EOL communication and EOL care outcomes. Thirdly, the potential mechanisms by which EOL communication may impact on the goal of care at the EOL in NH have been hypothesized by performing a scoping review and then tested by a qualitative descriptive study involving 32 bereaved family carers and 14 nurses who were interviewed across 13 Italian Northwest NHs from December 2018-May 2019. Fourth, the same set of interviews was phenomenologically analysed to identify the contributors to the shift in the care goal. Fifth, a descriptive two-tailed embedded multiple-case study based on 23 paired interviews between family carers and nurses was adopted to elaborate and confirm the foundations for a first theory attempting to describe the contribution of EOL communication to palliative-oriented care in NH. Finally, a concurrent descriptive qualitative study based on data collected through in-the-field notes and a research diary during the primary study was performed to highlight the challenges researchers had to tackle with when conducting qualitative research on EOL communication in NH.

Results. The first study suggested common elements between good EOL care and palliative-oriented care for terminally ill NH residents: family carers were more satisfied with the EOL care when they received physical,

emotional and psychosocial support and their relative died peacefully with physical and spiritual needs addressed. Moreover, this study suggested that discussing the need to adjust the care approach may facilitate a sensitive transition from curative- to palliative-oriented care. The second study highlighted that EOL communication may promote a palliative-oriented approach at the EOL in NH residents with a two-fold increase (OR = 2.23, 95% CI 1.58-3.14) in the likelihood of a family carers' decision to limit or withdraw life-sustaining treatments. The scoping review and qualitative findings based on family carers' and nurses' interviews emerged four potential mechanisms by which EOL communication may work, including (i) promoting family carers' understanding about their relative's health conditions, prognosis, and treatments available; (ii) fostering shared decision-making between HCPs and residents/family carers; (iii) improving knowledge of residents' preferences; and (iv) improving knowledge of family carers' preferences. These interviews also allowed to identify a role of unforeseen acute events such as urinary infections or pneumonia – known as trigger events – and a role of the NH environment as contributors to the transition towards palliative-oriented care. Trigger events represented an opportunity to discuss changes in a resident's health status and the need to adjust the care plan; the NH environment first influenced the recognition and discussion of trigger events and then mediated the transition through the culture of care and the quality of relationships. The multiple-case study shed light on the complex and dynamic interactions within and among EOL communication mechanisms and contextual factors: the NH environment influenced the timing and quality of communication that in turn impacted the quality of EOL by mainly acting through family carers' preferences, while resident's preferences were poorly known with a limited effect on the EOL care goal. The last study identified the major challenges when conducting qualitative research about EOL communication in NH and provided practical solutions.

Conclusion. Improving EOL communication appears to be a promising way to promote a timely transition towards palliative-oriented care in NH. The effectiveness of EOL communication may depend on the timing and depth of communication which are influenced by the NH environment. Our findings highlight the need for early, thorough and ongoing communication to enhance family carers' understanding and shared decisions at the EOL, and emphasize the necessity to improve residents' engagement in EOL discussion and pay attention to the NH environment design. A first theory describing the contribution of EOL communication to palliative-oriented care in NH has been elaborated, while challenges encountered in conducting this research program as well as solutions adopted inform on the feasibility and the acceptability of EOL research in NH.

Keywords: communication, end of life, family carers, meta-analysis, nursing home, palliative care, professional staff, qualitative research.