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## **Patient-physician communication at the end of life: a European perspective**

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# Summary

Throughout Europe, researchers and practitioners increasingly recognise the ethical basis of including the patient in end-of-life medical treatment decisions and the benefits of good end-of-life communication on patient-centred outcomes. There remains however a paucity of European cross-country research on end-of-life communication *practices*. End-of-life communication is also complicated by the changing characteristics of the population reaching the end of life; the population in need of palliative care is increasingly old, frail and suffering from multiple morbidities. However, people with these characteristics are often neglected in research on end-of-life communication.

This thesis addresses the lacunae in research on end-of-life communication in Europe in cross-country perspective and for older people. The thesis begins by introducing the topic of patient-physician communication at the end of life and the rationale for researching specific aspects of end-of-life communication. The research section is split into two parts: part one consists of comparative research on end-of-life communication in Europe; part two focuses exclusively on the situation in the Netherlands with a particular focus on older people.

### **Part One - End-of-life communication in Europe: cross-country comparisons**

Chapter two draws on EURO SENTI-MELC data. EURO SENTI-MELC involves representative GP networks in Italy, Spain, Belgium and the Netherlands collecting data on the care provided to patients in the last three months of life of all patients who died under their care. Chapter two reveals that, on average, more end-of-life topics were discussed between the patient and the GP in the Netherlands, followed by Belgium, Spain and Italy. Discussions of each one of the end-of-life topics measured in the survey were most prevalent in the Netherlands, followed by Belgium. GPs from all countries tended to discuss fewer topics with older patients, non-cancer patients, patients with dementia, patients for whom palliative care was not an important treatment aim and patients for whom their GP had not provided palliative care. The chapter concludes by recommending early end-of-life discussions with older patients, those with cognitive decline if possible, and those with non-malignant diseases.

Chapter 3 also draws on EURO SENTI-MELC data, but looks at the prevalence of two aspects of advance care planning: GP-patient end-of-life treatment discussions and patients' appointment of surrogate decision-makers. There was a higher prevalence of GP-patient end-of-life treatment preference discussions and surrogate appointments in Belgium and the Netherlands compared to Spain and Italy. Despite some country-specific differences, previous GP-patient discussion of the primary diagnosis, more frequent GP contact, GP provision of palliative care, the importance of palliative care

as a treatment aim and deaths in the patient's own home or a hospice/palliative care unit were positively associated with preference discussions or surrogate appointments. A diagnosis of dementia was negatively associated with preference discussions and surrogate appointments. In line with the recommendations of the previous chapter, early preference discussions, particularly for patients with cognitive decline, and the provision of palliative care encouraged anticipatory decision making.

Chapter 4 consists of a secondary analysis of qualitative interview data from older British, Dutch and Belgian patients. The study focuses on patients' attitudes towards and experiences of patient-physician end-of-life communication and provided a contrast to the cross-country differences reported in Chapters 2 and 3 by emphasizing similarities in patients' preferences and experiences across different European countries. Themes identified from patients' interviews in all three countries were 'confidence and trust', 'disclosure and awareness' and 'participation in decision-making'. Confidence and trust were reinforced by physicians' availability, time and genuine attention and hindered by misdiagnoses and poor communication style. Most participants preferred full disclosure, though some remained deliberately ill-informed to avoid distress. Patients expressed a variety of preferences for, and experiences of, involvement in medical end-of-life decision-making and a few complained that information was only provided about the physician's preferred treatment. A variety of experiences and attitudes regarding disclosure and participation in decision-making were reported from each country, suggesting that people's communication preferences are highly individual. Physicians are advised to be sensitive to this diversity and avoid stereotyping. In regard to communication style, physicians should provide clear explanations, avoid jargon, and continually check understanding.

### **Part two - End-of-life communication for older people: the Dutch experience**

Chapter 5 draws exclusively on three years of Dutch SENTI-MELC data. In this chapter, GP end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia' is described and compared. This study reveals that organ failure patients receive less palliative care from their GPs than cancer and old-age/dementia patients, whereas old-age/dementia patients, the group most likely to lose decision-making capacity, have the least end-of-life discussions and advance care planning of the three patient groups. These results highlight the need to integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic illness trajectory.

Chapter 6 draws on data from the Longitudinal Aging Study Amsterdam (LASA) to examine participants' preferences for four life-sustaining treatments in hypothetical

cases of cancer and dementia and the factors associated with a preference to forgo treatments. A majority preferred to forgo a treatment in both cancer and dementia scenarios. Different elements of the multidimensional variable 'social support' influenced preferences in distinct ways: larger social networks were associated with forgoing treatment in the dementia scenario, whereas, in the cancer scenario, a live-in partner and greater emotional support were associated with preferring all treatments. Current health was not associated with preferences (except anxiety - associated with a preference for treatment in dementia). Understanding social support influences may encourage professionals to explore patients' expectations and fears about social support during advance care planning.

Chapter 7 also draws on data from LASA, but looks at how participants' general treatment goals and values relate to their specific treatment preferences in hypothetical cancer and dementia scenarios. Treatments were desired less in the case of cognitive compared with physical decline and for a sizable proportion of participants, specific treatment preferences did not agree with their general end-of-life goals. Poor understanding of the risks and burdens of life-sustaining treatments or different understandings of their purpose (such as to meet short-term goals rather than to be dependent long-term) may lead to disagreement between general and specific end-of-life preferences.

Chapter 8 draws on LASA data collected in 1998, 2005, 2008 and 2011. This study describes 'euthanasia' and 'care' advance directive (AD) possession over time and factors associated with their possession. The data provide insight into the influence of the 2002 Dutch euthanasia law on 'euthanasia' and 'care' AD possession. In the two data collection cycles following the enactment of the 2002 Dutch euthanasia law (2005 and 2008), there was a significant decrease in possession of 'euthanasia' and 'care' ADs. In the third data collection cycle following the euthanasia law's enactment (2011), however, possession of 'euthanasia' and 'care' ADs had increased so that there were no significant differences with pre-law levels. These findings suggest that legal changes recognizing euthanasia ADs actually negatively affected possession in the first instance. Health factors had little or no influence on AD possession. This suggests a stability of preferences in various states of health and supports the legitimacy of ADs.

### **General discussion**

Chapter 9 begins with a comprehensive description of methodological strengths and limitations. Strengths stemmed primarily from the use of large data sets from different European countries, representative for populations of GPs or older people, containing measurements on participants' demographics, physical and psychological health and

their available social support. Limitations were largely due to issues of feasibility or were inherent to cross-country research, secondary data analysis, or using data collected with a broad aim to answer more focused research questions. The chapter also includes an epistemological reflection that argues that surveys were the most appropriate methodology for mapping variations between countries, over time and between different population groups. The key findings from the preceding chapters, and their interpretations, are then described in the context of the original research questions. In particular, the findings reveal marked differences between European countries in the occurrence of end-of-life discussions between patients and GPs. These findings reflect differences in the open discussion of death and dying, priority given to beneficence or autonomy in clinical practice, and palliative care service organisation (particularly GPs' training in, and responsibility for, palliative care). The similar characteristics of those patients for whom end-of-life communication is limited is also highlighted: non-cancer patients, older patients, and those suffering cognitive decline. Such patients, however, will characterise Europe's future palliative care population and the findings have important implications for the delivery of patient-centred palliative care. Finally, recommendations for policy and practice are also given. The thesis provides suggestions for strengthening palliative care in primary care settings and improving physicians' communication skills and suggests that these measures may be more effective in encouraging patient participation in end-of-life decision-making than legally strengthening ADs.