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Evans, N.C.

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Chapter 9

General discussion

“The single biggest problem in communication is the illusion that it has taken place.”

George Bernard Shaw, 1856-1950.

This thesis addresses – at least in part - the paucity of research on end-of-life communication in Europe, particularly in a cross-country perspective and for older people. This chapter begins with a comprehensive description of methodological strengths and limitations, and the approaches taken to minimise the impact of limitations. This is followed by some epistemological reflections on the study of social phenomena through primarily quantitative means. The key findings from the preceding chapters, and their interpretations, are then described in the context of the original research questions. Finally, the implications of this thesis for policy and practice, and recommendations for future research, are outlined.

Methodological strengths and limitations

The data included in this thesis come from a variety of sources across Europe (see Box 1). Although this strengthens the overall findings, the different data sources have various limitations. Some of these stem from practical or feasibility issues, whereas others are inherent to cross-country research, secondary data analysis, or using data collected with a broad aim to answer more focused research questions.

<p style="text-align: center;">Quantitative data and their sources</p> <p><u>Ten end-of-life topics</u>: primary diagnosis; incurability of disease; life expectancy; possible medical complications; physical complaints; psychological problems; social problems; spiritual/existential problems; options for palliative treatment; and the possible burden of treatments. Data sources: EURO SENTI-MELC (Spain, Italy, Belgium, the Netherlands).</p> <p><u>Elements of advance care planning</u>: general end-of-life care goals, medical end-of-life treatment preferences, appointment of surrogate decision-makers and preferred place of death. Data sources: LASA (the Netherlands) and EURO SENTI-MELC (Spain, Italy, Belgium, the Netherlands).</p> <p><u>Advance directives</u>: possession of euthanasia and care directives. Data source: LASA (the Netherlands).</p> <p style="text-align: center;">Qualitative data and their sources</p> <p><u>Older patients' attitudes towards and experiences of patient-physician end-of-life communication</u>: patient interviews. Data sources (primary studies): 'Medical and ethical quality of care when taking end-of-life decision' (Belgium); 'End-of-life care in general practice in the Netherlands' (the Netherlands); 'Ethnicity and cancer: examining psychosocial transitions for older people' (UK).</p>
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Box 1. Aspects of end-of-life communication examined.

Cross-sectional, retrospective surveys of representative general practitioner networks on end-of-life care in Belgium, the Netherlands, Spain and Italy

The EURO SENTI-MELC data was collected to describe end-of-life care provided in general practice. The analyses included in this thesis fall within that remit and are not secondary analyses; the research questions were however more focused than the

general aim. The strengths and limitations of this approach, already touched upon in previous chapters, are elaborated on below.

Strengths

In EURO SENTI-MELC, representative networks of general practitioners (GPs) in four European countries recorded the care received before death of all practice patients who died and this yielded comprehensive and comparable data. The GP networks were representative in terms of GPs' age, sex and geographical distribution for the whole country in the case of the Netherlands and Belgium, and for particular regions for Italy and Spain[1]. The retrospective nature of the research, and the exclusion of sudden and unexpected deaths from analyses, enabled the identification of patients nearing the end of life for whom palliative care may have been appropriate which is a challenge in prospective studies due to difficulties prognosticating dying[2].

In the Netherlands, Belgium and Spain, data were collected by existing sentinel networks and their co-ordinating institutes. This conferred a number of advantages: GPs did not participate due to a particular interest in death and dying or palliative care, reducing selection bias, and GPs received a high level of training and support and were familiar with reporting procedures. In Italy, a sentinel network was created specifically for the study, GPs were not however aware of the topic under surveillance when recruited, minimising selection bias. Recall bias was minimised through weekly death registrations. These measures contributed to the high level of reporting and low yearly turn-over of GPs[1].

The standardized registration form used for recording patients' end-of-life care underwent a thorough development procedure. Where possible, questions from previous Belgian and Dutch studies were used[3-9]. New questions were developed, after a review of the relevant literature, in collaboration with a multidisciplinary expert panel and approved by all research partners[1]. This process enhanced the validity of the measure, ensuring that items included covered all domains considered important to high quality end-of-life care. The form underwent forward and backward translation, allowing for adjustments aimed at providing equivalence of concepts and services[10]. The final form was piloted in each country (minimum ten GPs)[10]. Co-ordination of data collection, entry and cleaning by experienced research institutes also resulted in data of a high quality: missing data were retrieved via telephone if possible and 5% of data were double entered as a quality check.

Limitations

Limitations with the use of GP sentinel networks included the voluntary nature of participation, which may have biased selection towards GPs interested in research. Furthermore, the Italian network was created especially for the end-of-life surveillance; participants were therefore less familiar with the data collection procedure. The Spanish and Italian sentinel networks also only covered specific regions, though they were representative of the GPs within those areas.

For reasons of feasibility and practicality, the GP (and not patient) population is sampled. Because over 95% of the population in each of the four countries surveyed is registered with a GP[11,12], it was hypothesized at the beginning of EURO SENTI-MELC that such an approach could provide a representative sample of patients nearing the end of life. Additional analyses revealed that deaths registered by the networks were fairly representative of deaths in the four countries, with a few notable exceptions. The percentage of deaths recorded as 'non-sudden' by the networks[1] were comparable to those of reported in a previous European death certificate study[13]. Some deaths were however excluded or under-reported. Firstly, Dutch nursing home residents were excluded from analyses as they receive multidisciplinary care coordinated by the nursing home physician rather than their GP. Secondly, comparison of the Dutch and Belgian non-sudden death data with data from death certificate studies (excluding Dutch nursing home deaths) confirmed the representativeness of deaths recorded apart from a slight underrepresentation of women in the Netherlands and of non-sudden hospital deaths and people under the age of 65 in Belgium[1]. Comparison of all deaths recorded in Italy and Spain with death rates for the country or reference population confirmed their representativeness[1]. Due to a lack of national data on place of death, some sudden deaths in hospitals may have been missed by GPs in Spain and Italy; however, this could not be confirmed.

There are also a number of limitations associated with the measurement instrument. EURO SENTI-MELC GPs report on different aspects of patients' end-of-life care. The breadth of information however is, at times, at the expense of detail about any one item. The EURO SENTI-MELC items analysed in this thesis primarily concern patient-physician end-of-life communication, specifically the discussion of ten end-of-life topics between the patient and the GP and aspects of advance care planning, such as medical end-of-life treatment preferences, appointment of surrogate decision-makers and preferred place of death (Box 1). No information however was available concerning the timing, duration, frequency or quality of discussions or patients' desire for such discussions. In addition, Dutch SENTI-MELC data were used to compare GPs'

end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia'. There was however no separate category for cause of death from dementia, which had to be constructed later and may have resulted in an underestimation of dementia deaths. The under-reporting of deaths from dementia is however also a problem in death certificate studies[14]. The exclusion of nursing home residents further reduced the size of the old-age or dementia group, resulting in relatively few deaths in this category.

There are also limitations associated with GPs' reporting. Although the weekly reporting of deaths ensured recall bias was minimized, the reporting of certain aspects of end-of-life care, such as communication, which could have taken place considerably earlier, may have been subject to recall bias. Socially desirable responses may also have been provided for items that reflected particularly on GPs' care competencies, such as advance care planning and GP palliative care provision. Although the registration form underwent forward and backward translation and attempts were made to provide cultural equivalence of concepts and services[10], understanding of some concepts, such as 'palliative care', which differ across countries, specialities and individuals[15,16], may have varied. As well as GPs' potentially varied understanding of such terms, GPs and patients may have had different interpretations of what was and was not discussed during the patient-physician interview. Patients and physicians may have differed in their perception of what constitutes the 'discussion' of a certain topic; an issue reflected in previous research which has found that patients' and physicians' recall of topics discussed differs[17]. EURO SENTI-MELC also relied on GPs to report care in other settings, although they were asked to maximize information from other sources.

Analysing the data presented further challenges. The Spanish network collected data for one year only, resulting in a smaller sample, fewer deaths per GP and lower statistical power. Furthermore, sampling in all countries occurred at the level of the GP; patient data were therefore clustered by GP. Multi-level analysis may therefore have been appropriate in order to take into account the dependence among patients nested within the same GP. This analysis strategy was not, however, advocated for the cross-country papers because, due to the process of anonymization in Belgian, it was not possible to determine the GP but only the group practice. It was not, therefore, possible to ascertain which patients were treated by which GPs in those practices. This hampers multi-level effects analyses because they can only correct for differences between GP practices and not individuals, and the hypothesis that patient-physician communication behaviour or care is clustered around practices is less valid than the clustering around individual GPs. There were also few observations per cluster (153

GPs/practices from the participating countries supplied less than two registration forms during the period 2009-2010) and multi-level models with an average of less than five observations per cluster, as was the case for the Spanish data (mean 3, median 2), have been found to be unreliable[18]. Moreover, all previous analyses carried out on SENTI-MELC data found that accounting for group level clustering had no or little effect on the results[4,19]. As such, when choosing between two sub-optimal analysis strategies, the simplest approach - to treat the data as unclustered - was taken to aid interpretability of results. In chapter 5, only Dutch EURO SENTI-MELC data were used, and the problems with the identification of Belgian GPs and the small number of observations per cluster from Spain were no longer applicable. Furthermore, three years of data rather than two were included, resulting in larger cluster sizes. Multi-level analysis was therefore appropriate for these data.

Secondary analysis of qualitative interview data

Secondary analysis involves 'further analysis of an existing data set which presents interpretations, conclusions or knowledge additional to, or different from, those presented in the first report on the enquiry as a whole and its main results'[20]. Such analyses are most readily associated with quantitative data within a positivist research paradigm. The secondary analysis of qualitative data however raises a number of theoretical and methodological considerations: primarily, the concern that an understanding of the context in which qualitative data are created, vital to the interpretation of such data within a constructivist research paradigm, may be lost. The analysis carried out in chapter 4 represents a supplementary secondary analysis of qualitative data: the emergent theme of patient-physician communication was examined in studies that looked more broadly at terminally ill patients' attitudes towards and experiences of death, dying and end-of-life care.

Strengths

To ensure that the theme of patient-physician communication was sufficiently represented, interviews from available studies were subject to a thorough quality assessment before their inclusion for secondary analysis. The efforts made to maintain sufficient context in order to interpret the data was the major strength of this analysis. Context was deemed sufficient if it provided the 'conditions of discursive production'[21]. This level of contextual information was elicited from full interview transcripts, transcribed verbatim and from detailed field notes. A sensitive and nuanced translation of Dutch and Flemish transcripts into English was achieved through the language expertise of the researchers undertaking the secondary analysis and the use of professional translators[22]. Furthermore, at least one researcher from each of the primary studies was available to provide further information on any

contextual queries. Rigour of reporting of the secondary analysis process was achieved through following recommended guidelines[21,23]. A further strength of the study was the use of the same analytical approach (thematic analysis) for the primary studies and the secondary analysis and checking the 'fit' of resultant themes with at least one researcher from each of the primary studies.

Limitations

The study was framed as an exploratory secondary analysis to begin to address the paucity of cross-country qualitative research on end-of-life communication in Europe. Ideally, cross-country qualitative research would be carried out by the same research team, with the interview guides translated sensitively for equivalency of terms and meanings, and with an ongoing data collection process until a saturation of themes had been achieved. Such research was, unfortunately, beyond the scope of this thesis.

Within the context of a secondary analysis, however, the main limitation was the varied foci of the primary studies. As such, only common themes on patient-physician end-of-life communication in three northern European countries could be examined because any between-country differences may have been the result of different interview guides. This also meant that it was not possible to achieve a saturation of themes in any traditional sense, but rather all themes that were present in all three countries were identified. A further weakness of the study was the lack of interviews from southern European countries, particularly in light of the differences between northern and southern Europe reported in chapters 2 and 3.

Longitudinal Ageing Study Amsterdam (LASA)

The Longitudinal Ageing Study Amsterdam's main aim is to study the determinants, trajectories and consequences of physical, cognitive, emotional and social functioning in relation to ageing[24]. One aspect of ageing covered by the study is end-of-life preferences and care. Therefore, in a similar fashion to the analyses undertaken of EURO SENTI-MELC data, the analyses conducted of LASA data were not considered secondary analyses.

Strengths

The main strength of LASA is its nationally representative sample of older adults. Men and the oldest old were over-sampled in the stratified random sampling scheme to maintain representation of these high mortality groups throughout the study[24]. This over-sampling was taken into account in analyses. LASA also has a low drop-out rate and most attrition is due to mortality, with much lower attrition due to frailty, refusal to participant and loss of contact[24]. The second major strength is the wide range of

data available on participants' socio-demographic characteristics, social support, physical and mental health in each data collection cycle and over time.

Limitations

The outcomes analysed, specifically general end-of-life care goals, preferences for life-sustaining treatments and possession of advance directives (ADs), were measured via participant self-report. Self-report may be subject to greater desirability bias than more objective measurements. The independent measures used in analyses also included a mix of validated, self-report (subjective) and measured (objective) variables. Some self-reported measures however, such as self-perceived health, physical limitations and experience of pain, might be considered particularly subject to variances of 'mood state', the propensity to view the world in negative or positive terms[25]. As the analyses sought to find factors that influence end-of-life preferences however it was precisely the subjective experience of the participant that was most important.

There was a relatively high proportion of missing values for end-of-life general goals and treatment preferences. Non-responders were, in general, older, more frequently female, had lower educational attainment and were church members. The difference in the personal characteristics of responders and non-responders affects the external validity of findings: their generalizability to the wider population. Because responders and non-responders differed on variables found to be associated with treatment preferences (age, sex, church membership and education), preferences for life-sustaining treatments may be slightly underestimated. Although the missing values for AD possession were very low, across the collection years, non-responders were found to be significantly older, more frequently female and to be non-church members. Because these characteristics are all associated with possessing an AD, estimates of AD possession may also be slightly underestimated.

In general, missing values for independent variables were rare. There were however more missing values for some variables that are often considered to be sensitive topics, such as household income, social support (network size, practical and emotional support) and experience of pain.

Depth of information about specific LASA items sometimes had to be sacrificed to achieve the breadth of items measured. For example, participants were not provided with detailed descriptions of life-sustaining treatments or their associated burdens. It is, therefore, unclear how informed preferences were.

Also, unfortunately, some measures were not recorded at every data collection cycle. This affects the ability to trace time trends. AD possession was not, for example, measured in the 2001 data collection cycle. In addition, the trend in possession of euthanasia and care ADs described in chapter 8 may have been subject to some degree of cohort effect: the first measurement sampled only the first cohort, whereas subsequent measurements sampled both the first and second cohorts. Finally, the interval between data collection cycles may be too long for end-of-life monitoring. If ADs are drafted close to death their prevalence may be underestimated because of the three-year interval between measurements.

Epistemological reflections

This thesis takes, primarily, an epidemiological approach to the study of social phenomena: large-scale survey data are used to examine social processes such as patient-GP communication, to elicit people's preferences for medical end-of-life treatments and to ascertain the extent of their end-of-life planning through the discussion of medical end-of-life treatment preferences, appointment of surrogate decision makers and AD possession. The scale of analysis – mapping variations between countries, over time and between different population groups – meant that surveys were the most appropriate methodology. This quantitative approach however is open to critique. Firstly, it might be considered reductionist: to quantitatively measure 'end-of-life communication', this broad topic had to be reduced to a number of comparable, measurable items that could feasibly be collected and examined (see Box 1). This thesis however does not claim to represent the entirety of end-of-life communication but instead concerns itself with aspects of end-of-life communication identified as important to the delivery of high quality end-of-life care in the research literature and by palliative care experts to provide the most clinically relevant evidence[1].

Secondly, the approach might be considered 'atomistic' in that it treats a society or culture as a sum of individual behaviours and neglects the cultural context within which these behaviours take place[26]. This criticism itself, however, removes quantitative approaches from the wider body of research and underestimates the importance of qualitative research – which explores not just people's behaviour, but the meaning of actions within the context of social and cultural realities – in survey design and interpretation of results. Findings from large-scale surveys can also generate hypotheses to be tested in subsequent qualitative research and confirm (or challenge) the generalizability of associations identified in small context-specific qualitative studies. The knowledge generated from quantitative and qualitative research can, therefore, be complementary and jointly contribute to the

understanding of social phenomena[27]. Differences between countries revealed in this thesis have been interpreted by highlighting differences in certain aspects of culture, such as the open discussion of death and dying, the importance of beneficence and autonomy, and (viewing health systems as specific cultural systems) palliative care service organization. Nonetheless, simply ascribing cross-country variation to 'cultural differences' has been avoided. This was a conscious attempt to unpack some of these culturally influenced differences in behaviour yet acknowledge that 'cultural' differences cannot be truly understood unless a 'culture' is studied as a whole and understood on its own terms. Therefore evaluations of the quality of care provided in the four countries compared have also been avoided; not only because of the lack of information on patients' desire for, or the quality of, end-of-life communication but also because such value based judgments would be ethnocentric.

In addition to the primarily epidemiological approach taken, this thesis also incorporated a secondary analysis of qualitative interview data in chapter 4. This analysis 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. The secondary analysis also highlighted the paucity of cross-country qualitative research, particularly in light of the increasing popularity of cross-country quantitative research.

Key findings and their interpretation

Six research questions were originally posed. The first two concerned comparative end-of-life communication research in Europe, whereas the final four focused on various aspects of end-of-life communication in the Netherlands with a focus on older people.

Part I - End-of-life communication in Europe

The first research question was, 'what proportion of people nearing death have end-of-life discussions with their GP and which factors influence their occurrence in different European countries?' To answer this question, the concept of 'end-of-life discussions' was operationalized by mapping the prevalence of discussion of ten end-of-life topics and aspects of advance care planning in Italy, Spain, Belgium and the Netherlands. The prevalence of GP-patient discussion of ten end-of-life topics prior to patients' deaths was estimated and compared in chapter 2, whereas GP-patient medical end-of-life treatment preference discussions and patients' appointment of surrogate decision-makers in the four countries was estimated and compared in chapter 3. Chapter 2 reveals that all topics except primary diagnosis and physical complaints were discussed with less than half of patients from Italy, Spain and

Belgium. In contrast, most topics were discussed with more than half of patients in the Netherlands. In all four countries, the primary diagnosis and physical complaints were the most frequently discussed topics, whereas 'spiritual and existential issues' was the least frequently discussed topic. In addition, more topics, on average, were discussed with each patient in the Netherlands (mean=6.37), followed by Belgium (4.45), Spain (3.32) and Italy (3.19). Chapter 3 reveals 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. GP-patient discussion of treatment preferences occurred for 10%, 7%, 25% and 47% of Italian, Spanish, Belgian and Dutch patients respectively. Furthermore, 6%, 5%, 16% and 29% of Italian, Spanish, Belgian and Dutch patients appointed (either verbally or in writing) a surrogate decision-maker. As surrogate appointments were made known to the GP almost entirely verbally, they were considered an important aspect of end-of-life communication.

These findings reveal the limited discussion of end-of-life topics that have been identified as important for the provision of high quality end-of-life care in general practice. They also highlight some important cross-country differences. Patient-GP discussion of end-of-life topics and aspects of advance care planning was most frequent in the Netherlands, followed by Belgium. There were few differences between Italy and Spain, although the odds of a Spanish patient having discussed the 'primary diagnosis', 'incurability of disease', 'medical complications', 'physical complaints', 'options for palliative treatment' and the 'burden of treatment' with their GP were significantly higher than those of an Italian patient. These cross-country differences are discussed extensively in chapters 2 and 3: they are most likely linked to variation in the priority given to the principles of beneficence and autonomy in clinical practice, GPs' responsibility for and training in end-of-life care, the social acceptability of discussing death and dying, involvement of family members in decision making, and legal and policy contexts. The cross-country differences do not represent country 'rankings' because what is considered 'good' end-of-life communication, 'good' care and, indeed, a 'good' death, may vary between countries. It is however possible to use the results to identify specific factors which may encourage end-of-life communication and those which may limit it. GP-patient communication on all items measured was found to be most frequent in the Netherlands, where there is a strong emphasis on end-of-life care in primary care settings and GPs have greater personal responsibility for palliative care provision. Dutch GPs have also been found to receive more training in palliative care than GPs from other European countries[28] and Dutch health care policy places a strong emphasis on palliative care provision in primary settings[29].

Despite cross-country differences in the prevalence of discussions, the personal and care characteristics of patients for whom patient-GP discussion of end-of-life topics and aspects of advance care planning occurred were remarkably similar across countries. Both the discussion of more end-of-life topics and aspects of advance care planning were, overall, more frequent with patients for whom palliative care was an important treatment aim and patients for whom their GP had provided palliative care, and less frequent with patients diagnosed with dementia. In addition, GPs tended to discuss more end-of-life topics with younger patients and cancer patients and report more discussions of treatment preferences or surrogate appointments for patients with whom they had previously discussed the primary diagnosis and had more frequent contact. The associations between GP-patient end-of-life discussions and GP care factors underline the importance of the GP-patient relationship and GPs' competencies in identifying the need for palliative care. A coherent picture also emerges of the characteristics of patients for whom limited GP-patient end-of-life discussions take place, exposing relatively less frequent engagement in discussions with older patients, non-cancer patients and those with cognitive decline in general practice. The strong relationship between aspects of advance care planning and GP-patient discussion of the primary diagnosis suggests that the foundations of good end-of-life communication are laid in the early stages of the illness trajectory. Although patient-GP non-discussion of the primary diagnosis does not automatically equate to non-disclosure of the diagnosis or prognosis, high proportions of patients dying of cancer have been reported to be unaware of their diagnoses in both Italy and Spain[30,31].

The second research question was: 'for older patients, are there common themes and challenges in patient-physician communication at the end of life in different European countries?' Common themes were identified from British, Dutch and Belgian older patients' interviews on attitudes to death, dying and end-of-life care in chapter 4. Whereas chapters 2 and 3 tend to highlight between country differences in the prevalence of end-of-life discussions if not in the characteristics of the patients engaged in discussions, chapter 4 highlights similarities across countries in older patients' attitudes towards and experiences of patient-physician end-of-life communication. Common themes from patients' interviews included: 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. These patients can be considered as being in a state of 'partial awareness' of dying,

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which includes the suspicion of, or pretence of not, dying. Patient-centred care does not dictate that a patient must be aware of dying but rather requires working with all levels of death awareness. Indeed, for some patients, denial is an important coping mechanism[32]. It is important that prognosis information should be frequently and sensitively offered, but never forced upon such patients. Patients from all three countries also expressed a variety of preferences for and experiences of personal and family involvement in medical end-of-life decision-making. A few patients complained that information was only provided about the physician's preferred treatment. This represents a 'framing effect', when information is presented in a way as to bias the patient towards the physician's preferred outcome[33], and limits informed decision-making. Framing effects are difficult to avoid, especially if patients appeal to physicians to tell them 'what they would do', however when describing treatment options physicians should discuss both their possible risks and benefits and the consequences of limiting treatment to provide patients with complete information.

Within each of the common themes identified across the three countries, participants from each country reported diverse experiences and attitudes. This diversity demonstrates that there is no 'idealized' model for older patients, or for end-of-life communication in any one country, and highlights the importance of assessing individual patients' preferences for end-of-life communication and participation in decision making.

Part II - End-of-life communication for older people: the Dutch experience

Limited end-of-life communication and palliative care for non-cancer patients is often attributed to their less predictable illness trajectories. Non-cancer patients are however often studied as a group and compared with cancer patients. Although physical, psycho-social and spiritual suffering at the end of life has been increasingly described for archetypal illness trajectory groups, such as cancer, organ failure and frailty/dementia, there remains a paucity of research comparing end-of-life *care* between illness trajectory groups. The third research question, 'how does GP end-of-life communication and care provision differ by patient 'chronic illness trajectory group?' sort to address this lacuna. This was addressed in chapter 5 by describing and comparing the end-of-life care and communication received by cancer, organ failure and old age and dementia patients in the Netherlands.

The study revealed less frequent palliative treatments, palliative care use, end-of-life discussions and advance care planning amongst organ failure and old-age/dementia patients than cancer patients. Comparing illness trajectory groups revealed that organ failure patients received the least palliative care, whereas old-age/dementia patients,

the group most likely to lose decision-making capacity, experienced the least end-of-life discussions and advance care planning of the three patient groups.

It has been suggested that primary care is perhaps the most appropriate setting for most of non-cancer patients' end-of-life care[34,35]. In the Netherlands, where there is already a strong emphasis on end-of-life care in primary care settings, differences in GPs' end-of-life care provision associated with illness trajectory group remain. These results highlight the need to further integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic illness trajectory to enable all patients to live as well as possible with progressive illness and die with dignity and comfort in line with their own preferences.

The fourth research question was: 'what are older people's preferences for life-sustaining treatments in hypothetical cases of cancer and dementia and which socio-demographic, social support, physical and mental health factors are associated with their preferences'? Chapter 6 reports Dutch older people's life sustaining treatment preferences and factors associated with their desire to forgo one or more treatments. The majority of older people preferred to forgo at least one life-sustaining treatment in both the hypothetical cancer (78%) and dementia (85%) scenarios, indicating that treatments are desired less in the case of cognitive compared with physical decline. In light of findings that many older people would prefer to forgo life-sustaining treatments at the end of life, particularly in the case of dementia, it is imperative that preferences are discussed with relatives and healthcare professionals in a timely manner to avoid unwanted interventions. Although in previous studies current health state had been associated with life sustaining treatment preferences[36-39], current health factors had limited influence on treatment preferences. Indeed, social support factors were more influential. 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. Social support, therefore, made forgoing less likely in hypothetical scenarios of poor physical, but not mental, health. The lack of significant association between health state and treatment preference suggests that preferences remain stable in different health states. Furthermore, an understanding of social support influences may encourage professionals to explore patients' expectations and fears about such support during advance care planning.

Some authors have suggested that determining general end-of-life values and goals may be more useful in guiding clinical decisions than knowing specific life sustaining treatment preferences[40-42]. The fifth research question, therefore, was: 'what is the relationship between older people's general end-of-life goals and specific life-sustaining treatment preferences?' The agreement between Dutch older people's general preferences for quantity vs. quality of life and specific end-of-life treatment preferences is described in chapter 7. For a substantial proportion of Dutch older people, specific life-sustaining treatment preferences did not agree with their general end-of-life goals. Agreement ranged from 51-76% in a hypothetical scenario of cancer and 41-60% in a hypothetical scenario of dementia scenarios, depending on the treatment. 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 on long-term) may lead to disagreement between general and specific end-of-life preferences. A stepwise process of discussing general care goals, followed by specific treatment preferences is therefore recommended to frame discussions within the context of general goals, different end-of-life scenarios and the risks and burdens of treatments.

Finally, the sixth and last research question was: 'Is there a trend in older people's euthanasia and care AD possession over time and which socio-demographic, social support, physical and mental health factors are associated with possession?' Trends in 'euthanasia' and 'care' AD possession amongst Dutch older people from 1998 to 2011 are described in chapter 8. Data, collected before and after the implementation of the 2002 Law on Euthanasia and Assisted Suicide, were also appropriate for studying the impact of the law on AD possession. This is particularly relevant because few studies have examined societal influences, such as legal and policy changes, on AD uptake. The findings revealed significant decreases in possession of 'euthanasia' and 'care' ADs following the enactment of the 2002 euthanasia law. The decline in euthanasia ADs mirrors declines in euthanasia requests and incidence after the enactment of the euthanasia law and may reflect uncertainty regarding the functioning of the new law[43]. By 2011, however, there were no significant differences in possession of 'euthanasia' or 'care' ADs compared with pre-law levels, perhaps indicating increasing public confidence in ADs use and interpretation by physicians.

The characteristics of participants in possession of 'euthanasia' and 'care' ADs also differed. Few factors were associated with the possession of care ADs. Care AD possession was associated with the oldest old compared with the youngest old age category and fewer physical limitations. Factors associated with euthanasia AD possession (positive association with increasing age, female gender, higher education

and higher household income, and negative association with Catholic or Protestant church membership) however were similar to factors associated with AD possession in previous studies[44-53]. In contrast to previous studies, however, health factors had no influence on possession of a euthanasia AD, and limited influence on possession of a care AD. The limited influence of health factors on AD possession suggests stability of preferences in various states of health and supports the legitimacy of ADs.

Recommendations for policy and practice

Taken together, the findings from this thesis lead to a number of recommendations for policy and practice based around strengthening the provision of palliative care in primary care settings and improving end-of-life communication and advance care planning.

Strengthening the provision of palliative care in primary care settings

1. GP training in palliative care

Currently, palliative care is not an obligatory part of GP training in any of the countries from which data for this thesis were collected[54,55]. Dutch GPs, who, in general, benefit from more palliative care training, more frequently discussed all end-of-life communication items measured. Including palliative care as an obligatory element of the GP training curriculum and ensuring continuous training and participation in initiatives aimed at strengthening palliative care provision in primary care settings, such as the British Gold Standards Framework (GSF)[56] or the Dutch 'Palliatieve Thuiszorg' (Palliative homecare – PaTz)[57] is, therefore, highly recommended (see Box 2).

2. Recognizing palliative care needs

Dutch GPs' seemingly had difficulties recognising, and discussing, the end-of-life for organ failure and old-age/dementia patients compared with cancer patients. There are a number of different models for prognosticating the end of life: some are based on the probable amount of time remaining before death[58] and others are based on health and care characteristics[59,60]. These models, however, tend to show poor discrimination for non-cancer patients[59] and physicians have a tendency to over-estimate their patients' life expectancy[61]. Difficulties in prognosticating the dying phase highlight the need to deliver palliative care based on patients' psycho-social, physical and spiritual needs rather than on prognostication of 'dying'. Recognizing these needs and integrating palliative care and optimal disease management is, therefore, a priority for GP training.

The Gold Standards Framework (United Kingdom)

Within the primary care setting, the GSF aims to support GPs and district nurses to: identify patients in the last years of life; assess patients' symptoms, needs and preferences; and to plan care commensurate with patients wishes.[56] The GSF achieves this through the provision of training, tools, outcome measures and local support (<http://www.goldstandardsframework.org.uk/>).

Palliatieve Thuiszorg (Palliative Homecare – PaTz) (the Netherlands)

The PaTz project, based on the British GSF, focuses on developing and supporting partnerships between GPs and nurses in palliative home care in the Netherlands. PaTz has three main aims: better cooperation between GPs and nurses; the early identification and registration of patients with palliative care needs; and the creation of patient-centred palliative care plans[57].

Box 2. Initiatives for strengthening palliative care provision in primary care settings

Improving end-of-life communication and advance care planning

1. Timely initiation of end-of-life discussions and advance care planning

Timely end-of-life discussions and advance care planning facilitate symptom assessment and encourage patient participation in decision-making. Due to difficulties prognosticating dying, especially for non-cancer patients (see above), and indications that the foundations of good end-of-life communication are laid early in the illness trajectory, it is advisable to broach sensitively end-of-life issues soon after diagnosis of any life-limiting illness. For patients with dementia, for example, 'timely', due to necessity, equates to 'early'. Indeed, the recent EAPC white paper on palliative care for older people with dementia recommends that advance care planning starts at diagnosis, when the patient 'can still be actively involved and patient preferences, values, needs and beliefs can be elicited'[62].

2. Effective communication

End-of-life communication training should encourage physicians to develop effective communication skills, particularly when communicating with older patients. Such skills include determining patients' preferences for participation in decision-making (including non-involvement), providing clear explanations, avoiding jargon and partial information provision and continually checking patients' understanding.

3. The process of advance care planning

This thesis reveals that, for a substantial minority of older people, general goals and specific life sustaining treatment preferences did not agree. Life-sustaining treatments were also more frequently desired in hypothetical scenarios of cancer than dementia. These findings underline the importance of a stepwise process of eliciting preferences for care prior to possible future incapacity. Specific treatment preferences should be discussed within the context of general goals, different end-of-life scenarios and the risks and burdens of treatments. These preferences should also be revisited regularly.

This process of considering end-of-life values and goals and articulating preferences typifies advance care planning[63], which may or may not lead to the formal recording of preferences in an AD.

The findings that current health factors had very limited influence on older patients' life-sustaining treatment preferences and possession of euthanasia and care directives, suggests a stability of preferences in various health states and supports the legitimacy of discussing treatment preferences for future hypothetical states of health. The less frequently studied influence of social support factors was, in contrast, found to be highly influential on life-sustaining treatment preferences. Healthcare professionals are, therefore, also encouraged to explore patients' expectations and fears about social support at the end of life.

4. Macro-level initiatives to strengthen patient autonomy at the end of life Finally, attempts to encourage AD possession through the strengthening of their legal status may not have the intended effect. If the impetus for legal changes and policy initiatives is to strengthen patient autonomy at the end of life, encouraging advance care planning and informal end-of-life discussions may be more effective.

Recommendations for further research

The findings also lend themselves to recommendations for further research, of both a quantitative and qualitative nature, to improve the mapping of variations between countries, over time and between different population groups and to develop an in-depth understanding of variations.

End-of-life communication in Europe

The four countries included in the EURO SENTI-MELC study exemplify a typical northern-southern Europe dichotomy. The addition of countries that do not conform so readily to these stereotypes, such as Ireland (where the Catholic church is still highly influential in medical decision-making[64]) or Norway (where physician-patient relationships have been described as relatively paternalistic[65]) would benefit the understanding of cross-country differences.

It would also be beneficial to employ a mixed methods approach to future EURO SENTI-MELC studies to attempt to understand the social processes underlying these cross-country differences. A related recommendation is the need for primary qualitative research to understand what is considered 'good' end-of-life care and communication amongst patients, physicians, carers and members of the general public in different European countries.

End-of-life communication for older people

The Dutch SENTI-MELC data were used to compare the care and end-of-life communication received in general practice by 'cancer', 'organ failure' and 'old-age or dementia' patients. The study, however, did not examine palliative care needs. To identify inequities in service provision, future studies might examine palliative care needs alongside access to services[66]. Although comparing the care 'needs' of different patient groups across the multiple palliative care domains (physical, psychosocial and spiritual) is challenging, past approaches include comparing symptom burden[67,68] and scores on standardized physical and mental health assessment scales[68] as well as qualitative approaches[69]. Qualitative research should also explore physicians' reasons for initiating palliative care and treatments, discussion of the end of life and advance care planning with different patients.

LASA data were used to examine the influence of social support next to socio-demographic, physical and mental health factors on preferences for life-sustaining treatments and possession of euthanasia and care ADs. Social support factors, other than marital status, are rarely taken into account in research on medical end-of-life preferences. They were, however, found to be highly influential, at least with regard to life-sustaining treatment preferences. Future qualitative research should explore the influence of social support on older people's life sustaining treatment preferences, whereas quantitative research might aim to examine these associations in other populations and countries.

Finally, examining the time trend in euthanasia and care AD possession in the Netherlands suggested that macro-level, legal changes negatively affected their possession, at least in the period immediately following the euthanasia law's enactment. Similarly, the implementation of the 1991 Patient Self-Determination Act in the United States did not lead to a subsequent increase in AD possession[70-72]. It would therefore be worthwhile to examine the effect on AD possession of recent legal changes in other European countries, such as Germany[73], Switzerland[74] and Portugal[75], if indeed data on AD possession before the implementation of legal changes are available.

Final remarks

This thesis reveals marked differences between European countries in the topics that patients and GPs discuss before death. At the same time, it highlights the similar characteristics of those patients for whom end-of-life communication is limited: non-cancer patients, older patients, and those suffering cognitive decline. These patients, however, will characterise Europe's future palliative care population and the findings

therefore have important implications for the delivery of patient-centred palliative care. As well as identifying the patient groups that are neglected with regard to communication at the end of life, the thesis also highlights priorities for how this communication could be improved. For example, the importance of eliciting older people's end-of-life treatment preferences and framing preference discussions within the context of general care goals, different end-of-life scenarios, the risks and burdens of treatments and any personal concerns, such as the presence or otherwise of social support. Finally, 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.

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