QUALITY COMMUNICATION ABOUT END-OF-LIFE DECISIONS IN COMPTETENT PATIENTS WHO WISH TO DIE AT HOME.

GUIDELINES FOR GENERAL PRACTITIONERS

Final report for the general public of the project 'Medical and ethical quality care when taking end-of-life decisions: development of a protocol for first-line health care.

Reginald Deschepper[1/2], Robert Vander Stichele[1/3], Freddy Mortier[1],

Luc Deliens[2/5]

With the collaboration of

Jan L. Bernheim[2], Lucas Ceulemans[3], Els De Keyser[2/4], Greta Van Der Kelen[2], Lieve Van Den Block[2]

Translation: Jan L. Bernheim

[1] Centrum voor Milieufilosofie en Bio-ethiek, Universiteit Gent
[2] Onderzoeksgroep Zorg rond het Levenseinde/Vakgroep Medische Sociologie, Vrije Universiteit Brussel
[3] Wetenschappelijke Vereniging van Vlaamse Huisartsen, Berchem
[4] Vakgroep Metajuridica, Vrije Universiteit Brussel
[5] EMGO-instituut, Afdeling Sociale Geneeskunde, VU medisch centrum, Amsterdam

Contents

1. Introduction.

The new law on euthanasia raises questions on patient-physician communication. Must the physician raise the issue himself, or wait for the patient to ask questions? In fact, euthanasia is only one of the several possible end-of-life decisions (ELD) which involve difficult choices[1]. Other ELD include the forfeiting or discontinuing of life-prolonging treatments and the intensification of pain and symptom treatment, both of which may similarly shorten life. Such decisions obviously require due regard for the wishes and opinions of patients. Discussions of these subjects are delicate for both patients and physicians[2]. Causes for this difficulty include the lack (until recently) of training in communication about the end of life. Physicians have little to fall back on when having to talk to people at the end of their lives. On the other hand, caregivers are ever more often confronted with articulate patients, who demand to themselves determine how they will die. Thus, there is a clear need for guidelines for communicating prudently about wishes and questions at the end of life.
This what we set out to do. We propose a number of practical recommendations for how to deal with such situations. These guidelines are meant both to facilitate end-of-life decisions and to help physicians to act in conformity with ethical and legal norms.

The development of such guidelines has been attempted in other countries. Most apply to distinct end-of-life decisions such as euthanasia or treatment discontinuation[3-5]. Because these guidelines are tied to local law and deontology, they are of limited use for Flanders (or Belgium).

The interuniversitary and multidisciplinary team having developed the present guidelines included general practitioners, sociologists, an ethicist, an anthropologist and an oncologist. The present guidelines aim at, first, optimal integral end-of-life care, and, second, the communication between the involved parties that is a prerequisite for the former. The guidelines are meant for general practitioners, and deal with adults who wish to die at home. They may also be of use to other caregivers (nurses, specialists, chaplains and moral counselors etc...), and to any person in any capacity involved in end-of-life care.
We have as much as possible avoided medical jargon, so that also the lay person can here learn what to expect from a family physician, and what not.

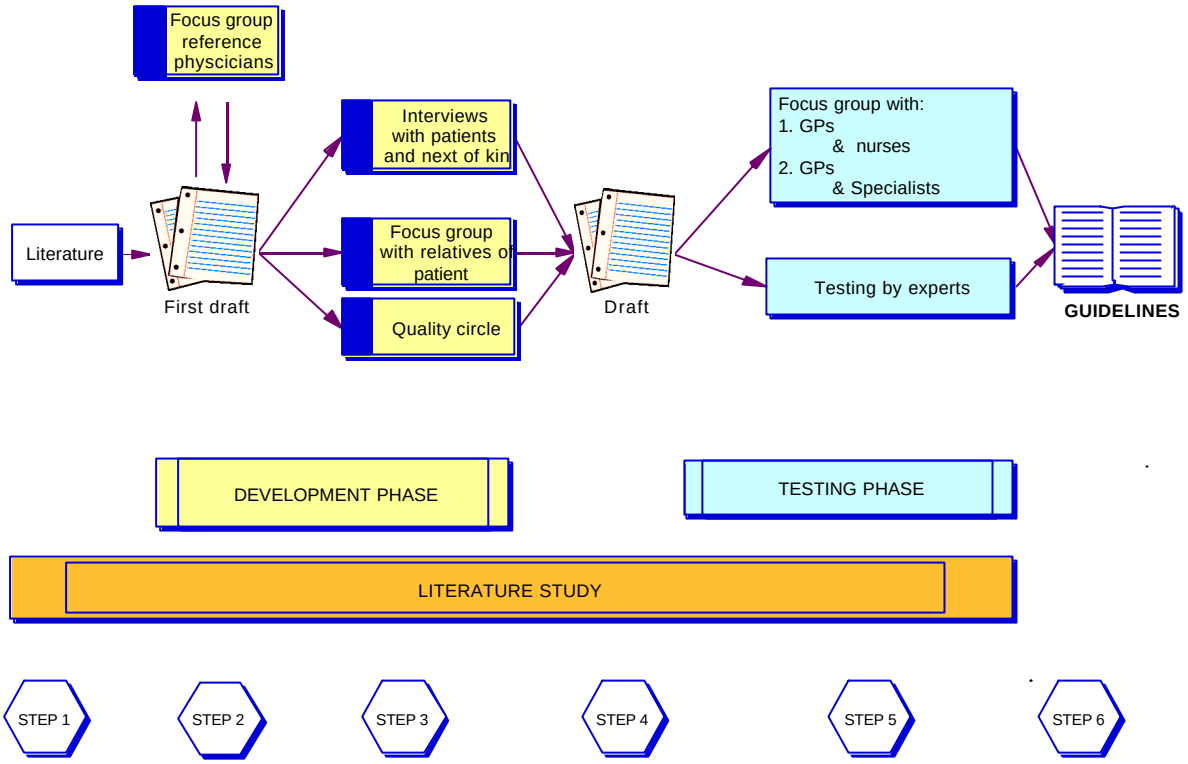
2. Methods

2.1 General procedure

Usually, the drafters of clinical guidelines largely make use of medical evidence. For the end of life, we had to in addition take into account the views and wishes of the participants (patients, physicians, relatives, nurses...). The main ingredients for the guidelines came from two sources: scientific literature and the needs and wishes of the participants. The latter were identified by the gathering of qualitative research data.

In developing the guidelines we followed a step-by-step procedure (fig.1). First came a literature study, which led to a first draft of guidelines consisting of loosely interconnected quotations and ideas.

Figure 1 Outline of procedure



This first draft was submitted to a focus group of GPs who were as reference physicians involved in palliative care. The aims were to identify the priority themes and the most desirable structure (step 2)..
In a next step, using qualitative methods (interviews, focus group and quality circle), we obtained data on the views of the diverse protoginists. This was necessary because most of the available literature was foreign, and therefore based on different contexts of law, organisation of health care and communication between patient and physician.[6].
Combining the literature and qualitative research data, we drafted considerably revised and complemented guidelines (step 4). This second draft was tested by submission to two focus groups, one of GPs and specialists, and another of GPs and nurses. This draft was also sent to a number of experts in Belgium and the Netherlands, with a request to review and comment one or more of the chapters (step 5).

The guidelines were again revised taking into account the comments of the focus groups and the experts (step 6).

Throughout the development and testing of the guidelines, as quality assurance, several forms of consultation were employed. On the one hand, there were regular meetings between investigators and promoters, and on the other hand there was a spounding board with diverse persons having extensive field experience in end-of-life care. This sounding board discussed design, planning and results, and gave additional advice.

2.2 Data from the literature

The primary literature for the guidelines came from a PubMed search (the principal databank for medical journal articles), using the following key words: 'Palliative Care'[MESH] OR 'Terminal Care'[MESH] OR 'Suicide, Assited'[MESH] OR 'end of life'. These results served as a basis for more detailed searches (e.g. by limiting to 'guidelines', or using additional *sear*ch terms such as 'communication'). We made a selection on the basis of the abstract (when available), and obtained copies of the selected articles.

In addition, we searched the web using more general databanks such as EBSCO and catalogs of university libraries, and made use of the links that were available on many websites. Relevant documents were copied or ordered.

The collected literature was read by the different investigators. Each article received a card on which he following characteristics were noted: relevance (ranging from 1=low to 5=very high relevance), the setting of the research, the type of ELD, and the principal findings that were useful for the guidelines. Texts with relevance 4 or 5 served for the guidelines.

2.3 Qualitative Research

Literature data being insufficient, empirical research was undertaken with the following aims:

a) in the design phase:
- filling the gaps left by the literature in the first draft.
- optimally integrating the views of the participants (GPs, patients, nurses etc...)
- customising the guidelines to the specifically Belgian context.

b) in the testing phase: checking of the guidelines for deficiencies by the diverse relevant disciplines and expertises (palliative care, oncology, law, spiritual care etc...)

A qualitative research methodology was chosen because we were dealing with:
- the first exploration of a complex and delicate subject
- obtaining in-depth data
- understanding the views and perceptions of the diverse participants

2.3.1 Research methods utilised

Several data-collection methods are available in qualitative research. In the development phase, we made use of focus groups, interviews and a quality circle. For the testing, we used focus groups and written evaluation by experts

Focus groups

A focus group is a proven method in qualitative research in which a number of people (preferably 8 to 12) meet to discuss a subject.. An advantage of focus groups is that, contrary to interviews, group dynamics contribute to the expression of personal views and opinions. The reactions of other participants in turn elicit further discussion.
We used focus groups to learn the views of reference physicians[1], 'ordinary' GPs, specialists, nurses and relatives of patients. Also in the testing phase of the guidelines we organised two focus groups, one with GPs and nurses, and the other with GPs and specialists.

Interviews

[1] Reference physicians are GPs with post-graduate training in palliative care who advise colleagues.

Patients are central in this research. To integrate their views into the guidelines, we organised semi-structured interviews with pre-terminal patients and, where possible, with their next of kin. When possible, each patient or next of kin was interviewed a second time after three months. '.Terminal', always a difficult definition, was here 'a life expectancy of no more than about 3 months'.

Taking into account the vulnerability of these persons, a semi-structured format was chosen, in wich the interviewer used a list of topics, but the interviewees were left all latitude to tell 'their own story'.

Whenever possible, patients were interviewed in the presence of their closest relative, but the patient's views were always central. After three months, when possible, a second similar interview was taken. If the patient had died, the relative was interviewed a second time. The first interview dealt with the views, wishes, experiences and expectations of the patient. The second interview was mainly a review of the past months. What happened? Were expectations met? What was good and what should have been better? The focus was on the end-of-life decisions which had been taken.

The delicate nature of interviews with patients at the end of life requires several precautions. Only patients informed about their diagnosis and prognosis were interviewed, overly confronting questions were avoided etc. The study protocol with the interview schedule was approved by the Ethical Committe of the Ghent University Hospital.

Quality circle
The method of the quality circle involves the meeting of the actors in a process in order to on a basis of equality seek solutions to the problems they encounter. In this study it consisted of GPs, nurses, a palliative care volunteer and relatives of patients. The circle met four times, and discussed bottlenecks and solutions relative to communication about the end of life. .

Testing by experts
As a last verification, one or more themes of the guidelines were critically reviewed by 33 Dutch and Belgian experts belonging to various disciplines and domains of expertise, including law, ethics,communication, general practice, oncology, palliative care, nursing and secular or religious moral counselling. Both scientists and practitioners were addressed. They provided written comments to the investigators.

2.3.2 Study schedule and participants

The collection of the qualitative data spanned two years (from February 2001 till February 2003). Qualitative data related on the one hand to the development of the guidelines, and on the other to its testing.

The first 18 months were spent developing the guidelines. The general research questions were:

- Which themes must be covered by the guidelines? Where do the data from the literature need to be complemented?
- Can the literature data, most of which were collected in other settings or contexts (e.g. foreign hospitals) be confirmed, or are there contradictions or incompatibilities with the Belgian situations to which the guidelines relate?
- What is to be the format of the guidelines? What template for the different themes is the most user-friendly for GPs?

The last 6 months were used to test the guidelines. The following questions were central:

- Are any errors or deficiencies left?
- Are the recommendations realistic and practically applicable?
- Does the implementation of the guidelines require additional conditions?

Though the patient-physician relationship is central, we tried to integrate the views of all protagonists. Besides patients and GPs (including GPs with special training in palliative care and/or euthanasia), also relatives, specialists, nurses, spiritual caregivers and several experts (lawyers, ethicists, oncologists,...) participated in this research (see Table 1).
In the development phase, this multi-pronged approach (triangulation[2]) aimed at getting the broadest possible view on the themes, obstacles and possible solutions.

In the testing phase, the aim was to have the diverse disciplins detect deficiencies, make suggestions and identify additional conditions of application. The broad testing had to ensure that the guidelines were acceptable not only by GPs, but also by the other involved actors. The table below indicates the persons having been involved in the development and testing phases of the guidelines.

Table 1 Persons involved in the development and testing phases of the guidelines

Participants	Development phase	Testing phase	Methods
Reference physicians	8	-	Focus group (N=8)
Terminal patients	17	-	Interviews (N=17)
Relatives/next of kin	17	-	Interviews (N=8), Focus group (N=7), Quality circle (N=2)
GPs	5	15	Quality circle (N=5), Focus group (N=12), Testing experts (N=3)
Palliatieve care volunteer	1	-	Quality circle (N= 1)
Specialists	-	10	Focus group (N=3) Testing experts (N=7)
Nurses	2	11	Quality circle (N=2), Focus group (N=6), Testing experts (N=5)
Spiritual caregivers	-	3	Testing experts (N=3)
Psychologists	1	1	Quality circle (N= 1), Testing experts (N=1)
Lawyers	-	2	Testing experts (N=2)
Ethicists	-	10	Testing experts (N=10)
SCEN-physicians[3]	-	8	Testing experts (N=8)

[2] Triangulation: method in which one attempts to approach a phenomenon from diverse perspectives, i.e. by diverse actors and/or on the basis of different types of data collection. This method is one of the tenets of qualitative research to avoid limited-perspective bias.
[3] SCEN is the abbreviation of 'Steun en Consultatie bij Euthanasie in Nederland' (Support and Consultancy for Euthanasia in The netherlands). These physicians advise their colleagues re euthanasia.

Depending on the participants and the specific goals, we used different types of data collection: interviews, focus groups and quality circle. For testing, we also used the written replies of experts (Testing experts)

2.3.3 Data analysis

All interviews and meetings of the focus groups were audiotaped and completely transcribed. We used NVivo software to analyse the texts. The analysis was based on grounded theory[9,10], in which relevant themes (also called categories) were identified and compared. Three investigators independently abstracted the themes that were present.

The written comments of the experts were synthesised into a report in which all suggestions for modifications were arranged by theme. The guidelines were revised accordingly.

3. Content and scope of the guidelines

The focus group with reference physicians suggested four cardinal themes which were to become the backbone of the guidelines: truthtelling, exploration of the patient's wishes regarding the end of life, disproportionate interventions with patients having a poor prognosis and dealing with requests for euthanasia in the last phase of life.

The first theme, *truthtelling*, involves the communication and discussion of a (fatal) diagnosis and prognosis, and the inevitability of incumbent death. This is crucial for patient autonomy. The central concerns are the patient's wish for information and his toleration of bad news. This implies that the physician should as soon as possible discuss with the patient to what extent he wishes to be informed about 'bad news'.[11]. In a strict sense, truthtelling is not part of end-of-life care, since it belongs with a much earlier phase of disease. However, because the truth is a pre-condition for the other themes, truthtelling needed to be dealt with.

The second theme, *exploration of the patient's wishes regarding the end of life*, concerns covenants with the patient about how, when the time comes, he wishes to die, and what he wants to avoid. Also this theme is preferably dealt with well before the terminal phase, and certainly at a time when the patient is fully competent.

The third theme is about *disproportionate interventions with patients having a poor prognosis*. How must a GP deal with patients' or relatives' requests to start or continue treatments whose burdens are expected to outweigh the benefits?

The fourth theme addresses requests for *life shortening with lethal drugs* (euthanasia and physician-assisted suicide). How does one deal within the law with a request for life termination? What must the physician do if he cannot for personal philosophical reasons satisfy such a request? Can a physician himself bring up the subject of euthanasia?

Formating of the guidelines
Each theme is formated according to a defined template providing first a context and definitions and then the objectives of the theme and the role of the GP. After a brief reminder of the *legal requirement and deontological precepts* follow the actual practical recommendations. Next attention is drawn to *frequent pitfalls.* An example of the latter is deferring discussions with the patient so that he can no longer express his wishes or make arrangements for an imminent death.

Each theme is supplemented with a checklist allowing the physician a control for omissions. The first list concerns quality practice aiming at optimal treatment of the patient. The second covers the physician's liability and accountability (e.g. re the consultation of another physician and the keeping of records).

Finally, a recapitulative scheme of the theme is given.

The four themes are preceded by an introduction emphasising that the guidelines are not to be seen as a strict protocol, but rather as a form of support leaving all due space for contextual considerations and for weighting pros and cons of different courses of action. This is followed by a glossary of terms, many of which may have different meanings for different people (e.g. the term 'euthanasia').

After the four principal themes, some specific problems in end-of-life care dealt with: the administration of fluids and nutrition, the continuity of care by the GP, and the use of drugs for euthanasia.

Besides a printed volume, an electronic version of the guidelines will be available for internet consultation (www.zorgleidraad.be). The advantage of the latter is offering layered information in the form of general guidelines with hyperlinks to more detailed information. These links also connect with the original sources of the recommendations or with other relevant sites.

4. Discussion and conclusions

Talking with patients about end-of-life decisions is a sensitive matter, often meeting with some reluctance. How it is to be done is not always clear, and will vary from case to case. Guidelines on communication and information therefore meet an urgent need. After a patient has died, also the physician has to go through a coping process. He may then doubt the correctness and adequacy of his interventions. Feelings of uncertainty may be exacerbated by societal developments regarding patient autonomy and legislation on euthanasia. At any rate, life termination can only be preceded by thorough information on prognosis and the available alternatives, and by due consultation.
Currently, physicians must often take decisions on the basis of what they intuitively deem the best for the patient. The availability of guidelines on communication may offer them support, and contribute to optimising the quality of the end of life.

References

1. Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichelen R, Vanoverloop J *et al*. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet* 2000;**356**:1806-11.

2. Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch.Intern.Med.* 2000;**160**:1690-6.

3. Hastings Centre. Guidelines on the termination of life-sustaining treatment and the care of the dying. Bloomington: Indiana Press, 1987.

4. Buckman R. Who's for CPR? *J.R.Coll.Physicians Lond* 1992;**26**:461-2.

5. Besse TC, Hesselman GM. Richtlijn euthanasie. In Willems-Bootsma SW, ed. *Oncologieboek. Deel 2: richtlijnen palliatieve zorg*, Utrecht: Integraal Kankercentrum, 2001.

6. Guidelines on the termination of life-sustaining treatment and the care of the dying. Bloomington: Indiana Press, 1987.

7. British Medical Association. Withholding and withdrawing life prolonging treatment: guidance for decision making. 2001.

8. Deliens L,.van der Wal G. Overeenkomsten en verschillen in de euthanasiewetten van België en Nederland. *Ned.Tijdschr.Geneeskd.* 2003;**147**:169-74.

9. Strauss A, Corbin J. Basics of qualitative research: techniques and procedures for developing grounded theory. Thousand Oaks: Sage Publications, 1998.

10. Miles BM, Huberman AM. Qualitative analysis: an expanded sourcebook. London: Sage, 2000.

11. Bernheim J. Het doktersdilemma tussen patiëntenautonomie en artsenbeneficiëntie bij het levenseinde. II Een arts-patiënt informatiecontract (ICC) als procedureel-ethische oplossing. In Deliens L, Mortier F, eds. *Het levenseinde in Vlaanderen*, 2001.