Medical Decision-Making at the End of Life: the Research Agenda

A new research domain

In the past decade many textbooks have been issued on the subject of death and dying and on medical care at the end of life. Influential medical journals have published large numbers of commentaries and editorials on the merits and shortcomings of modern medical care for patients who are in the terminal stage of life. Somewhat more recently this discussion is being influenced by support from empirical studies on health care at the end of life. The papers in this volume show that end-of-life decision-making is a rich and promising research domain. A wide variety of researchers, including physicians, epidemiologists and ethicists, have presented data from studies on many different topics within this domain of medical decision-making. As such, this volume presents an overview of topics that are currently being studied. This overview is obviously far from complete, and lacks the contributions of many other important researchers. It is considered to be new in its focus on empirical research concerning the clinical and epidemiological aspects of end-of-life decision-making. Other types of research, for instance research from disciplines such as bioethics or sociology, are not dealt with here, although their importance for clinical practice and public policy-making is beyond any doubt. However, whereas the most important aim of end-of-life medical care is to improve the quality of the terminal stage in life for patients and relatives, including the dying process, it is felt that valid and reliable data on current practices and attitudes can make a highly important contribution to providing opportunities for such improvement.

Research in medical end-of-life care

When medical end-of-life care is directed at contributing to the quality of dying for the patient and the family and friends, the related research domain can be defined as all research aimed at identifying conditions for a 'good' death and developing and evaluating medical interventions, including decisions to forgo interventions, aimed at realizing those conditions. This delineates a very broad and multidisciplinary research domain, that can be structured along various different dimensions, of which the most important are determinants, interventions and participants. The possible determinants of a 'good' death are listed in Table 1, and demonstrate that the modi-

fiable dimensions of the patient's experience are especially important. They act as a guide to the appropriate medical and health care interventions.

Table 1. Determinants of and interventions towards a good death.*

Modifiable dimensions of the patient's experience
– Physical symptoms
– Psychological and cognitive symptoms
– Social relationships and support
– Economic demands and care giving needs
– Hopes and expectations
– Spiritual and existential beliefs
Fixed patient characteristics
– Clinical status (disease/prognosis)
– Socio-demographic characteristics
Care-system interventions
– Professional interventions
– Health-care institutional interventions
– Family and friends interventions
– Socio-economic policy interventions
– Social, judicial interventions

* Based on Emanuel EJ, Emanuel LL. The promise of a good death. Lancet 1998;351(Suppl 2):21-29.

The relevant participants are primarily the patient, the family and friends, and the health care professionals, especially physicians and nurses. Because some of the possible interventions may have a life-shortening effect, they have a special status in the public, professional and political debate. The decisions involved are listed in Table 2. For these types of decisions the public, medical professionals and policy-makers may also be considered to be relevant participants in the sense that in some countries some decisions cannot be made, or are at least illegal.

Table 2. Medical decisions concerning the end of life.

Forgoing life-prolonging treatment, that is,
– decisions about whether or not to withdraw or withhold potentially life-prolonging treatment
Intensifying symptom management, that is,
– alleviation of pain or other symptoms with, for instance, opioids, or terminal sedation with benzodiazepines or barbiturates, in doses large enough to invoke hastening of death as a possible or certain side effect
Physician-assisted death, that is,
– euthanasia: the administration of drugs with the explicit intention of ending the patient's life at the patient's explicit request
– assisted suicide: the prescription or supplying of drugs with the explicit intention of enabling the patient to end his or her own life
– life-ending without explicit request of the patient by administration of drugs

A conceptual framework for medical decisions that possibly involve a life-shortening effect has been developed in the first paper of this Volume by Van der Wal. Further combining determinants, interventions and participants will result in a large three-dimensional matrix, that could be filled with only a very limited amount of empirical information, but that may form a useful framework for a research agenda on end-of-life research.

Decisions to withdraw or withhold life-prolonging therapy

Part I of this volume presents a broad overview of current research efforts concerning medical decision-making with respect to whether or not to initiate or continue (potentially) life-prolonging treatment. Dutch epidemiological studies have shown that non-treatment decisions, that is, decisions to withhold or withdraw life-prolonging treatment, are very common in current end-of-life care, and that the relevant decision-making involves technologically advanced, as well as more basic medical interventions. Although non-treatment decision-making is undoubtedly a less controversial issue than end-of-life decisions in which life-shortening medication is involved, a large number of Swedish studies demonstrate that non-treatment practices and general opinions often do not coincide, and vary between different societal groups. This may (partly) be explained by the fact that non-treatment decision-making appears to be a rather complicated process, both from the physician's perspective, as is shown by Asch and Faber-Langendoen, and from the patient's perspective, which is demonstrated in the work of Pearlman and others. Whereas it is often argued that the patient's preferences and goals should be the focus of end-of-life health care, correct interpretation of such preferences and goals and adequate inclusion of them in the decision-making process appears to be difficult. Qualitative research may provide important clues in this respect, as is argued by Martin and colleagues.

Administration of (potentially) life-shortening drugs

Most research in this field focuses on the attitudes of physicians, nurses, patients and the general public towards (the legal status of) euthanasia and physician-assisted suicide. It shows, for instance, that in the United States between approximately 30% and 100% of physicians, patients and the general public, depending on the exact question posed, had positive attitudes towards euthanasia and physician-assisted suicide. In Australia this percentage was the same for physicians, but in surveys among patients and the general public positive attitudes ranged between 65% and 75%. Somewhat more recently, research has been carried out to examine the practice of administrating (potentially) life-shortening drugs. Although there are differences between the countries with regard to the frequency with which euthanasia and physician-assisted suicide are performed, it is important to realize that these interventions occur in a very limited number of deaths. Comparison between Australia, Belgium and the Netherlands showed no evidence of large differences in incidence between countries with more or less restricting

legislations. Studies in the Netherlands and in Oregon, the only two places in the world where there is a 'liberal policy' in combination with policy guidelines to control the practice of physician-assisted death, are consistent in their conclusion that such regulatory systems do not seem to increase the incidence of physician-assistance with death, or have a negative effect on the prudence of the decision-making. It is noticeable that much more research has focused on euthanasia and physician-assisted suicide than on the administration of potentially life-shortening drugs to alleviate pain and symptoms, a practice that occurs much more frequently.

End-of-life decisions for neonates

A field of particular interest in end-of-life decision-making is neonatology. Whereas rapid advances in neonatal care during the past three decades have made survival for severely affected newborns much more likely, almost all clinicians caring for infants have to deal with questions about the appropriateness of life-sustaining treatment for extremely pre-term infants or infants with very serious congenital anomalies. In their paper, Meadow and Lantos point out that decision-makers in neonatal intensive care cannot avoid the probabilistic aspects of disease and illness. Reliable prognostication is, they argue, a very important aspect of adequate decision-making, and especially studies on the (predictors of) long-term morbidity of affected newborns should be part of the research agenda. This also applies to searching for pathways to achieve the greatest possible common ethical grounds in the decision-making, as is stated by Kollée. Insight into other than the purely medical aspects of end-of-life decision-making, such as ethical, cultural, legal, historical and many other aspects, can be gained from international comparative studies, such as the landmark project presented in this volume by Marina Cuttini on behalf of the EURONIC Study Group.

End-of-life decisions for patients with dementia

Meier's paper shows that patients with dementia are a specific group with specific problems concerning end-of-life care and research methodology in this field. Important characteristics are that dementia causes a myriad of suffering, not only for patients but also for family and care-givers, and that patients are incompetent, especially in the later stages of the disease, and cannot express their symptoms. This can result in insufficient palliative care. Finally, the prognosis of patients with dementia is often uncertain, which may lead to doubts about the appropriate goals of medical care. In his contribution, Ribbe focuses on end-of-life decisions for patients with dementia. Although there has been limited research on this topic, the withdrawing or withholding of treatment, such as antibiotics for pneumonia and the artificial administration of food or fluids, seems to be relatively common in this patient group. End-of-life care for demented patients could benefit from research on determination of the important sources of suffering for these patients, their prognosis and the methods of decision-making. Other important issues that need to be studied are medical interventions,

such as the implementation of specific palliative care approaches, and the development and implementation of guidelines for decision-making.

Framework for future research

Descriptive and explanatory studies

Most studies on palliative care and medical end-of-life decision-making focus on the very terminal stage of the disease. However, in many diseases this terminal stage is preceded by a period during which the physician and, usually somewhat later, the patient are already certain that the disease will be fatal in the foreseeable future. This results in a process in which patients gradually disengage from their routine daily responsibilities and gradually redefine their goals. Medicine and health care can naturally follow and support this process, as is illustrated in the Figure.

Often there is no single moment of transition between life-prolonging treatment and palliative care. For instance, doctor and patient may decide against chemotherapy or surgery, but agree about the use of antibiotics in case of pneumonia, or continued

Time	Patient perspective	Treatment goals and choices
Birth		
↓	full life	All medical interventions aim at prolonging life or improving quality of life.
Transition 1		
↓	incurable disease, quality of life fair-good	Some options to prolong life are not used, for instance, early detection of new diseases, chemotherapy. Chronic disease and life threatening complications are treated.
Transition 2		
↓	incurable disease, quality of life poor	Burdensome treatment will be worse than current life. Life-threatening complications may not be treated (antibiotics, treatment at ICU), tube feeding may be withheld or withdrawn.
Transition 3		
↓	death better than life	Decision that death is better than current life. Withholding or withdrawing life-prolonging treatment, increasing opioids, physician-assisted death.
Death		
↓		Care for relatives and friends
Bereavement		

Figure.

mechanical ventilation. There is very little empirical information about these transitions from the perspective of the patient and the physician, or their practical consequences. This means that there is an urgent need for follow-up studies that document these processes in an early stage, when death may still seem far away, but inevitable. These studies should focus on the determinants of the patient's experiences of the quality of the dying process, the contribution of health care and the determinants of the medical decisions taken during that period, often combining quantitative and qualitative approaches. In addition to these patient-oriented studies, there is a need for more large scale epidemiological studies, describing where and how patients die, what kind of health care they receive at the end of life and what kind of medical end-of-life decisions may have been involved. More basic biomedical research could also have important contributions by improving our understanding of dying and death as a biological process.

Intervention research

There is already a certain tradition in clinical intervention research aimed at relieving specific symptoms, such as pain, bowel obstruction and anorexia. However, there is certainly room for more research in this area, and priorities may be guided by better knowledge of the frequency of specific symptoms and complaints during the terminal phase of life. In addition to cancer, AIDS and neuromuscular diseases, many other diseases, such as COPD, chronic heart failure and dementia, deserve attention. Another type of intervention research focuses on the decision processes described earlier. Medical decision-making at the end of life differs in many respects from standard clinical decision-making, because prolonging life will loose its paramount importance as outcome criterion, leaving even more room for patient preferences with respect to quality of life. This shift of perspective in an already emotional period demands specific skills of the physician and nursing staff, to enable them to arrive at decisions that serve the best interest of the patient and the family and friends. Especially decisions to refrain from further life-prolonging treatment, but also the other decisions mentioned in Table 2, deserve more research. Interventions to improve the physician-patient communication and the decision-making process might include specific training of physicians, developing guidelines, creating consultation possibilities, et cetera. Finally, interventions in the health care system, such as terminal care units in nursing homes, outreaching consultation teams, paid care leave for a member of the family, should be evaluated.

International comparisons

Opinions and practices with respect to death and dying may vary between societies, due to cultural, political, legal and health care differences. This probably also applies to medical practice during the terminal phase of life. Despite the overwhelming similarity in clinical approaches throughout the western world, due to universally applicable technologies and research methods, there is much less consensus about the role of medical care in the terminal phase of life. There probably is consensus that medical

care has a role in alleviating suffering, and that patients may refuse life prolonging treatment, but the resulting practice may differ from country to country. The prevalences of decisions to withhold or withdraw life-prolonging treatment and decisions to alleviate pain with a possible life-shortening effect may differ. Physician-assistance with suicide and euthanasia, although illegal, are probably practiced in every country, but the frequencies and reasons for doing so may differ. Health care provisions for terminally ill patients, as well as the availability of other means to create the best conditions for a 'good' death may also differ. Therefore, there is considerable opportunity for international comparative studies in all areas in which variations may be expected. International comparative studies can be important to determine which approaches provide a better quality in the dying process. This will range from the perception of a 'good' death and the prerequisite conditions, the availability of different types of health care provisions for terminally ill patients, such as palliative services and professional home care, and the frequency of the different types of medical decisions that are made during the terminal stage of life. This requires the development and the use of standardized questionnaires and measurement instruments, as well as uniform study designs, in order to identify differences in experiences, opinions and practices and the possible cultural, social, judicial, political and health care determinants.

Priorities in the research agenda

Research on end-of-life health care includes end-of-life decision-making as well as the evaluation of specific clinical palliative interventions. The latter is an already more or less established research domain. In end-of-life decision-making, information about the effectiveness of palliative interventions is one of the elements in the clinical decision process. In summary, three main priorities for research on end-of-life decision-making can be identified. The first is to study the natural history of dying and the determinants of a 'good' death as perceived by patient and relatives. Such studies would include the variables mentioned in Table 1, and should preferably be follow-up studies, monitoring at least the last six months of life and taking into account the sequence of events and the transitions that take place, not only in patient experiences and attitudes, but also in the medical decisions, as illustrated in the Figure. The second priority is to perform international comparative studies using uniform designs and measurement instruments, in order to identify possible differences in the frequencies of end-of-life decisions and to relate these differences to patient and physician characteristics, and especially to relevant characteristics of the health care system, attitudes of the medical professionals and the public, the legal system, et cetera. This will form a starting point for more in-depth studies. For patient follow-up studies and for epidemiological studies, a core set of research instruments and outcome measures is indispensable. For both types of studies instruments have already been developed, but for many aspects of study these instruments may have to be refined or new ones developed. This issue could be defined as the third research priority.

It is obvious that much effort is still required to establish a firm body of scientific knowledge that will contribute to the quality of medical care in the terminal stage of life for many people in many countries. This volume and the work of the conference might represent a small step towards that ultimate goal.

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