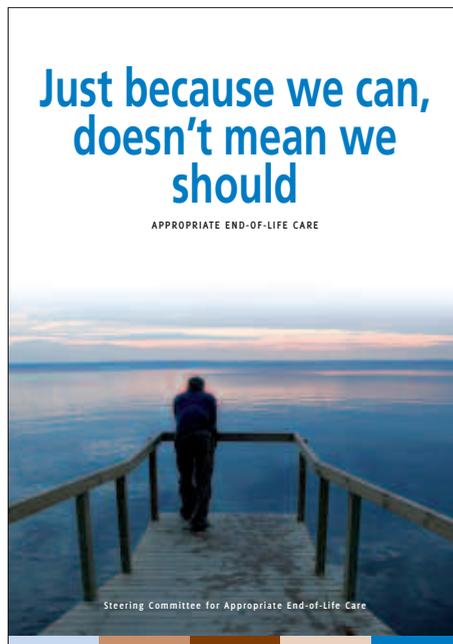


Just because we can, doesn't mean we should

APPROPRIATE END-OF-LIFE CARE



Steering Committee for Appropriate End-of-Life Care

Publication details

In April 2013, the Royal Dutch Medical Association (KNMG, a federation of medical practitioners' professional associations) instituted a steering committee to promote the provision of appropriate end-of-life care. Representation on this Steering Committee includes general practitioners, medical specialists, elderly care physicians, nurses, and patient/senior citizens' organisations:

- G. (Gerrit) van der Wal, MD, PhD, former Inspector-General of the Netherlands Healthcare Inspectorate (IGZ), chair of the Steering Committee;
- J. (Jettie) Bont, MD, PhD, general practitioner, Hilversum;
- L. (Lucas) Koch, MD, general practitioner and member of academic staff at the Dutch College of General Practitioners (NHG);
- J. (Job) Kievit, MD, PhD, NVVH, surgeon and professor of healthcare quality at Leiden University Medical Center
- S.E.J.A. (Sophia) de Rooij, MD, PhD, NIV, professor of internal medicine (specialising in geriatric medicine) at AMC Amsterdam and UMC Groningen;
- M.G.M. (Marcel) Olde Rikkert, MD, PhD, NVKG, professor of geriatrics, Geriatrics department/ Radboud Alzheimer Centre, Radboud UMC, Nijmegen;
- P.E.J. (Petra) van Pol, MD, NVVC, cardiologist, Rijnland hospital;
- P.C. (Peter) Huijgens, MD, PhD, emeritus professor of haematology, VUmc, Director of IKNL;
- J.C.M. (Jan) Lavrijsen, MD, PhD, Verenso, elderly care physician, senior research specialist (geriatric medicine) and programme manager at the Complex and Palliative Care department, Primary Healthcare, Radboud UMC;
- J.H. (Henk) Bakker MHA, chair of V&VN;
- M. L. (Marjolein) van Meggelen, MZO, networking consultant at Comprehensive Cancer Centre the Netherlands, V&VN Palliative Care department;
- W. (Wilna) Wind, Director of the Federation of Patients and Consumer Organisations in the Netherlands (NPCF);
- M.H.P. (Anemone) Bögels, MBA, Director of Leven met Kanker (Living with Cancer, formerly the Dutch Federation of Cancer Patient Organisations);
- A.A.M. (Ans) Willemsse-van der Ploeg, Union of Catholic Senior Citizens' Associations (Unie KBO);
- Y.M. (Yvonne) Heygele, consultant at the Network of Elderly Migrants' Organisations (NOOM).

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Contact information

KNMG: PO Box 20051 3502 LB Utrecht The Netherlands - +31(0)30 282 38 00 - www.knmg.nl

Appropriate end-of-life care online: www.knmg.nl/passendezorg

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Summary

The powers of modern medicine are growing. Whereas a cancer diagnosis once almost certainly meant a death sentence, nowadays it is possible to live on for years, and sometimes even be cured. However, these improvements in treating illness and prolonging life also have a flipside. Some treatments are extremely invasive, while others have severe side effects and can have damaging consequences. When are medical interventions no longer useful, and when are other types of care more appropriate? Do doctors and patients stop to consider the patient's quality of life after a planned course of treatment? Do they discuss the issues of whether the patient even wants the treatment, or whether it is realistic? Do they talk about what the patient deems genuinely important, and about what type of care is best suited to achieving their wishes?

These are subjects that care providers should discuss at an early stage with patients who can be assumed to be approaching death due to their illness or vulnerable state. Because care can only be considered appropriate if it is in line with the wishes of the patient. This means that patients must be given the opportunity to consider for themselves whether they wish to continue with medical treatment, or to decide against it and follow a different path – one that may create room for acceptance, closure, saying goodbye, and properly targeted palliative or other care.

Although everybody agrees, in practice these discussions are still too seldom carried out. What is stopping us? And how can we ensure that people in the Netherlands receive appropriate care during the final stages of their lives (i.e. the care that best reflects their wishes)? Patient, doctor, nursing and senior citizens' associations have researched this issue, and present their findings in this report titled 'Just because we can, doesn't mean we should: Appropriate end-of-life care.' The report outlines mechanisms that can sometimes lead to excessively prolonged treatment, with too little focus on quality of life and the choices that healthcare providers can make together with patients when facing the final stage of their lives. The report also proposes measures for ensuring that the most appropriate care is provided during this time. In this respect, the most important instruction to care providers is: treat the patient, not the disease. Do not focus solely on the remaining medical possibilities, and dare to be honest about the results. Question thoroughly, and listen to what the patient wants. The important task for patients and their next of kin is to think about their prospects and possibilities, ask lots of questions, and express their

wishes and expectations. This will allow each of the organisations involved to support these common goals with their own objectives and capacities in mind.

Why do we just treat, treat, treat? Mechanisms

Why do doctors and patients often pursue treatment for too long? The causes can be found at various levels: in society, in the healthcare system, at the doctor's surgery and in the home. This report discusses a range of causes, the most important of which are outlined below.

Talking about death is unusual. Although we all die, few Dutch people talk to their next of kin and care providers about their preferences for treatment (including the absence or cessation thereof) during the final stages of their lives. Nor is it customary to document any wishes regarding the end of one's life. This is reflected in day-to-day care.

'Never give up' is the default attitude in our society. Accepting or submitting to illness and imminent death is not common – fighting is. Family members, friends and colleagues encourage patients to fight for their life, and to clutch at straws. This is reflected in the tendency of doctors and patients to 'keep on going', whatever happens.

Action is better than inaction. Doctors are often stuck in 'treatment mode'. They are trained to cure people, and opting for alternative (or no) treatment can feel like failure. Some doctors also have trouble 'letting go' of treatment, because it feels like relinquishing control. Doctors prefer not to raise the topic of ceasing or foregoing treatment ('inaction'), because they do not wish to deny their patients hope for recovery. In turn, patients often give their doctors an overly positive impression of their condition and the effects of treatment, in the hope of receiving further treatment. This creates what is sometimes referred to as the 'coalition of hope'.

Guidelines focus on 'action'. Many guidelines, for example, do not cater for the elderly or patients with multiple illnesses, and devote too little attention to the option of foregoing treatment. The 'recommended' treatment in the guidelines takes too little account of the effects on the health and well-being of the patient, as well as on the quality of their life and death, despite these being extremely important considerations for the patient. There is also a lack of awareness regarding the guidelines for palliative care. All of the above results in treatment choices that focus primarily on the duration of life (or on extending it), and not quality of life.

Education focuses on 'action'. Training programmes for doctors, nurses and other carers devote relatively little attention to competencies surrounding the consideration (or rejection) of treatment options. Hospital culture – which is primarily curative – also plays a role here. The hectic nature of medical practice often makes it difficult to actually apply lessons learned in communication and shared decision-making. Workloads are high, and the education requirement to perform enough treatments takes priority. Palliative care is also a rare element in training programmes, as is the cultivation of knowledge and expertise on the elderly.

Payment for treatment. In the current healthcare system, healthcare institutions and care providers (in hospitals in particular) are paid for each act of treatment performed. This therefore creates a financial incentive to perform treatments that can be declared, instead of deciding against further treatment.

With so many care providers and so little coordination, who is responsible? Care and treatment of patients in the final stages of their lives often involves care providers from a range of organisations and specialisations. This can make coordination difficult, especially when it comes to ceasing treatment, and especially now that more and more care providers are working part-time.

No holistic view of the patient. The number of (ultra-)specialised doctors and nurses is on the rise. Although this leads to more specific and effective treatments, it also increases the likelihood of 'tunnel vision' on one particular condition, and a lack of attention for the quality of the patient's life 'as a whole'.

Medical perspectives often still take priority when it comes to making treatment decisions. In hospitals, doctors often decide on the course of treatment, which can cause other aspects that are relevant to the patient (such as well-being and social/cultural aspects) to be overlooked. This approach also takes too little account of the patient's own wishes.

Palliative care comes too late. Palliative care (such as pain relief, help with mental or social issues or nursing support) often only reaches patients once curative treatment options have been exhausted. Patients often refuse palliative care because it makes them feel as though they have been 'given up on'.

Discussing possible refusal of treatment is more time-consuming. It is often faster and easier for healthcare professionals to make a concrete treatment proposal than to explain why recovery is no longer an option, as well as giving an overview of what the patient can expect during their remaining weeks or months of life. High

workloads also play a role here.

Talking is hard. These types of discussions require healthcare professionals to have skills that are not a compulsory part of basic degree programmes. What is the best way to respond to sadness, powerlessness, disappointment, anger, frustration, fear or hope? Such an intensive process demands more than simply the ability to deliver bad news.

What should we tell patients? Doctors often find it hard to decide how much information to share with patients. Should doctors share all the information they have, or limit themselves to the options they consider worthwhile? What will be of greatest help to the patient?

At the same time, patient-oriented shared decision-making must not give patients and their families the feeling that they are medically responsible for deciding whether to proceed with treatment, and if so, what kind.

The great unknown: patients' culture and outlook on life influences their perception of death. Decisions regarding whether or not to proceed with treatment are inextricably linked with the beliefs about life and death held by the patient, their family members, care providers and society. Differing beliefs about pain relief, for example, can complicate discussions regarding appropriate end-of-life care. This will become an increasingly relevant factor in the future.

People document their wishes and preferences regarding end-of-life care too late, and often not thoroughly enough. This sometimes means that healthcare professionals must carry out a particular intervention, even if the chances of success are small. But even if a patient has a clearly documented prohibition of treatment, care providers sometimes decide to proceed with a certain treatment nevertheless.

What can we do? Measures

The report outlines twenty-three measures that can help to break through these mechanisms and ensure appropriate care. The organisations who contributed to this report first wish to see progress on the five points listed below.

1. Make end-of-life acceptance and talking about death more common

The organisations aim to create more opportunities in society for the acceptance of illness and death. The media can play a major role in this respect. Discussions need to become more commonplace about the end of life, about our wishes and

expectations, and about options other than continued treatment. Adjusting people's (often high) expectations from modern medicine may also help in this regard. After all, the final stages of life are not only about maximum healthcare (and prolongation of life), but about the most appropriate care, quality of life and well-being.

One tool for facilitating this discussion between patients, their next of kin and care providers is the brochure titled 'Start talking about the end of your life early' (*Spreek op tijd over uw levenseinde*) issued by associations for patients, senior citizens and healthcare providers. There is also a version available for doctors. The Dutch College of General Practitioners (NHG) and the National Society of General Practitioners (LHV) will distribute more information for patients via www.thuisarts.nl. They are also considering adding short videos to www.thuisarts.nl for patients who have difficulty speaking Dutch.

Many people also find it quite hard to officially document their wishes concerning the final stage of their lives. Options are now being considered for easily accessible neutral declarations of intent and 'do not resuscitate' tokens. The Union of Catholic Senior Citizens' Associations (Unie KBO) and the Protestant-Christian Senior Citizens' Association (PCOB) have been actively involved in the development of a neutral do-not-resuscitate token, in conjunction with other organisations. Facilitators are also used to help get the discussion going during meetings regarding end-of-life matters. The Network of Elderly Migrants' Organisations (NOOM) has already developed methods for assisting elderly migrants in formulating their wishes for the future. The topic of 'speaking about end-of-life care' will be included in this process. NOOM also provides ad-hoc training courses for care providers on the subject of diversity during the final stages of life. In doing so, these organisations collaborate closely with one another (as with other interventions) to support and promote discussion of the topic at an early stage.

They foster an inclusive approach to the subject, as well as consideration for the values associated with life outlook and spiritual care. For our aim is to enable a productive dialogue between patients and care providers who, based on their own cultural and personal beliefs, each have their own ideas concerning end-of-life care. Organisations for patients and senior citizens (including elderly migrants) wish to create good-quality information and teaching materials. This subject should also become a standard component of professional development courses for care providers, including how to deal with differences in the perception of illness, old age and death. It is important that patients, informal carers and any experts from relevant communities be included in this process.

2. Greater clarity on patients' wishes and improved coordination, including handover

Coordination among care providers can be improved. It is important for GPs to talk to

vulnerable elderly patients and those with life-threatening illnesses early concerning their wishes and expectations during the final stages of their lives (care, well-being, accommodation) and to record them in the patient's file. This will facilitate transfer of information. A National Transmural Agreement (LTA) can help to promote this type of collaboration. One positive initiative in this regard is the plan to expand and amend the GP (NHG) directive for information exchange between GPs and specialists when referring patients and expand information exchange among GPs themselves. Care providers and providers would do well to create a fixed point of contact for patients and their next of kin, and to constantly offer clear information on who is coordinating care and directing treatment. The 'Guide on the division of responsibility and collaboration in healthcare' by the KNMG (among others) also explicitly stipulates this as a standard. The guide received widespread support, however in practice it remains difficult to implement these agreements. Difficulties aside, however, it would help to bring appropriate care a few steps closer.

3. Shared and improved decision-making

Shared decision-making among care providers and patients is one of the most important basic principles for ensuring appropriate care. Although patients decide for themselves, they must be able to weigh up the options with the assistance of care providers. To achieve this, the Netherlands Federation of Medical Specialists and the Federation of Patients and Consumer Organisations in the Netherlands (NPCF) discuss the topics of 'joint decision-making' and 'improved decision-making' during the final stages of life in their project titled 'Deciding Together' (*Samen Beslissen*). The V&VN Dutch Nurses' Association will also devote attention to options that contribute to quality of life during the final stages and making them easier to discuss, as well as to the importance of recording these choices in the patient's file.

It would be beneficial for all hospitals to implement a multidisciplinary consultative team to assist with complex treatment decisions, which should also involve participation by general practitioners, elderly care physicians, nurses and other care providers (e.g. nurses, spiritual counsellors and others). There is still a long way to go in this respect. The V&VN will alert institutional Nursing Advisory Boards (VARs) to the need for multidisciplinary consultative bodies (and participation therein) regarding complex treatment decisions.

Thankfully the focus on clinical reasoning, palliative reasoning, moral deliberation and advance care planning is already growing, especially in the field of geriatric medicine. When being admitted to an institution or during a first-line consultation, care providers ask patients who are nearing the end of their lives more and more often about the kinds of care they still or no longer want, allowing these wishes to be taken into consideration at the outset. This advance care planning model can serve as an example to other care providers and institutions, which should also

include training programmes. The NHG is currently looking at developing courses in advance care planning.

4. Guidelines should be directed not only at ‘action’ but also at ‘inaction’ (alternative action)

When dealing with patients nearing the end of their lives, doctors and nurses should think in terms of scenarios and discuss the possible outcomes with regard to functioning, well-being and quality of life with patients and their next of kin. In addition to checklists, amending guidelines to include the possibility of occasionally deciding against treatment is also especially helpful in this respect. The Federation of Medical Specialists wishes to ensure that the option of ‘alternative action’ be included in current guideline programmes for when treatment objectives are no longer feasible. In illness-related standards, the NHG plans to include an overview of the pros and cons of various treatment options, as well as any associated decision-making tools.

This initiative is supported by the Comprehensive Cancer Centre the Netherlands (IKNL) and the National Health Care Institute (ZiN).

5. Shift the focus of the healthcare system from production to appropriateness

Until recently, doctors could not charge for consultations in which the possibility of foregoing treatment was discussed. In 2014 (partly at the request of the Steering Committee behind this report), it was made possible to charge for an ‘Intensive consultation for the careful consideration of treatment options (190063)’. Medical specialists and hospital administrators now need to work actively on contractual agreements with health insurers regarding ‘intensive consultations’, and their implementation. This will also encourage listening to and making joint decisions with patients.

Open letter to an oncologist: 'Every day counts, but quality is a must'

General practitioner Hans van den Bosch suffered from intravascular large B-cell lymphoma (ILBCL). He wrote an open letter to his oncologist, arguing against oncological treatments that are applied without the patient knowing exactly what it is they are opting for, and which can severely affect their quality of life. Although his oncologist saw 'lack of treatment' as a missed opportunity, Van den Bosch decided against treatment in order to retain control of both his life and death. Medisch Contact published the letter. Van den Bosch has since passed away.

Dear H,

I hear your genuine concern, and can feel how much you care: am I really making the right decision? You are afraid that I am throwing away a chance. But there is no need to be afraid. My decision to do so is a very deliberate and well-considered one, because the path to reaping any possible benefits is not my path. When you and I say 'Every day counts', although we are using the same words, we mean two very different things. Your meaning, from your specialist oncology paradigm, is: every day of postponed treatment is one too many. My meaning, from my general paradigm of ongoing patient-oriented care with consideration for context, is: every day that I can enjoy with my loved ones around me is a gift, and more valuable to me than any potential longer-term survival.

Your paradigm is necessary for the betterment of both the discipline and care for oncology patients. Although it is true that I have seen progress made in the decades gone by, it has also been slow and the cause of much personal suffering among individuals and their loved ones.

I therefore find context very important. I believe that every doctor, particularly when it comes to issues of life and death, should be more concerned with context. In modern oncology, this is simply too seldom the case.

Context-sensitive questions are those such as: How can I be of help to this patient at this stage of his/her life? And how can I contribute to their well-being? This is much more than a question of survival. I come from a background where the Christian belief in salvation was taught, a large Catholic family. First I was a Cub Scout, then a Scout, altar boy, seminarian, then it was on to advanced grammar school and medicine.

From the very beginning I wanted to become a GP, motivated by the philosophy I mentioned above: to be there for people in their own situation and with their own issues, and to contribute to their health and well-being.

My wife and I both attended grammar school, studied the classics, and are familiar with their approach to life and death, to virtue and their ethical values. This approach is at odds with the hubris (or pride) that even today still pervades much of medical treatment. But fighting the good fight, choosing one's own demise (the ultimate form of control over one's life) are also emergent properties of the classical values and virtues that form the cornerstones of our lives.

Taking responsibility for oneself and others is a part of this, and requires taking control. You have undoubtedly noticed that I am in control. It has always been that way – it is the context in which I work.

And that is the crux of the matter. Patients often embark – far too quickly and without being fully informed – on a course of treatment from which there is no turning back. Starting such courses of treatment also means an instant surrender of control. The more severe the treatment, the greater the loss of control. After all, patients are reduced to a kind of basic existence, with great loss of quality of life and often very unpleasant opportunistic infections and other complications, which may or may not have ongoing consequences. In this context, the concepts of 'informed consent' and 'shared decision-making' are still very underdeveloped in practice.

I had already completed my PhD when I started studying to become a GP, after which I went on to study epidemiology, decision theory and medical ethics. I know what is involved.

The surplus of GPs in the early eighties meant that I ended up working in a nursing home – the ‘other side’ of medicine. Nursing homes contain many residents who at some point began a course of treatment in hospital, but without stipulating any conditions regarding how and when it would stop. This experience has taught me never to begin without first formulating and discussing a start/stop scenario. Back on the front line as a GP, I can now see that this is one of the pitfalls of modern oncology.

But it is not in my nature to relinquish control. Especially given the severity of the treatment for my level of malignancy, which would leave me – robbed of all dignity – merely hoping that I might belong to the 30-40 per cent of patients who respond. What kind of survival is that, and where would it lead? And with a treatment mortality rate of ten per cent besides. Hardly a comfortable (not to mention undignified) deathbed. I would never forgive myself.

I have tried to lead as dignified a life as possible, and that is also the way I wish to die. At home, surrounded by my loved ones. That means it will be soon, but we have accepted that fact. Now we are together and enjoy every day, which I will not be trading in for stints in some impersonal academic centre, with my entire life reduced to the so-called ‘fight against cancer’.

I hope that I have made my position clear.

Hans.

Source: *Medisch Contact*, 26 June 2014.

[Click here for the entire article \(in Dutch\).](#)

1

Introduction

The powers of modern medicine are growing. Diagnostic instruments and interventions are becoming faster, more precise, and usually less invasive for patients, while new and more specialised treatment options allow patients to live longer. Not so long ago a diagnosis of cancer or kidney failure was almost certainly a death sentence, whereas nowadays it is sometimes possible to live with such conditions for years, or sometimes even be cured. Quality of life for people with a chronic illness is also improving, partly due to technological medical innovations. All of these developments mean that people are having more and more years added to their lives.

These benefits also have a flipside, however. Although patients are reaching higher and higher ages, at the end of their lives they are living with more simultaneous illnesses and limitations, and take more medications that often affect one another. Some treatments are extremely invasive, and sometimes even so aggressive that they carry a large risk of complications or side effects. Particularly during the final stages of life, such interventions are not always useful and can even be harmful, partly because they are aimed primarily at 'survival'. Other considerations (such as quality of life and continued functioning) sometimes fall by the wayside. In some cases, it can also mean that patients do not fully realise that they are nearing the end of their lives. This can lead to insufficient opportunity for acceptance, closure and saying goodbye, and regularly results in people passing away in the wrong surroundings.

Feelings of dissatisfaction and discomfort are becoming more common in this respect both within and outside of the healthcare system, a fact revealed during the recent symposium: 'Never give up? Ongoing treatment during the final stages of life' (*Geef nooit op? Doorbehandelen in de laatste levensfase*), held by the Royal Dutch Medical Association (KNMG) in April 2012. Around that same time, a survey among doctors conducted by medical journal *Medisch Contact* revealed that sixty per cent of respondents agreed with the statement that patients in the final stages of their lives receive treatment for longer than is either desirable or necessary. This not only refers to oncology patients, but also the vulnerable elderly and patients in the final stages of chronic organ failure, such as COPD, heart failure or kidney disorders. In a 2013 publication titled 'Should we really do all we can?' (*Moet alles wat kan?*), the Netherlands Organisation for Health Research and Development (ZonMw)

demonstrated that there are many factors that can explain this tendency to overtreat. The same was revealed by the book titled 'On Overtreatment' (*Over(-)behandelen*), published by the Vita Valley innovation network in 2013, which addressed these issues among the vulnerable elderly from a primarily ethical perspective.

Spurred on in part by civil-social organisations, this subject is now enjoying increased attention in the media. Patients' and senior citizens' organisations have put it on the agenda, sometimes in conjunction with care providers such as doctors, nurses, other carers and spiritual counsellors. Appropriate end-of-life care is now a widely-shared concern: how can the Netherlands make sure that people in the final stages of their lives no longer receive treatments that do them more harm than good?

The KNMG therefore decided to institute a steering committee to foster appropriate care for those nearing the end of their lives, with a focus on reducing overtreatment. Appendix 1 describes the mission, approach and composition of the steering committee. In performing its duties, the committee sought to involve related activities and initiatives that were already underway in practice. Where possible, it also hopes to promote these activities in a wider context.

This report is about an important aspect of the committee's remit, i.e. identifying the mechanisms that may explain why inappropriate care is provided, as well as the interventions that can offer some counterweight. The committee believes that austerity targets and patients' calendar age should be irrelevant as criteria. To this end, chapter 2 provides some definitions, and outlines the scope of the report. Chapter 3 contains an overview of all the mechanisms that influence choices made during the final stages of life, and chapter 4 describes the related interventions, all of which can contribute to the reduction of overtreatment and to improved quality of life during the final stages. Lastly, chapter 5 specifies the five most important interventions, as the committee wishes to give priority to those that are easy to slot into modern practice and which can produce visible results within a relatively short period.

2

Definitions and scope

In order to promote appropriate end-of-life care, the Steering Committee has identified mechanisms that can influence choices that are made during the final stages of life. This requires a number of concepts to be clearly defined, such as 'end-of-life', 'appropriate care', 'palliative' and 'curative' care, 'overtreatment' and 'undertreatment'.

End-of-life, final stages of life

'End-of-life' refers to the stage in life involving either advanced old age, or a condition that is life-threatening in the near future.

Appropriate care

For practical reasons, the committee has decided not to adopt a definition of 'appropriate care', as it would slow things down and is not necessary for arriving at the intended analysis. Appropriate care, however, must be patient-oriented, safe and effective, in that order. These qualities are based on the six internationally-accepted aspects of quality healthcare.¹ It is also desirable for appropriate care to be accessible, fairly distributed and functional. Calendar age as a criterion is irrelevant, and appropriate care should have nothing to do with cost-cutting or the efficiency of healthcare. Although it is not impossible for appropriate care to result in lower healthcare costs, it can sometimes lead to higher costs.

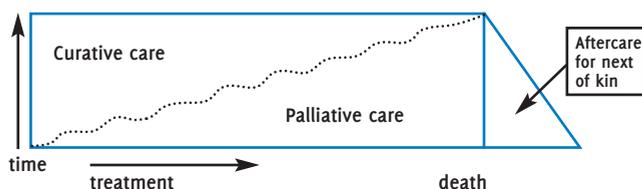
Treatment objectives

In general, treatment is aimed at curing a condition and/or relieving complaints and symptoms. Doctors do not always explicitly state their objectives when issuing treatments, and in practice there are often multiple simultaneous treatment objectives. For this reason, the final stages of life in particular regularly contain 'grey areas'. What makes these areas even 'greyer' is the fact that there are usually no 'black-and-white' outcomes (e.g. whether a treatment will work or not), but only calculated probabilities and risks. Clarity regarding treatment objectives is particularly important in cases involving advanced old age or conditions that can be life-threatening in the long term (such as cancer, heart failure, COPD and dementia). This concerns not only to the objectives themselves, but also to the degree to which they can be realised. The purpose of treatment can change at any time from being 'curative' to being 'palliative', symptom-oriented treatment. The first of these is primarily aimed at curing the disease and/or prolonging life, while the second

¹ Institute of Medicine: Crossing the Quality Chasm, National Academy Press, Washington, D.C., 2001.

focuses on improving quality of life for the patient (and their next of kin). Palliative care, after all, is aimed at reducing suffering at a range of levels – physical, mental, social and existential. It also aims to help patients adapt effectively to the burden of chronic illness that they are experiencing. Palliative care can easily be combined with curative treatments, or life-prolonging care. As patients near the end of their lives, the emphasis in healthcare generally shifts from curative to palliative.²

Figure 1. The new palliative care model.



In this spectrum of treatment objectives, patients have the right to make their own choices. In addition to refusing treatment, for example, patients may also deliberately decide not to eat or drink in order to accelerate the dying process, or ask a doctor for euthanasia or physician assisted suicide (although patients have no right to euthanasia). The decision to accelerate death or to ask to purposefully end one's life are also forms of appropriate care. The Steering Committee did not focus on these choices, however.

Overtreatment and undertreatment

Before defining the concepts of overtreatment and undertreatment, we must first examine the nature and scope of inappropriate end-of-life care. Such a study was commissioned by the steering committee. The researchers asked patients, next of kin and care providers to give examples of inappropriate care. The responses to the open questions revealed two key forms of inappropriate care, namely 'curative overtreatment' and 'palliative undertreatment'. In a limited number of cases, 'curative undertreatment' was also mentioned.

'Curative overtreatment' refers to treatments aimed at curing diseases or prolonging life, the outcome of which is undesirable. This includes aggressive or otherwise severe treatments, or diagnostic procedures that reduce quality of life. In terms of the aforementioned palliative-care model, this relates to the diagonal line – which enables care and treatment oriented towards quality of life – being applied too late. 'Palliative undertreatment' primarily affects patients who receive too little palliative care during the final stages of their lives. This includes relief from pain and symptoms, as well as attention to other needs and wishes of the patient and their

² Mistiaen P, Francke AL, Claessen SJJ, Onwuteaka-Philipsen BD. Kennissynthese nieuwe palliatieve zorg model. [Synthesis of expertise in the new palliative care model.] Utrecht: NIVEL, 2014.

next of kin during this time. Key aspects here include maintaining the patient's ability to function, and improved well-being. In the palliative care model, this means that care providers must ensure that the patient receives enough symptom-related palliation and support, during the stage when curative or life-prolonging treatment has reduced or stopped.

One important question from the study concerns the definition of appropriate care. Many respondents shared the opinion that care is appropriate if it is 'in line with the patient's wishes'. In this context, the respondents often named the principles of shared decision-making. In order to make a well-considered decision, patients must be informed of all the available options in good time. The attending practitioner can then involve the patient as much as possible (and to the extent they desire) in the decision-making process. It is also important to listen properly to the patient's troubles and needs at other times, so that these can be attended to in a prompt manner.

Other criteria for appropriate care mentioned by patients include sufficient physical and mental care, effective symptom management, support and guidance for the patient and their next of kin, and suitable accommodation. In this last respect, most respondents expressed a preference for receiving treatment at home. Appendix 4 contains a detailed summary of this study into the nature and scope of appropriate end-of-life care. Focus groups were held in order to gain more insight into the nature of some of the circumstances identified, their underlying mechanisms and to assess the feasibility and desirability of some interventions. Appendix 5 presents a summary of the results.

Focus

Most of the steering committee's activities revolved around 'curative overtreatment'. One important reason for this focus is the fact that while the Netherlands devotes a great deal of attention to improving 'palliative undertreatment', the solutions aimed at preventing 'curative overtreatment' are relatively underrepresented. The committee also wishes to point out that 'curative overtreatment' and 'palliative undertreatment' can both be caused by the same problem, namely that of care providers concentrating too much on the disease, and not enough on the patient.

This stage of illness was the committee's primary concern, in which patients and care providers must stop to consider the fact that the patient's life is nearing a stage requiring reflection on, and discussion of, whether current or future 'curative' treatments are still desirable (this not only concerns treatments, but also potentially invasive diagnostic processes). As this stage approaches, it is important to discuss whether initial or follow-up treatment should be applied/continued, and to establish the intended purpose of any such treatment. This may involve a single decision at

one time, or multiple successive decisions, right up to the final days of life. Although the focus here is more on treatment than general care, these decisions also apply equally to nursing, care and support.

3

Inappropriate end-of-life care: Mechanisms responsible for overtreatment

3.1 Introduction

The committee has produced a summary of mechanisms that can explain why there is sometimes too little focus on the quality of care, and on the choices that can be made together with patients as they near the end of their lives. Examples of these mechanisms include the tendency by doctors and patients to ‘just keep going’; the financial incentives in the healthcare system that reward such measures; a lack of communicative ability among some care providers; and a lack of available time in which to open (or re-open) the dialogue. It is not always clear whether these mechanisms genuinely lead to curative overtreatment.

The committee has tested the mechanisms in various ways, and substantiated them where possible.³ This process included a literature study⁴ (see Appendix 2), hearings with experts from a range of disciplines (see Appendix 3) and conducting independent research (see Appendix 4). The report by the Steering Committee is a consensus document.

This chapter provides an overview of the mechanisms that help to explain why patients who are approaching the end of their lives are subjected to too many treatments aimed at prolonging life, or to unnecessary diagnostics. The overview distinguishes between mechanisms effective at the macro, meso and micro levels. The macro level is that of society and the healthcare system. The meso level is the level of individual healthcare institutions, and the micro level refers to the individual relationship between patient and care provider. At the micro level, a distinction is also drawn between mechanisms that affect care providers, and those affecting patients and their next of kin.

The distinction between these three levels is in a sense artificial, as macro-level factors can influence events at the meso and micro levels, and vice versa.

3.2 Mechanisms at macro level: culture, the healthcare system, legislation

Giving up is not an option

Partly due to the *Alpe d'HuZes* charity cycling events, nearly everyone in the Netherlands is familiar with the motto: ‘Giving up is not an option’. In actuality, this motto literally prescribes is that one simply ‘must’ keep going. When applied to an illness such as cancer (for which the charity event is organised), this means that

³ There is little scientific evidence available regarding the effects and importance of the various mechanisms.

⁴ For purposes of readability, this report does not continually refer to the individual sources.

patients should accept ‘any possible treatment’, as giving up is not an option, neither for yourself nor for your next of kin. This idea, that ‘giving up is not an option’, is not a stand-alone idea. Newspaper articles talk about ‘how we are getting to know the enemy’ and of how ‘the fight is far from over’. The fact that such powerful, warlike terms appeal to so many of us says something about our society. In terms of illness and health, this is currently the predominant culture in the Netherlands. Patients who fight bravely on are the heroes, and those who do not are the losers, who may not have fought hard enough.

Terminal patients regularly talk about the social pressures they perceive as a result. Family members, friends and colleagues all encourage them ‘not to give up’, to put up a fight and clutch at straws – if not for their own sake, then for their loved ones. Accepting or submitting to illness and imminent death is not ‘normal’ – fighting is. It is therefore emphatically clear that this mechanism extends beyond the doctor-patient relationship: both patients and doctors that refuse to give up are labelled positively and given all the support they could want. Patients who consider refusing treatment receive less attention from their social environment, and notice that their attitude is more often seen as negative.

It is unusual to talk about death

‘Giving up is not an option’ also has a sister mechanism: for many people, it is not normal to talk about illness and death. Nor is it customary to document any wishes regarding the end of one's life. Although we all die, relatively few Dutch people talk to their next of kin and care providers about their preferences for treatment (including the forgoing or cessation thereof) during the final stages of their lives.

The healthcare system focuses on production

Healthcare institutions operate like businesses, and must make profits in order to invest and ensure continuity. This encourages a desire to increase the field of operation and patient/client numbers, and with them, turnover. The (corporate) culture of a hospital, for example, may put too much emphasis on performing as many treatments as possible, which in turn may provide partnerships and doctors with a subconscious incentive to potentially pay less attention to quality of life and the available options regarding patients in the final stages of their lives. Nurses and carers can be pulled into this culture of production, resulting in excessive workloads and less time for social contact with patients.

Under the current healthcare system, payment is issued for each act of treatment carried out, which can result in financial incentives to perform declarable procedures. Foregoing further curative treatment is generally less attractive from a financial

perspective. This filters through to the section/partnership/department level: doctors who perform fewer treatments may be called to account. The same applies at the institutional level: hospitals are evaluated according to their productivity figures, and will encourage doctors – either explicitly or implicitly – to administer procedures. Doctors who consult with patients and their next of kin regarding the foregoing of treatments (or the possibility of doing so) cannot bill them unless relevant agreements have been made with the insurer. Although the doctor is genuinely ‘doing something’, there is not always a payment waiting at the other end. In 2014 however (and partly at the request of the steering committee), the Dutch Healthcare Authority (NZA) defined a new care activity: ‘Intensive consultation for the careful consideration of treatment options (190063)’.⁵

3.3 Mechanisms at the meso level: institutions

Minimum standards for licences, and the concentration of healthcare

In order to retain licences for performing certain types of treatment, hospitals and treatment centres must carry out some procedures a minimum number of times per year. The reasoning behind this is that certain procedures are so complex, risky and/or expensive that they may only be performed by a limited number of hospitals/treatment centres, in order to maintain levels of experience.

Hospitals that fail to reach the minimum standard for a certain procedure will lose their licence to perform it. In such cases, insurers will not cover the care or treatment in question and doctors will be expected to send their patients to a different hospital. For hospitals and the relevant doctors, not being allowed to perform the procedure can lead to a loss of prestige, production and income. In cases of doubt, this can provide an incentive for the hospital (and therefore also the doctors who work there) to perform the procedure anyway, even though it may no longer contribute to the quality of the patient’s life during the final stages. Such scenarios can become complicated if patients must urgently attend a hospital where the care providers do not know the patient or their situation.

Offering complex care exclusively in a concentrated setting and imposed minimum standards can lead to the limited consideration of treatment options that are not curative or life-prolonging.

Institutions evaluated according to death rates

Hospitals are required to openly publish their rates of death for certain conditions, the logic being that hospitals with lower death rates provide better-quality care. In this case, quality is defined primarily in terms of survival. Death rates are also used

⁵ This activity (190063) may be claimed by hospitals starting 1 January 2014. As of June 2014, such activities will also be recorded as such on the invoices sent to health insurers. Provided agreements have been made between the care provider and the insurer, this activity will be paid for. Starting in 2015, it will be possible to apply rate differences for products that do/do not include intensive consultations (within the free sector).

See also: www.nza.nl/regelgeving/beleidsregels/BR_CU_2111__Prestaties_en_tarieven_medisch_specialistische_zorg

to publish public hospital rankings. This could potentially result in patients who are in the final stages of their lives receiving curative or life-prolonging treatment for too long.

However, the reverse is also possible, i.e. doctors who decide against treatment because the risk of death is too high. In these cases patients may be sent back to their GP, or be referred to a teaching hospital. An excessive focus on death rates can also lead to patients being released sooner following a procedure, in order to prevent them from dying in the hospital.

More and more (ultra-)specialised doctors and nurses

Partly due to medical advances, we are observing a shift from generalist care professionals to specialists, super-specialists and sub-specialists. Specialist doctors and nurses view their patients from the perspective of their own field and specialisation, which can sometimes cause them to lose sight of the patient ‘as a whole’ within the context of their own lives. Although these super-specialisations and sub-specialisations do provide the opportunity for effective, specific treatments, they also present a risk, i.e. that the healthcare professionals involved may become too focused on treatment for survival, potentially resulting in too little consideration for quality of life and the choices to be made during the final stages.

The increasing advances in the field of diagnostics also need to be mentioned in this context. Here too, while various levels of specialist diagnostics provide patients with better opportunities, there is also a downside. Diagnostics, after all (or increased levels thereof), mean that more illnesses are being ‘found’, possibly resulting in higher levels of treatment.

Insufficient collaboration among care providers

Care and treatment for patients during the final stage of their lives often involves care providers from a range of disciplines, such as nurses, carers, doctors, social workers, physiotherapists and spiritual counsellors. These care providers often work in a variety of settings, such as general practice, home care, hospitals and nursing homes. Each of these care providers will examine, act and speak according to their own expertise and from their own perspective.

In many cases these care providers collaborate effectively, but not always. For example, care may not be coordinated effectively, or necessary information may be communicated too late or be incomplete, resulting in patients being treated for too long and/or unnecessarily. This potential lack of collaboration is a stubborn problem, and is exacerbated by the fact that more and more care providers are working part-time.

GPs in particular tend to work in groups, raising the importance of mutual communication. Nowadays there are also more substitutes who replace GPs in their

absence, especially outside office hours. The timely exchange of up-to-date information is required for all of these reasons. It is often poorly executed in practice, however, potentially resulting in care providers making decisions that are less appropriate for patients entering the final stages of their lives. An acting GP, for example, may decide to send a patient to hospital, not knowing that an agreement had been made with that same patient not to do so. Poor communication may be particularly problematic in acute situations, when files that are not kept up-to-date can contribute to the provision of inappropriate care.

Authorisation is another relevant factor in this respect: in practice it is still far too common for care providers to be denied access to patients' (electronic or other) files. And even if access is granted, the files often include the 'hard' medical facts but leave out the 'soft' data, such as the patient's end-of-life preferences concerning resuscitation, blood transfusions, hospitals, etc.

Poor coordination, confusion regarding the primary practitioner, no fixed point of contact

Especially when it comes to patients who are nearing the end of their lives, it can be unclear who is responsible for their treatment and who is coordinating it. This can lead to inappropriate care. Many patients (the elderly in particular) are treated by a variety of first and second-line care providers, and in practice it is often unclear who is coordinating treatment, who the primary practitioner is and who the fixed point of contact is for the patient and their family. Although 'transmural' consultation is common, it is often difficult to organise. GPs who know their patients well are often not involved in the decisions made in the hospital. Conversely, GPs sometimes also fail to consult sufficiently with their counterparts in hospitals.

For this reason, in 2010 the KNMG worked with other care organisations to produce a guide that was specifically aimed at improving these three aspects of care. This 'Guide to the division of responsibility for collaboration in healthcare' (*Handreiking verantwoordelijkheidsverdeling bij samenwerking in de zorg*) states that a person responsible for treatment, for coordination and an official contact person must be established for each patient. The guide received widespread support, however in practice it remains difficult to implement these agreements. Solutions are now being developed for all three aspects, but it is still unclear precisely what works and what does not.

Previously, in 2006, the Dutch College of General Practitioners (NHG) and the National Local Nurses' Association (*Landelijke Vereniging Wijkverpleegkundigen, LVW*) published the 'National First-line Collaboration Agreement (LESA) for Palliative Care' (*Landelijke Eerstelijns Samenwerkingsafpraak (LESA) Palliatieve zorg*), which contained recommendations similar to those in the guide.

Poor quality in decision-making and application of decision-making methodologies. Decisions made during the final stages of life often involve processes that include the patient, their next of kin and a variety of care providers. Those included will vary depending on the patient and their particular setting. Some cases involve the use of decision-making models or methodologies, such as shared decision-making, advance care planning, clinical reasoning, palliative reasoning or moral deliberation. Recent years in particular have seen an increased focus on quality during the decision-making process. Patients and their loved ones are more involved in decisions regarding the continuation or cessation of treatment, the services of care providers from a range of disciplines are put to better use, and the shared decision-making process is implemented sooner.

Much can still be improved, however. In hospitals, for example, the medical perspective is often the dominant one in multidisciplinary consultative bodies (MDOs). These consultations often (and sometimes only) include doctors from various disciplines, resulting in a lack of attention to other perspectives (e.g. functional, social, mental, spiritual). GPs are often also absent.

Furthermore, it is precisely the exclusive presence of doctors that can lead to patients being subjected to longer treatment: after all, there is 'always' a specialist who can think of another procedure to try. Other care institutions also sometimes organise too few regular opportunities for multidisciplinary reflection. The professionals involved could encourage this more, fostering a culture in which other, non-medical perspectives are also taken into account.

In hospitals, other institutions and the home care sector it is still unclear as to which decision-making methodology works best, and what is the best way to involve patients and their next of kin. Care professionals are also often far from familiar with how to use these methodologies, and the results frequently go undocumented or are unavailable when needed.

Strict divide between curative and palliative care

In practice, there is still too great a divide between curative and palliative care. This means that patients do not receive any palliative care until all possible curative treatments have been exhausted. Patients also seem to resist palliative care, as it makes them feel as though they have been 'given up on', and they are worried about being abandoned by their doctors. It has also been shown that patients maintain hope for a cure as long as some form of treatment is still taking place, even though it may be experimental. It also turns out that patients receiving chemotherapy for cancer find their 'chemo-free' periods to be the most stressful. One of the possible causes for all of this is the fact that the concept of palliative care is still a vague one, and one that needs to be more clearly defined. 'Supportive care' could be a better term than 'palliative'.

Guidelines focus on 'action', not 'inaction'

The protocols for many treatments are based on guidelines. The content of these guidelines, however, is often based on research among young people only suffering from a single condition. Guidelines therefore often fail to cater to the elderly, or to patients with multiple illnesses (multimorbidity).

Guidelines also devote little to no attention to the option of consulting with the patient to discuss foregoing curative or life-prolonging treatment, with a view to improving quality of life (and death). And in the few sets of guidelines that do devote attention to this matter, it can be too cursory. Young and inexperienced doctors in particular tend to follow all of the prescribed steps very rigidly (sometimes too rigidly), which can result in a failure to acknowledge the negative aspects of treatment. They sometimes find it difficult to substantiate arguments in favour of deviating from the guidelines.

Treatment outcomes are also generally described in terms of survival (e.g. duration) and severity (and the reduction thereof). There is still too little consideration for outcomes related to the patient's ability to function, well-being, their quality of life and quality of death. Medical specialists are still too unfamiliar with applicable palliative care guidelines.

Education focuses primarily on diagnosis and treatment

The emphasis of medical degrees and other training courses for doctors is on diagnosis and treatment. Relatively little attention is devoted to all the activities and competencies related to the option of foregoing treatment. This includes questions such as: would continued treatment still benefit this patient's quality of life? And what are the possible/best ways to open this dialogue with the patient?

Although medical degree programmes now teach students seven competencies (known as the CanMEDS)⁶, medical expertise often still takes priority. Advanced specialist programmes especially tend to focus on treatment and expertise; this is less true for programmes that train general practitioners, elderly care physicians and doctors for the intellectually disabled.

This phenomenon has various causes in medical specialist programmes. The education funding available to hospitals, for example, is tied to medical interns (AIOs in Dutch). In order to retain these programmes, hospitals must ensure that the medical intern is able to perform the number of procedures set out in the programme requirements. In turn, medical interns focus on attaining the required minimum number of procedures, potentially at the expense of other competencies. Hospital culture also plays a role here. From day one, medical interns are swept up into an environment that is focused on healing and curing (diagnostics and prescribing/ongoing treatment). The hectic nature of day-to-day medical practice often makes it difficult to actually apply the communication and shared-decision-

⁶ These are known as the CanMEDS competencies, named after the Canadian Medical Education Directives for Specialists. The competencies are, in order: medical expertise, collaboration, scholarship, communication, health advocacy, management and professionalism.

making skills learned in foundation medical programmes. Workloads are too high, and the education requirement of having to perform enough treatments takes priority.

Medical interns also say that educators often determine the extent to which they are able to practice non-treatment-related competencies. Educators are role models for medical interns: as long as educators themselves continue to focus on treatment, so too will medical interns.

Palliative care receives relatively little coverage in training programmes, as does knowledge and expertise in the field of geriatric medicine. The same applies to nursing and care worker programmes. The fact that students are often quite young also makes it difficult to incorporate end-of-life considerations into medical programmes.

Doctors and scientific research

It is important for hospitals (especially academic medical centres) to conduct scientific research, at the level of both departments and individual doctors. Doctors and hospitals conduct research with the best of intentions: they hope for results that will serve the interests of both patients and medical progress. This research pressure, however, can be an incentive to offer patients additional (sometimes experimental) treatments. After all, research demands a minimum number of participants, and doctors/hospitals sometimes receive remuneration for each patient who takes part.

These are often what are known as ‘phase 1 studies’, which actually only study the safety of a drug. Patients who are asked to undergo (potentially additional) treatment as part of a phase 1 study will tend to agree to it, as it gives them hope. It also means that patients remain in contact with medical specialists, which many find important.

Some patients also find it hard to accept that, while one hospital will not provide any more active treatment, another will as part of a study. This sometimes causes patients to switch hospitals, or even go to hospitals abroad.

Medical innovations ‘should’ be used

Innovation is modernisation, and innovative procedures or treatments can be less invasive and/or more effective for patients than those customary up until that time. Examples include robotic surgery, implantable cardioverter-defibrillators (ICDs), aortic valve surgery via the groin, and proton therapy. This can be a reason for both care providers and patients to want to try these innovations. However, there is still often a lack of clarity regarding which patients are/are not suited to the innovative procedure, as well as the potential long-term negative consequences or risks. But by

then it is too late: the innovation already has such a good ‘reputation’ that patients and care providers wish to opt for it. Hospitals that do not yet offer or perform the procedure are under pressure to do so, otherwise patients will go to a hospital where the procedure is on offer.

The added value of innovations has not always been demonstrated by the time they are introduced, which is why innovations are sometimes offered as a temporary option. While they are still on offer, it is imperative to use the innovations as much as possible in order to scientifically prove their added value. Once the temporary period has expired, however, doctors and patients hardly view the innovation as such anymore, but rather as one of the options acceptable as part of their policy. By this time, institutions have often already made significant educational and financial investments, making it especially difficult to remove the innovation from the available options.

3.4.1 The micro level: factors affecting care providers

Lack of time

Discussing the possibility of foregoing treatment takes time, usually more so than simply offering a course of treatment. For both doctors and other care providers, it is often easier and less time-consuming to make a concrete treatment proposal rather than to explain that all curative treatment options have been exhausted. The latter also requires an explanation of all that the patient can expect during their final weeks or months: how much time they have left, the symptoms that can appear, how they can be managed, which care providers can provide the right support, and so on. One consultation is usually not enough.

Because workloads in the healthcare system are so high, care providers can tend to opt for the quicker, easier solution of providing more treatment. For example, it is faster to call an ambulance than to explain why one should not be called, and dealing with possible resistance from family members.

‘Action’ is better than ‘inaction’

More so than other care providers, doctors tend to always be in ‘treatment mode’. Medical specialists, for example, are trained to be of use to patients, and are intrinsically motivated to cure them and keep them alive. General practitioners, elderly care physicians and doctors for the intellectually disabled have less of a tendency to ‘spring into action’.

This ‘treatment mode’ is often cited as a cause of inappropriate end-of-life care. Doctors’ preference for action rather than inaction is logical, but also complex. A complicated web of factors seems to be at play here. In addition to medical degree programmes and the intrinsic desire to cure, this also includes factors of a more

cultural and psychological nature that affect doctors, other care providers, patients and family members. For example, doctors can feel as though they have failed if 'action' is no longer possible, and 'inaction' is the only option left. This also results in the need to fully substantiate any decision to remain 'inactive', which is much less necessary when proposing another course of treatment. Consciously or not, all doctors would rather be those who fight to the end for their patients, who 'pull out all the stops' and who do not leave their patients in the lurch. One common view is that doctors who 'do something' are doing good. Some doctors also have trouble 'letting go' of treating the patient, because continued treatment also maintains the feeling of being in control. Both patients and care providers find it difficult to come to terms with death in this regard. The Dutch word for medicine also even contains the word for 'healing' ('geneeskunde'). Doctors do not always have the expertise to know what lies in store when deciding not to take action, or how to deal with it. For the same reason, care providers, patients and family members continue to hope for improvement, sometimes against their better judgement. With regard to hope, it would seem that doctors and patients unwittingly encourage each other to 'take action'. Doctors prefer not to raise the topic of ceasing or foregoing treatment ('inaction'), because they do not wish to deny their patients hope of recovery. In turn, patients often give their doctors an overly positive impression of their condition and the effects of treatment, in the hope of receiving further treatment. This creates what is sometimes referred to as the 'coalition of hope'.

Lack of communicative (and other) competencies

Many care providers find it difficult to talk to patients and their next of kin about approaching death. These types of discussions require skills that are not a compulsory part of basic degree programmes. What is the best way to respond to sadness, powerlessness, disappointment, anger, frustration, fear or hope? This requires more than just the ability to deliver bad news, and is often part of a longer-term process involving several parties and in which multiple decisions must be made. During the final stages of life, this can be a reason why care providers continue to provide treatment – it is a way of avoiding difficult conversations and decisions.

Patient autonomy (and its limits)

Care providers often find it hard to decide how much information to share with patients. In making end-of-life medical decisions, doctors will undoubtedly follow the Medical Treatment Contracts Act (*Wet op de geneeskundige behandelingsovereenkomst, WGBO*) which sets out the principle of informed consent. This means that care providers must first inform patients, and then ask their permission before carrying out any treatment or procedure. This causes some

dilemmas in practice, however. Does it mean that doctors must provide patients with all available (e.g. detailed) information, including their own recommendation? Or can doctors limit the discussion (exclusively) to the options they consider worthwhile, leaving out any that they deem pointless? These questions are the subject of much discussion.

In practice, doctors wish to respect their patients' autonomy, however they also grapple with the question of how this affects their own position. Patient autonomy, after all, can lead a doctor to offer many treatment options, sometimes too many: the patient is informed of all the possibilities, after which they must decide for themselves how far they wish to go (this is referred to as the 'mechanistic' or 'informative' model). At the other end of the spectrum we find the paternalistic model, in which doctors only provide information on the options they deem worthwhile. The age of the patient can also play a role here: many elderly patients still live with the image of a paternalistic doctor ('the doctor should just tell me what to do, he studied medicine after all').

Nowadays, many doctors and patients opt for shared, patient-oriented decision-making (a 'participatory' or 'deliberative' model). In doing so, however, patients and their families must not feel as though they are medically responsible for deciding whether or not to proceed with treatment.

Differing cultural and personal beliefs among care providers

The beliefs, norms and values held by care providers and patients are of great importance in the provision of appropriate end-of-life care. Decisions regarding whether or not to proceed with treatment are inextricably linked to the beliefs about life and death held by the patient, their family members, care providers and society as a whole. Certain religious beliefs, for example, allow for the perception of pain and suffering as a test from God, with purifying effects. There is also a range of opinions regarding the importance of autonomy, and the question of who should make decisions in certain situations, i.e. the patient, their family, or the doctor. Differing cultural or personal beliefs between care providers and patients or their families can stand in the way of discussions about appropriate end-of-life care. This mechanism can play a major part, as the numbers of care providers and patients with differing cultural and personal beliefs is increasing.

3.4.2 The micro level: factors affecting patients and their families

Action is easier, and seems safer than inaction

Just like doctors, patients and their families also find 'action' easier than 'inaction'. It is a complex mechanism, and involves many different factors.

For example, the authority and expertise of doctors sometimes makes it hard for

patients to reject a treatment proposal made by their doctor. 'If a doctor offers me a certain treatment, who am I to turn it down?' 'If the doctor didn't think the treatment was worthwhile, why would he suggest it?'

This effect is often strengthened by family members who encourage patients to continue with treatment. Common views include: 'more is better', '(so-and-so) has a right to treatment' and 'think of all those insurance payments'. Next of kin wish to support the patient in this way, either consciously or subconsciously. 'Doing all you can' is often an expression of affection: 'We all love you so, please don't leave us just yet'.

Faced with these difficult decisions, both patients and their families often display optimism, sometimes against their better judgement. This has been demonstrated by various studies, in which patients continue to hope for a cure, even when death is imminent and unavoidable. Expectations of modern medicine remain sky-high, even when scans and examinations have proven that a cure is no longer possible.

Last but not least, patients 'feel' as though action is safer than inaction. Continued treatment means the doctor is not letting you down. Every appointment with a care provider offers security and structure, precisely during a time full of insecurity and stress. 'As long as there is chemotherapy, there is hope'. Patients derive therapeutic security from treatment, unaware of the fact that this security can also be provided by other options (conversations, palliative care).

Lack of awareness regarding end-of-life wishes and preferences (declarations of intention)

Patients are often underinformed regarding the various options for documenting their wishes and preferences regarding the final stages of their lives. These can include prohibitions of treatment such as resuscitation, insufflation, tube/drip feeding, antibiotics and/or blood transfusions. As long as patients have not documented their preferences, care providers can sometimes feel as though they must carry out a particular intervention, even if the chances of success are small.

But even if a prohibition of treatment has been drawn up, care providers sometimes decide to proceed with a certain treatment nevertheless. This can sometimes be appropriate, e.g. if the preference in question does not apply to the decision the care provider is faced with, or if the decision can be justified by medical considerations.

Greater differences in the cultural and personal beliefs of patients and their next of kin

Research has shown that patients and families from non-western backgrounds and/or with strong religious or other convictions sometimes wish to continue with treatment for longer than western doctors deem sensible or worthwhile. Because of

their personal beliefs, some patients and their next of kin sometimes wish to continue to the end; nobody wants to be the one to decline a further round of treatment, not even if suggested by a doctor. ‘Man proposes, God disposes’, ‘suffering is purification’ and ‘Allah gives life, Allah takes life’ are all ideas that contribute to this view.

For this reason, patients and their next of kin can find it difficult to discuss their preferences with care providers from different backgrounds. Rather than being sedated, for example, Islamic patients wish to undergo a lucid death. Occasionally there are also family members who express their difficulty with treatments such as pain relief or palliative sedation due to their religious backgrounds. During consultations, these patients and/or their families say that ‘pain and suffering are a part of life’, and often note that it is a difficult standpoint for western care providers to deal with. In turn, these care providers point out their desire to relieve the pain in accordance with their professional standards, however they also notice that it is hard to overcome differences in norms and values.

Complex decision-making

End-of-life decisions can be complex. They often involve many different people, and emotions play a major part. A multitude of factors (pain, sadness, prognoses, etc.) also mean that the process is rarely static: the decisions made by patients today will be different tomorrow, and different again a week later.

For various reasons, patients can also feel under pressure when making these types of decisions. This can be time pressure, since the sooner the curative treatment starts, the greater the perceived chances of success (realistic or not). They can also be under pressure from their next of kin or the people treating them, who each express their opinions of the treatment to the patient in their own way. All these factors can stand in the way of proper decision-making.

The considerations of a more medical nature are also problematic, however. Often there may be plenty of medical and other information available, but it is hard for patients to make sense of or evaluate. Digital information in particular is not always reliable. Much information is of a general nature, and not tailored to suit individual patients.

Information on some illnesses includes statistics and probabilities, which are hard for patients and their families to understand. Patients can only do so with assistance, e.g. from a doctor, nurse or somebody they know who has the right expertise. Decision-making tools can also help in this regard: these are instruments that provide patients with unbiased information on the various treatment options, and help to weigh up any pros and cons. These tools, however, do not always consider the way the functionally illiterate, vulnerable elderly, intellectually disabled or people with impaired cognitive ability process information.

Although the arguments for shared decision-making are justified, we are still searching for the best ways to support patients and their families in doing so. Incidentally, the extent of the role played by patients' level of education (and that of their family members) is still unclear in this respect, and how it can be dealt with.

4

Interventions for promoting appropriate care

4.1 Introduction

Based on the mechanisms described above, this chapter focuses on interventions aimed at reducing the instances of inappropriate care. As previously stated, the emphasis here lies on interventions that contribute to quality of life during the final stages, and on the choices to be made during this period. In doing so, the Steering Committee decided to create interventions that could be incorporated as much as possible into existing procedures, activities and initiatives, with the intention of promoting them in a broader context.

Below, one or more interventions is given for each of the identified mechanisms. The interventions that ‘belong’ to multiple mechanisms are also indicated wherever possible. Each intervention includes a table stating the purpose of the intervention, the form it will take (the ‘actual intervention’) and who could take the initiative in its implementation.

1. Mechanism: *Giving up is not an option*

In many sections of society, the dominant view is that illness should be fought in order to prevent death. Although this is of course a respectable view, it sometimes leaves little room for the acceptance and submission to illness and approaching death (particularly among the terminally ill). Many people see this culture as a significant cause of inappropriate care. We need to create more opportunities in society and the healthcare system so that non-treatment can also be regarded as a form of appropriate care. This requires greater attention to vulnerability and dependence during the final stages of life, and to the expectations of medicine that are often too high. These stages are not only about maximum medical treatment (and prolongation of life), but about the most appropriate care (including quality of life and well-being). See also mechanisms 16 and 20.

Purpose (of the intervention):		To create more opportunities in society for the acceptance of and submission to illness and approaching death, allowing non-treatment (including curative treatment) to be viewed as appropriate care.
1.1	To be achieved by:	Drawing attention in the media, political sphere and professional literature to the option of non-treatment (or non-curative treatment), and adjusting overblown expectations in order to create a more realistic impression of the capabilities of modern medicine.
	Who must act:	Opinion makers, journalists, cultural philosophers, ethicists, doctors (and doctors' organisations), nurses and care workers, patients, senior citizens (including elderly migrants).

2. Mechanism: It is unusual to talk about death

Many people do not discuss their wishes regarding the end of their lives, either with their next of kin, good friends, or with care providers. People who have made their wishes known generally receive more appropriate care during the final stages of their lives.

Many people do not set out their preferences in writing, and many do not have easy access to neutral declarations of intent, including ‘do-not-resuscitate’ tokens. See also mechanisms 7 and 21.

Purpose (of the intervention):		To have citizens, patients and their loved ones start thinking about their end-of-life wishes in good time, to encourage their discussion in private and with care providers early, as well as their documentation.
2.1	To be achieved by: Who must act:	A public campaign. (Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); care institutions; the government; insurers.
2.2	To be achieved by: Who must act:	(Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); insurers. The development of a neutral format for creating a written declaration of intent that is easily accessible. (Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); care institutions; the government; insurers.
2.3	To be achieved by: Who must act:	The development of a neutral ‘do-not-resuscitate’ token, and setting up an effective distribution channel. (Associations of) senior citizens (including migrants), doctors, nurses and care workers; ambulance services; care institutions; the government; insurers.
2.4	To be achieved by: Who must act:	Enabling and encouraging GPs of vulnerable elderly patients and patients with potentially life-threatening conditions to enter into dialogues about their end-of-life wishes and expectations (care, well-being, accommodation, etc.) at a time when it is not yet fully necessary. The National First-line Collaboration Agreement (LESA) on ‘advance care planning’ and resuscitation of vulnerable elderly should provide the basis for these discussions. These patients will receive support in the form of a brochure and an invitation to attend the consultation. An appropriate fee will be established. (Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); insurers.

3. Mechanism: The healthcare system focuses on production

In the current healthcare system (hospitals in particular), payment is made for each act of treatment performed, which can result in financial incentives for performing declarable procedures. From a financial perspective, foregoing further curative treatment is generally a less attractive option. See also mechanism 15.

Purpose (of the intervention):		To counterbalance undesirable incentives aimed at production during the final stages of life.
3.1	To be achieved by: Who must act:	(Continued) development of an adjusted costing system governing care for patients in the final stages of their lives. Ministry of Public Health, Welfare and Sport (VWS), the Dutch Healthcare Authority (NZA), insurers, doctors' organisations.
3.2	To be achieved by: Who must act:	Encouraging medical specialists and hospital administrators to become active in making contractual agreements regarding 'intensive consultations' for patients nearing the end of their lives, involving the careful consideration of treatment options (listening to the patient and shared decision-making), and carrying out these consultations. Partnerships/departments, doctors' organisations; institutions, the Dutch Healthcare Authority (NZA), insurers.

4. Mechanism: Minimum licensing standards; concentrated healthcare

Healthcare is becoming concentrated, with some complex, dangerous or expensive treatments being subject to minimum standards. Doctors, partnerships, departments and hospitals have a vested interest in attaining the applicable minimum. This is not always in the patient's best interests, however.

Purpose (of the intervention):		To ensure that decisions regarding whether or not to treat during the final stages of life are not secondary to achieving prescribed volumes.
4.1	To be achieved by: Who must act:	Developing indications that are as focused as possible and based entirely on appropriateness. (Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); care institutions.

5. Mechanism: Institutions evaluated according to death rates

Death rates are used to produce public hospital rankings, which can lead to patients receiving curative or life-prolonging treatment for too long, in order to prevent fatalities in the hospital.

Purpose (of the intervention):		The reduction of medically futile, life-prolonging treatments during the final stages of patients' lives.
5.1	To be achieved by:	Creating a team that can be consulted easily regarding a worsening patient before the patient requires resuscitation or admission to intensive care, and that will also record any wishes or treatment restrictions discussed with the patient.
	Who must act:	(Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); care institutions.

6. Mechanism: Increase in the numbers of (ultra-)specialised doctors and nurses

Specialist doctors and nurses propose treatments from their own (potentially narrow) perspective and field, but often fail to consider the patient as a whole. See also mechanisms 7 and 8.

Purpose (of the intervention):		To offer generalist end-of-life care by care providers who focus primarily on the patient instead of the illness, irrespective of where the patient is or is transferred to.
6.1	To be achieved by:	Appointing generalist care providers in hospitals (e.g. clinical geriatricians and elderly care physicians, GPs, nurses) and ensuring that they are given clear and influential positions.
	Who must act:	Doctors, nurses and care workers (and their associations); hospitals; insurers.
6.2	To be achieved by:	Implementing a directive/National Transmural Agreement (LTA) containing guidelines regarding collaboration between GPs and specialists, including consultation and visits to the patient by the GP. An LTA should serve as the basis for any regional transmural collaboration agreements.
	Who must act:	Doctors, nurses and care workers (and their associations).

7. Mechanism: Insufficient collaboration among care providers

Care and treatment for patients during the final stage of their lives often involves care providers from a range of disciplines. In practice, collaboration between these various providers is not always optimal. For example, care may not be coordinated effectively, or necessary information may be communicated too late or be incomplete. See also mechanisms 2, 6 and 8.

Purpose (of the intervention):		To ensure that patients' end-of-life wishes and other relevant information is recorded on file and communicated in good time.
7.1	To be achieved by:	The development and implementation of a National Transmural Agreement (LTA), outlining: <ul style="list-style-type: none"> • the necessary criteria during any handover to an emergency GP, hospice, nursing home or hospital; • the criteria for references; • the criteria for feedback; and • a protocol for standard times when contact should be made.
	Who must act:	Doctors, nurses and care workers (and their associations); care institutions.

8. Mechanism: Poor management, confusion regarding the primary practitioner, no fixed 'point of contact'

Many patients (the elderly in particular) are treated by a variety of first and second-line healthcare professionals, and in practice it is therefore often unclear who is coordinating treatment, who the primary practitioner is and who the fixed point of contact is for the patient and their family. Clear agreements prove difficult to make in practice. This mechanism is related to mechanisms 6 and 7. In 2010 the KNMG worked with other care organisations to produce a guide that was specifically aimed at improving these three aspects of care.

Purpose (of the intervention):		For all patients (i.e. especially those with multimorbidity or a life-threatening condition) to know who their primary practitioner is, who their contact person is (and how to reach them) and who is coordinating and directing their treatment.
8.1	To be achieved by:	Systematically documenting of the division of responsibility and providing this information in writing to patients or their next of kin. The 'Guide to the division of responsibility for collaboration in healthcare' (<i>verantwoordelijkheidsverdeling bij samenwerking in de zorg</i>) can serve as a guideline in this regard.
	Who must act:	Doctors, nurses and care workers (and their associations); care institutions; inspectorate.

9. Mechanism: Poor quality in decision-making and application of decision-making methodologies

Complex treatment decisions often involve the use of various decision-making methodologies/models. One of these has proven to be effective, namely that of shared decision-making, and should be used more often in order to foster appropriate end-of-life care. Although doctors, nurses and other care providers realise this too, they still find it difficult to apply the methodology in practice. See also mechanisms 15, 16, 17, 18 and 23.

The Netherlands Federation of Medical Specialists and the Netherlands Organisation for Health Research and Development (ZonMw) are currently running the 'Choosing Wisely' campaign (*Verstandig Kiezen*), based on the American programme of the same name. Among other things, this programme is aimed at reducing unnecessary diagnostic procedures and treatments and promoting shared decision-making, the latter in conjunction with the Federation of Patients and Consumer Organisations in the Netherlands (NPCF), as part of a project titled 'Deciding Together' (*Samen Beslissen*). Although the project is not aimed exclusively at end-of-life care, it makes sense to work and coordinate with this programme.

In both academic medical centres and hospitals, the medical perspective often dominates the decision-making process, even when multidisciplinary consultation (MDO) is involved. Such bodies often consist only of medical specialists, which can overshadow reflection on social, mental, spiritual, cultural and ideological aspects, as well as general well-being.

The wishes of many patients (either at home or in care institutions) concerning the final stages of their lives are often unknown. Promoting appropriate care during the final stages of life requires advance care planning. This means that, when being admitted to an institution or during a first-line consultation, care providers ask patients who are nearing the end of their lives about the kinds of care they still or no longer want. This information combined with the details provided as part of the handover (see also intervention 7) will form the basis of advance care planning.

Purpose (of the intervention):		For doctors, nurses and other care providers to start working according to the principles of shared decision-making.
9.1	<p>To be achieved by:</p> <p>Who must act:</p>	<ul style="list-style-type: none"> • Making the principles of shared decision-making freely available and easier to apply in practice; • Decision-making tools, such as texts, videos and websites (tested by target groups and evaluated by occupational groups), developed by all scientific associations for the three interventions that most commonly lead to curative overtreatment; • Offering the products created in an easily accessible and understandable manner; • Training doctors, nurses and care workers to work (and collaborate) according to the principles of shared decision-making; • Reorganising/delegating/distinguishing between time and quality (e.g. doctor discusses the diagnosis and (poor) prognosis with the patient, and works with nursing staff to accommodate accordingly). <p>(Associations of) doctors, nurses and care workers, patients and senior citizens (including elderly migrants); care institutions; insurers; education institutions, research institutions; ZonMw.</p>
9.2	<p>To be achieved by:</p> <p>Who must act:</p>	<p>All hospitals implementing a multidisciplinary consultative team (MDO) to assist with complex treatment decisions, in which the patient's general practitioner, elderly care physicians, nurse and other care providers (e.g. spiritual counsellor) can genuinely participate.</p> <p>Doctors, nurses and care workers (and their associations); hospitals; inspectorate.</p>
9.3	<p>To be achieved by:</p> <p>Who must act:</p>	<p>All care institutions in the Netherlands applying an advance care planning protocol upon or shortly after patient admission, by making it part of the institutional information (and other) systems, by training doctors and nurses in consulting skills, etc.</p> <p>Care institutions; doctors, nurses and care workers (and their associations).</p>

10. Mechanism: Strict divide between curative and palliative care

Patients often do not receive any palliative care until all possible curative treatments have been exhausted. That is too late.

Purpose (of the intervention):		To eliminate the strict divide between curative and palliative care.
10.1	To be achieved by:	Granting eligible patients (or those who desire it) palliative care via a palliative team in every hospital in a timely manner, and providing palliative care training both at the hospital and externally.
	Who must act:	Hospitals; doctors, nurses and care workers (and their associations).

11. Mechanism: Guidelines focus on 'action', not 'inaction'

Guidelines generally do not cater to the elderly, or to patients with multiple conditions, and they devote little to no attention to the option of foregoing or discontinuing treatment. Treatment outcomes are generally described in terms of survival (e.g. duration) and severity (and the reduction thereof). There is too little consideration for outcomes that relate to the patient's ability to function, their well-being, quality of life and quality of death.

Medical specialists are still too unfamiliar with applicable palliative care guidelines. See also mechanisms 16 and 20.

Purpose (of the intervention):		When dealing with patients nearing the end of their lives, doctors and nurses should think in terms of scenarios, making the possible outcomes explicit with regard to functioning, well-being and quality of life and discussing them with patients and their next of kin.
11.1	To be achieved by:	Drawing up a checklist to assist with thinking in terms of scenarios.
	Who must act:	Care institutions; occupational/scientific associations.
11.2	To be achieved by:	Screening and improving guidelines to ensure they include a clause or option stating that once the treatment objective can no longer be achieved, 'alternative action' will follow; making these guidelines easily accessible and drawing attention to them via the website, publications, education, etc.
	Who must act:	Doctors, nurses and care workers (and their associations); the National Health Care Institute (ZiN).
11.3	To be achieved by:	Including the effective application of the palliative care guidelines as part of accreditations and inspections.
	Who must act:	Doctors, nurses and care workers.

12. Mechanism: Training programmes predominantly focus on diagnosis and treatment

During medicine programmes, the emphasis is on diagnosis and treatment. There is relatively little attention for all activities and competencies with regard to forgoing treatment and communication in relation to this matter. Palliative care also plays a relatively small part in basic medical training. In addition, too little attention is paid to expertise in relation to vulnerable senior citizens. The same applies to nurse or care worker training.

Care for the elderly is one of the four core issues of CanBetter, which is part of the Modernisation of Further Education in Medicine. The objective is to develop and encourage education in this field through pilots in order to provide better training in elderly care to trainee doctors in all specialist fields.

The Advisory Committee for Care Professions and Training at the Netherlands National Health Care Institute wants to help develop a flexible professional structure and a training continuum based on this structure. In the basic principles described by the Advisory Committee, the importance of attention to appropriate end-of-life care during medical training is not explicitly stated.

Purpose (of the intervention):		To establish more and better-quality training activities during basic medical, nursing and care worker training that address the issue of forgoing treatment, communication about forgoing treatment and attention to palliative care.
12.1	To be achieved by: Who must act:	Encouraging and making requests to training institutions. Doctors, nurses and care workers; doctors', nurses' and care workers' associations.
12.2	To be achieved by: Who must act:	Getting the Advisory Committee for the Innovation of Healthcare Professions and Training Programmes (Adviescommissie Innovatie Zorgberoepen) to include appropriate end-of-life care as an explicit part of the training continuum. The Advisory Committee of the Dutch National Health Care Institute, nursing programmes at the HBO (higher vocational education) level, regional training centres, education institutions, lecturers.

13. Mechanism: Doctors want to conduct scientific research

It is important that doctors working in hospitals – especially teaching hospitals – are able to conduct scientific research. This can result in doctors encouraging patients to undergo more treatment in order to ensure the study meets its required minimum number of patients. Often, too little consideration is given to whether or not patients who satisfy the study's admission criteria should actually be admitted to the study (i.e. if participation may do more harm than good).

Purpose (of the intervention):		To prevent doctors encouraging patients to take part in treatment or research when it is clear that participation will or could harm the patient.
13.1	To be achieved by:	More explicit formulation of inclusion and exclusion criteria and harmful outcomes (and honestly informing patients and their next of kin).
	Who must act:	Medical ethics review boards, institutions, scientific associations.

14. Mechanism: Medical innovations 'must' be used

Due to the enormous progress in the field of medical science and care, the word 'new' when talking about medical innovation is often taken to mean 'better'. This applies not only to manufacturers, patients and care providers, but also policy makers. After all, innovation is good for our knowledge economy. How innovations are tested depends on the type of innovation. Medical technology is predominantly tested with regard to safety, while medicines are also tested for efficacy and efficiency. This is sometimes done via 'conditional admittance' to the basic package, whereupon data is then collected for four years. Time will tell how adequate this process is conducted and whether inefficacious/harmful innovations are recognised as such and subsequently removed from the basic package. For patients in the final stage of life, innovations are even more irresistible than for other groups, even if their efficacy has not been proven. After all, they do not have much time left, few options are available to them and they have little or nothing to lose. These patients therefore have a greater risk than other groups of suffering harm from the negative effects of unproven innovations. They also run this risk when the area of application of existing technologies is expanded.

Purpose (of the intervention):		More realistic representation, testing and decision-making with regard to medical innovations.
14.1	To be achieved by:	Better testing of medical innovations – both technological and pharmaceutical – and of expanded indications for existing technologies, particularly when being used for patients in the final stage of life.
	Who must act:	Dutch Federation of University Medical Centres (NFU), Netherlands Organisation for Health Research and Development (ZonMw), the Federation of Medical Specialists, scientific associations

15. Mechanism: Lack of time

Heavy workloads mean that care providers often have too little time to talk to patients about treatment options in the final stage of life. If the doctor, nurse or care worker is able to take the time to make a collective decision together with the patient, then the likelihood of the patient receiving appropriate care increases. For the interventions, see mechanisms 3 and 9.

16. Mechanism: Doing ‘something’ is better than doing ‘nothing’

Care providers – and doctors in particular – tend to be in ‘treatment mode’. This is certainly the case for many medical specialists. They are trained to ‘do’ something for their patients and have an inner drive to heal patients and preserve life. Doctors do not always have sufficient experience and expertise to know what doing ‘nothing’ entails and how you can deal with it. For the same reason, care providers, patients and their next of kin maintain hope, sometimes against their better judgement. When it comes to hope, it would seem that doctors and patients unconsciously encourage each other to administer treatment. Doctors do not like to talk about forgoing or discontinuing treatment as they do not want to shatter the patient's hopes. In turn, patients often give falsely positive accounts of their condition and how effective a treatment is in the hope of being given more treatment. This creates what is known as a ‘coalition of hope’. More opportunity should be given to creating a ‘coalition of reality’. For the interventions, see mechanisms 1, 9, 12 and 20.

17. Mechanism: Lack of communicative skills

Many care providers have difficulty talking to patients and their next of kin about the forthcoming end of life. Conversations like these require skills that are not included as a compulsory part of basic training. How do you deal with sadness, powerlessness, disappointment, anger, frustration, fear and hope? This is about more than just passing on bad news. It is frequently an extended process in which many people play a role and many decisions have to be made. For the interventions, see mechanisms 9, 11 and 12.

18. Mechanism: The patient's autonomy and limits to it

It is not always easy for care providers to decide how much information they should give the patient. Naturally, for medical decisions regarding end-of-life care, doctors will follow the Medical Treatment Contracts Act (WGB0), in which informed consent is the guiding principle. However, in practice, this leads to dilemmas. For example, there is currently a debate about whether a doctor should give patients all detailed information and his/her medical recommendation, or whether to restrict it to a discussion with the patient about the options that the doctor considers to be relevant, omitting those that he/she considers irrelevant (the paternalistic model). In short, doctors want to respect their patients' autonomy, but often struggle with how this affects the approach they take. For the intervention, see mechanisms 9 and 12.

19. Mechanism: Different cultural and personal beliefs

When providing appropriate care in the final stage of life, the beliefs, norms and values of care providers and patients play a very important role. Attention to the diversity of cultures and personal beliefs is therefore crucial. As standard, basic education, continued education and further training must include basic knowledge about different cultural and personal beliefs and how to deal with different perceptions of illness, old age and death. Attention must also be paid to the development of cultural sensitivity and intercultural skills. The development of expertise in this field will require the involvement of patients, family caregivers and possibly also experts from various communities. For the interventions, see mechanism 22.

Purpose (of the intervention):		Establishing basic knowledge about different cultural and personal beliefs and how to deal effectively with different perceptions of illness, old age and death as a standard part of training programmes.
19.1	To be achieved by:	<ul style="list-style-type: none"> • Developing education and training modules in collaboration with experts from the different communities. • Developing cultural sensitivity in doctors, nurses and care workers by initiating regular consultation at the institutional and partnership/departmental level in order to share experiences. • Conducting research into cultural diversity and personal beliefs.
	Who must act:	Doctors, nurses and care workers; doctors', nurses' and care workers' associations; institutions, training programmes, researchers.

20. Mechanism: Doing something is easier and seems safer than doing nothing

For doctors, it is easier to do 'something' than to do 'nothing'. The same applies to patients and their next of kin. As is the case for doctors, this is a complex mechanism that involves many different factors. For example, some patients have difficulty refusing any treatment that the doctor proposes. The expectations placed on modern medicine are sky-high, even if scans and examinations have shown that nothing can be done. And last but not least, doing 'something' feels safer than doing 'nothing'. A doctor who is still treating you has not given up yet. For the interventions, see mechanisms 1 and 11.

21. Mechanism: Insufficient knowledge of wishes and preferences regarding the end of life (declaration of intention)

Patients often have insufficient knowledge of the various possibilities to record their wishes and preferences with regard to the end of life. For the intervention, see mechanism 2.

22. Mechanism: Increasingly different cultural and personal beliefs held by patients and their next of kin

Based on cultural or personal beliefs, patients and their next of kin may hold certain convictions regarding end-of-life care that Western-educated doctors, nurses and care workers may not consider responsible or relevant. This can make it difficult for patients and their next of kin to notify care providers of their needs and wishes. Patients' organisations and associations for the elderly (including elderly migrants) must be given the opportunity to create informational and educational material regarding this matter. They must also be given the chance to teach their membership how to adequately phrase and express their needs and wishes with regard to the end of life. This information and education must focus on communication with care providers, understanding of healthcare and realistic expectations of healthcare in general (and care providers in particular). Attention must also be given to teaching patients to express symptoms, expectations for the future, and needs and wishes regarding appropriate end-of-life care. Collaboration with care providers can be of great value when educating and informing in this way. For the intervention, see mechanism 19.

Purpose (of the intervention):		Elderly people and migrants must be able to adequately express their wishes regarding care and the end of life.
22.1	To be achieved by:	Associations for the elderly and migrants (including elderly migrants) will provide their members with information and educational material on the matter.
	Who must act:	Associations for the elderly and migrants (including elderly migrants)

23. Mechanism: Complex decision-making

Decisions during the final stage of life can be very complex. Often, many different people are involved and emotions play a huge role. The decision-making process is also seldom static. A wide range of factors (pain, dyspnoea, sadness, predicted course of the disease, worries about next of kin etc.) can mean that a patient may decide differently tomorrow than they would today, and could make a completely different decision a week later. For the interventions, see mechanism 9.

5

The most important interventions

In Chapter 3, 23 mechanisms were described that relate to inappropriate care, focusing on ‘curative overtreatment’ in the final stage of life. Subsequently, in Chapter 4, one or more interventions were formulated that could promote appropriate care.

In this chapter, the Steering Committee will describe the five most important interventions. For these purposes, priority is given to the interventions that are compatible with current practice and that can achieve tangible results in a relatively short time. Some mechanisms have been combined due to their similar or overlapping nature.

In some areas, evidence is lacking. It is therefore extremely advisable that the interventions in question are accompanied by evaluation studies, preferably under the direction of the Netherlands Organisation for Health Research and Development (ZonMw). Furthermore, the Steering Committee recommends that ZonMw (as a follow-up to the ZonMw description ‘Should we really do all we can?’) establishes where there are gaps in knowledge and ensures these gaps are filled by research. This will ensure that the right initiatives can be implemented to promote appropriate end-of-life care.

The Steering Committee invites all parties to start implementing these interventions: if the cap fits, wear it. The basic principle is to dovetail with the working methods, activities and initiatives that are already part of current practice and to promote them in a wider sphere. In Appendix 6, there is a brief overview of what various stakeholders have already announced that they are going to do.

5.1 Acceptance of the end of life is becoming a more normal thing, as is talking about it.

In large sections of society, the dominant opinion is that illnesses should be fought until the point of death (mechanism 16). Naturally, you can respect this opinion, although often – even for terminal patients – it leaves little room for acceptance of and submission to the illness and impending death. Many people see this culture as being a major factor in inappropriate care (mechanism 1). The focus should be on the quality of life in the final stage and the choices available to the patient at this time, as well as promoting the idea within society and the healthcare sector that

forgoing or discontinuing treatment can also be an appropriate care option. This requires greater attention for patients' vulnerability and dependence during the final stage of life and adjusting the expectations placed on medical science. The final stage of life is no longer about administering as much treatment as possible (and extending life to the maximum extent), but providing optimal care (quality of life and well-being).

1.1 Purpose (of the intervention):		Create more room in society for acceptance of and submission to illness and impending death, in order to allow non-treatment (including curative treatment) to be considered appropriate care.
1.1.1	To be achieved by:	Focusing attention on the option of non-treatment (including curative treatment) in medical literature, the media and politics, and adjusting unrealistically high expectations in medical science by painting a more realistic picture of what medicine is capable of.
	Who must act:	Opinion makers; journalists; cultural philosophers; ethicists; doctors, nurses and care workers; doctors', nurses' and care workers' associations; patients; elderly people (including elderly migrants).

Many people do not talk to their friends, next of kin and care providers about their end-of-life wishes (mechanism 2). If patients make these wishes known, this generally enables more appropriate end-of-life care. And even if they do talk about it, this does not mean that they have recorded their wishes in writing. Many people

1.2 Purpose (of the intervention):		To encourage citizens and patients (and their next of kin) to think in advance about their wishes regarding the end of their life, discuss their wishes with their friends, next of kin and care providers and to record these wishes in writing.
1.2.1	To be achieved by:	A publicity campaign.
	Who must act:	Doctors, nurses and care workers; doctors', nurses' and care workers' associations; patients; elderly people (including elderly migrants); insurers.
1.2.2	To be achieved by:	Developing a neutral format for creating a written declaration of intention and making it easily accessible.
	Who must act:	Doctors, nurses and care workers; doctors', nurses' and care workers' associations; patients; elderly people (including elderly migrants); healthcare institutions; the government; insurers.
1.2.3	To be achieved by:	Developing a neutral do-not-resuscitate badge and setting up an adequate distribution channel.
	Who must act:	Associations for the elderly (including migrants); doctors, nurses and care workers; ambulance services; healthcare institutions; insurers; the government.

do not have easy access to neutral declarations of intention, including do-not-resuscitate badges. Patients also often have insufficient knowledge of the various possibilities to record their wishes and preferences with regard to the end of life (mechanism 21).

Based on cultural or personal beliefs, patients and their next of kin may hold certain convictions regarding end-of-life care that Western-educated doctors, nurses and care workers may not consider responsible or relevant. This can make it difficult for patients and their next of kin to make their needs and wishes known to care providers.

Patients' organisations and associations for the elderly (including elderly migrants) must be given the opportunity to create informational and educational material regarding this matter. They must also be given the chance to support their membership in adequately phrasing and expressing their needs and wishes with regard to the end of life. This information and education must focus on communication with care providers, understanding of healthcare and realistic expectations of healthcare in general (and care providers in particular). Attention must also be given to teaching patients to express their symptoms, expectations for the future, and needs and wishes regarding appropriate end-of-life care. Collaboration with care providers can be of great value when educating and informing in this way.

1.3 Purpose (of the intervention):		Elderly people and migrants must be able to adequately express their wishes regarding care and the end of life.
1.3.1	To be achieved by:	Associations for the elderly and migrants (including elderly migrants) will provide their members with information and educational material on the matter.
	Who must act:	Associations for the elderly and migrants (including elderly migrants).

When providing appropriate care in the final stage of life, the beliefs, norms and values of care providers and patients play a very important role (mechanism 22). Attention to the diversity of cultures and personal beliefs is therefore crucial. As standard, basic education, continued education and further training must include basic knowledge about different cultural and personal beliefs and how to deal with different perceptions of illness, old age and death. Attention must also be paid to the development of cultural sensitivity and intercultural skills. The development of expertise in this field will require the involvement of patients, family caregivers and possibly also experts from various communities.

1.4 Purpose (of the intervention):		Establishing basic knowledge about different cultural and personal beliefs and how to deal effectively with different perceptions of illness, old age and death as a standard part of training programmes.
1.4.1	To be achieved by:	<ul style="list-style-type: none"> • Developing education and training modules in collaboration with experts from the different communities. • Developing cultural sensitivity in doctors, nurses and care workers by initiating regular consultation at the institutional and partnership/departmental level in order to share experiences. • Conducting research into cultural diversity and personal beliefs.
	Who must act:	Doctors, nurses and care workers; doctors', nurses' and care workers' associations; institutions, training programmes, researchers.

5.2 Clarify patients' wishes and improve cooperation, including passing on information.

Caring for and treating patients in the final stage of life often involves care providers from many different disciplines. In practice, these care providers do not always work well together (mechanism 7). For example, the different care forms are not always well coordinated and important information is not always provided on time or in full (mechanism 6). It can help if GPs are more frequently able to talk to vulnerable elderly people and patients with life-threatening illnesses about their wishes and expectations regarding the end of life (care, well-being, living arrangements) at a stage when this is not yet imminent (mechanism 2).

2.1 Purpose (of the intervention):		To record the wishes of patients in their final stage of life and other relevant information in their dossier and to ensure it is passed on in a timely manner.
2.1.1	<p>To be achieved by:</p> <p>Who must act:</p>	<p>Developing and implementing a National Transmural Agreement (LTA), including:</p> <ul style="list-style-type: none"> • Conditions that must be satisfied in order to pass on information to GP practices, hospices, nursing homes or hospitals. • Conditions that referral letters must comply with. • Conditions that feedback must comply with. • A protocol for standard contact moments. <p>Doctors, nurses and care workers; doctors', nurses' and care workers' associations; healthcare institutions.</p>
2.1.2	<p>To be achieved by:</p> <p>Who must act:</p>	<p>Enabling GPs to talk to vulnerable elderly people and patients with potentially life-threatening illnesses about their wishes and expectations regarding the end of life (care, well-being, living arrangements) at a stage when this is not yet imminent. The National Primary Care Collaboration Agreement (LESA) for Advance Care Planning serves as a basis regarding resuscitation of vulnerable elderly people. These patients will receive support in the form of a brochure and will be invited to a consultation on this matter. An appropriate tariff will be set.</p> <p>Doctors, nurses and care workers; doctors', nurses' and care workers' associations; patients; elderly people (including elderly migrants); insurers.</p>
2.1.3	<p>To be achieved by:</p> <p>Who must act:</p>	<p>Realising a guideline/National Transmural Agreement (LTA) that includes basic principles for cooperation between GPs and specialists, including consultations with and visits to the patient by the GP. LTAs serve as a basis for regional transmural cooperation agreements.</p> <p>Doctors, nurses and care workers; doctors', nurses' and care workers' associations.</p>

Many patients, especially the elderly, are treated by multiple care providers. This is the case for medical practitioners in both primary and secondary care. In such cases, it is often unclear who is directing the treatment, who the primary practitioner is and who the contact person is for the patient and his/her family (mechanism 8). In practice, it is difficult to make clear agreements.

2.2 Purpose (of the intervention):		All patients – especially those with multimorbidity or life-threatening illnesses – must know who their primary practitioner is, who their contact person is (and how to reach this person) and who coordinates and directs their treatment.
2.1.1	To be achieved by:	Systematically recording the distribution of responsibilities and notifying/passing this information on to the patient or his/her next of kin in writing. The guide to distribution of responsibilities for healthcare cooperation can serve as a guideline in this matter.
	Who must act:	Doctors, nurses and care workers; doctors', nurses' and care workers' associations; healthcare institutions; inspectorate.

5.3 Deciding together and improving decision-making.

Different decision-making methods or models are used for decision-making during the final stage of life (mechanism 9). Shared decision-making is an intervention that has been proven to promote appropriate care. In general 'deciding together' should be the basic principle in the healthcare sector and work is being conducted to make this the case, such as the 'Deciding Together' (*Samen Beslissen*) initiative set up by the Federation of Patients and Consumer Organisations in the Netherlands (NPCF). Compatibility and coordination with this initiative is being sought.

In hospitals, the medical perspective is often the guiding force behind the decision-making process, including when multidisciplinary consultation is involved. Generally, the participants in such consultations are overwhelmingly medical specialists, which means that reflection on social, psychological, spiritual and cultural aspects, personal beliefs and well-being is usually drowned out.

Many patients – both those living at home and those living in healthcare institutions – have not made their wishes known with regard to the end of life. In order to promote appropriate care in the final stage of life, advance care planning is needed. In such cases, upon admission to an institution or a primary-care consultation, care

5.4 Don't just focus guidelines on 'doing something', but also on 'doing nothing' or 'doing something different'.

Generally, guidelines are not designed with elderly patients or patients with multiple diseases in mind. Furthermore, the guidelines pay little to no consideration to the option of forgoing or discontinuing treatment (mechanism 11). Treatment results are generally described in terms of survival rates/durations and the degree/reduction of disease burden. Too little attention is paid to results relating to the patient's well-being, quality of life and ability to function. There is still insufficient awareness amongst medical specialists of the applicable guidelines for palliative care. See also mechanisms 16 and 20.

4.1 Purpose (of the intervention):		With regard to patients in the final stage of life, doctors and nurses must think in terms of scenarios and consider possible outcomes regarding the patient's well-being, quality of life and ability to function, explicitly specify the expected results with regard to these aspects and discuss them with the patient and his/her next of kin.
4.1.1	To be achieved by: Who must act:	Creating a checklist for thinking in terms of scenarios. Healthcare institutions, professional and scientific associations.
4.1.2	To be achieved by: Who must act:	Screening and improving guidelines so that they include the option/clause that if the goal can no longer be achieved, then 'doing something else' (i.e. not doing nothing) is the next course of action, as well as making these guidelines easily accessible and focusing attention on them via the website, publications, education etc. Doctors, nurses and care workers; doctors', nurses' and care workers' associations; the Netherlands National Health Care Institute (ZiN)
4.1.3	To be achieved by: Who must act:	Establishing adequate use of the guidelines for palliative care as part of accreditations and visitations. Doctors, nurses and care workers; doctors', nurses' and care workers' associations.

5.5 Focus the healthcare system more on suitability and less on production.

In the current healthcare system, particularly in hospitals, billing is often conducted per procedure. There can therefore be a financial incentive to conducting declarable procedures. As a result, forgoing treatment is less attractive from a financial point of view (mechanism 3 and 15).

5.1 Purpose (of the intervention):		Offering a counterweight to the wrong type of production-oriented incentives during the final stage of life.
5.1.1	To be achieved by: Who must act:	Developing an adjusted funding system for end-of-life care. The Ministry of Health, Welfare and Sport (VWS), the Dutch Healthcare Authority (NZa), insurers, doctors' associations.
5.1.2	To be achieved by: Who must act:	Encouraging medical specialists and hospital administrators to actively make contractual agreements regarding 'intensive consultations' in order to achieve a careful balance of treatment options (listening and making shared decisions with the patient). Partnerships/departments, doctors' associations, institutions, the Dutch Healthcare Authority (NZa), insurers.

Heavy workloads mean that care providers often have too little time (mechanism 15) to talk to patients about treatment options in the final stage of life. If the doctor, nurse or caregiver is able to take the time to make a collective decision together with the patient, then the likelihood of the patient receiving appropriate care increases. For further information, see priority 4.

APPENDIX

1

Steering Committee for Appropriate End-of-Life Care

In April 2013, the Royal Dutch Medical Association (KNMG), a federation of medical practitioners' professional associations, set up a steering committee to help provide appropriate care to people in the final stage of life. GPs, medical specialists, elderly care physicians, nurses, patients' organisations and associations for elderly care are all represented on the steering committee.

Composition

- G. (Gerrit) van der Wal, MD, PhD, former Inspector-General of the Netherlands Healthcare Inspectorate (IGZ), chair of the steering committee
- J. (Jettie) Bont, MD, PhD, GP, Hilversum
- L. (Lucas) Koch, MD, GP and scientific officer, the Dutch College of General Practitioners (NHG)
- J. (Job) Kievit, MD, PhD, surgeon and professor of healthcare quality, Leiden University Medical Centre (LUMC), via the Association of Surgeons of the Netherlands (NVVH)
- S.E.J.A. (Sophia) de Rooij, MD, PhD, professor of internal medicine (specialising in geriatric care), Academic Medical Centre Amsterdam and University Medical Centre Groningen, via the Netherlands Association of Internal Medicine (NIV)
- M.G.M. (Marcel) Olde Rikkert, MD, PhD, professor of geriatrics, Geriatrics Department/Radboud Alzheimer's Centre, Radboud University Medical Centre, Nijmegen, via the Netherlands Society of Clinical Geriatrics (NVKG)
- P.E.J. (Petra) van Pol, MD, cardiologist, Rijnland Hospital, via the Dutch Society of Cardiology (NVVC)
- P.C. (Peter) Huijgens, MD, PhD, professor emeritus of haematology, VU University Medical Centre (VUmc), director of Comprehensive Cancer Centre the Netherlands (IKNL)
- J.C.M. (Jan) Lavrijsen, MD, PhD, elderly care physician, senior researcher specialising in elderly care and programme manager of the Complex and Palliative Care Department, Primary Healthcare, Radboud University Medical Centre, via the Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso)
- J.H. (Henk) Bakker MHA, chair, V&VN Dutch Nurses' Association
- M.L. (Marjolein) van Meggelen MZO, networks advisor, Comprehensive Cancer Centre the Netherlands (IKNL), V&VN Palliative Care Department
- W. (Wilna) Wind, director, Federation of Patients and Consumer Organisations in the Netherlands (NPCF)
- M.H.P. (Anemone) Bögels MBA, director, Living With Cancer (previously known as the Dutch Federation of Cancer Patient Organisations [NFK])

- A.A.M. (Ans) Willemse-van der Ploeg, Union of Catholic Senior Citizens' Associations (Unie KBO)
- Y.M. (Yvonne) Heygele, advisor, Network of Organisations of Elderly Migrants (NOOM)

Support

- E.H.J. (Eric) van Wijlick, policy advisor, secretary of the steering committee, Royal Dutch Medical Association (KNMG)
- G. (Gert) van Dijk, policy advisor, secretary of the steering committee, Royal Dutch Medical Association (KNMG)
- E.L.M. (Eveline) van Dieten, communication coordinator, Royal Dutch Medical Association (KNMG)
- T.S. (Tom) Hoyer, intern, Royal Dutch Medical Association (KNMG) (until July 2013)
- G. (Gonny) ten Haaft, editor, Netherlands Organisation for Health Research and Development (ZonMw), author

Researchers

- E. Bolt, MD, trainee GP, Academic Medical Centre Amsterdam, junior researcher, VU University Medical Centre (VUmc)
- B.D. Onwuteaka-Philipsen, PhD, professor of end of life care, EMGO Institute for Health and Care Research (EMGO+) at VU University Medical Centre (VUmc)

Tasks:

- a) Conducting an analysis/creating an inventory of the nature and scale of the issue.
- b) Describing the circumstances and mechanisms that could result in the provision of inappropriate or no end-of-life care.
- c) Investigating and identifying good ideas, best practices and instruments (including policy-support measures), and examining how these can be disseminated and implemented.
- d) Delivering and producing/commissioning the production of concrete products such as publications, viewpoints and instruments that can promote appropriate end-of-life care.
- e) Publicly addressing the issue and further stimulating the social debate.

This publication addresses three of these activities, namely a, b and c.

Firstly, the Steering Committee has analysed the mechanisms that explain why patients in this stage of life undergo treatment that is not or no longer appropriate (task b). Secondly, based on the described mechanisms, several interventions have been identified that can prevent inappropriate care (part of task c). Thirdly, the first results of a survey of the nature and scale of the issue are included in this publication (part of task a).

Activities:

- Examine relevant literature.
- Set a research assignment for the EMGO Institute for Health and Care Research (EMGO+) at VU University Medical Centre (VUmc) addressing the nature and scale of inappropriate care, by means of a questionnaire survey, amongst other methods. This survey has been widely publicised among various groups in Dutch society.
- Organise focus groups with patients/seniors/migrants.
- Organise a number of hearings with experts from various fields in the healthcare sector.

Based in part on the above activities, extensive discussions have been conducted within the Steering Committee to determine which mechanisms *do/could* indeed lead to overtreatment. Interventions have also been proposed within the Steering Committee that could reduce the amount of overtreatment in the final stage of life. Attention has also been paid to whether there are mechanisms that have been given too little or no attention so far.

You must bear in mind that little scientific research has been conducted into these mechanisms, so to a large extent, evidence for the prevention and importance of the various factors is still lacking. Data about practical variation (differences in curative treatment in various regions or by various care providers) and analysis of the determinants of this variation can be used as a method for quantifying the importance of the factors and identifying opportunities for interventions. Little research has yet been conducted into the proposed interventions, so evidence of their effectiveness is also lacking.

APPENDIX

2

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APPENDIX

3

Participants in the hearing

- A. van der Heide, MD, PhD, professor of end-of-life care and decision-making, Erasmus Medical Centre
- T.A. Boer, PhD, university lecturer in ethics, Protestant Theological University
- B. Meyboom-de Jong, MD, PhD, chair, National Care for the Elderly Programme (NPO)
- B.A.M. The, PhD, professor of long-term care and dementia, University of Amsterdam
- J.C.J.M de Haes, PhD, professor of medical psychology, Academic Medical Centre Amsterdam
- F.M. de Graaff, PhD, researcher, Bureau Mutant
- H. Bakir, PhD, theologian, lecturer and spiritual counsellor, Laurens Rotterdam
- A.C. Nieuwenhuijzen Kruseman, MD, PhD, professor emeritus of internal medicine and former chair of the Royal Dutch Medical Association (KNMG)
- H.J.T. Rutten, MD, PhD, professor of surgical oncology, Catharina Hospital
- C.A.H.H.V. Verhagen, PhD, internist-oncologist, Radboud University Medical Centre Nijmegen
- C.M.P.M. Hertogh, MD, PhD, professor of elderly care medicine & geriatric ethics, VU University Medical Centre (VUmc)
- D. Timmermans, PhD, professor of risk communication and patient decision-making, EMGO Institute for Health and Care Research (EMGO+) at VU University Medical Centre (VUmc)
- D.T. Ubbink, MD, PhD, university lecturer, Academic Medical Centre Amsterdam
- W.C. Peul, MD, PhD, professor of neurosurgery, Leiden University Medical Centre (LUMC)
- W. ten Wolde, programme manager, Ambulancezorg Nederland (Sector Organisation for Ambulance Services in the Netherlands)
- P.A.M. Vierhout, MD, PhD, former chair of the Regulatory Council for the Quality of Care
- G.P. Westert, PhD, professor of healthcare research and quality of care, IQ healthcare, Radboud University Medical Centre Nijmegen
- B. Berden, PhD, professor of organisational development in hospitals, Tilburg University, chair of the board, Elisabeth Hospital
- S.C.C.M. Teunissen, PhD, professor of hospice care, University Medical Centre Utrecht
- R. de Korte-Verhoef, PhD, EMGO Institute for Health and Care Research (EMGO+) at VU University Medical Centre (VUmc)
- A.L. Francke, PhD, professor of nursing and care provision, Netherlands Institute for Health Services Research (NIVEL)/EMGO Institute for Health and Care Research (EMGO+) at VU University Medical Centre (VUmc)

During the various hearings, the experts answered the following four questions:

1. What do you consider to be appropriate end-of-life care?
2. What do you consider to be the main cause of inappropriate end-of-life care?
3. In your opinion, which mechanisms have an impact (positive or negative) on appropriate end-of-life care?
4. What do you consider to be the three best interventions to ensure appropriate end-of-life care?

APPENDIX

4

Research into the nature and scale of appropriate end-of-life care

To get a picture of the problems that arise in the final stage of life, a large-scale survey was set up. The goal of the survey was to identify and prioritise the main problems with end-of life care in the Netherlands. A number of recommendations in the report are based on the results of this survey. In this appendix, you can find an overview of the survey results. A more comprehensive description of the results will be published in separate articles.

Summary

The researchers asked patients, next of kin and care providers to give examples of inappropriate care. These open questions revealed two particular types of inappropriate care, namely ‘curative overtreatment’ and ‘palliative undertreatment’. In a limited number of examples, ‘curative undertreatment’ was also reported.

‘Curative overtreatment’ relates to illness-oriented treatment that aims to cure the patient or prolong his/her life, but results in undesirable effects. This includes, for example, aggressive or otherwise harmful treatments or diagnostics methods that reduce quality of life. In terms of the aforementioned palliative-care model, this relates to the diagonal line – which enables care and treatment oriented towards quality of life – being applied too late.

‘Palliative undertreatment’ primarily affects patients who receive too little palliative care during the final stages of their lives. This includes relief from pain and symptoms, as well as attention to other needs and wishes of the patient and their loved ones during this time. Key aspects here include maintaining the patient’s ability to function, and improved well-being. In the palliative-care model, this means that care providers will ensure the patient receives enough symptom-oriented palliation and support when less/no more treatment is being administered to cure the patient or extend his/her life.

An important question in the survey addresses what is understood by the term ‘appropriate care’. Many respondents shared the opinion that care is appropriate if it ‘suits the wishes of the patient’. In this respect, the respondents often mentioned the principles of shared decision-making. In order to make a well-considered decision, it is necessary that the patient is given comprehensive and timely information. The medical practitioner can then involve the patient in the decision-making process as much as is possible/desirable. It is also important to listen carefully to the patient’s needs and problems at other moments to enable timely action to be taken.

Other conditions for appropriate care that the respondents raised include sufficient physical and spiritual care, effective treatment of symptoms, support and counselling of the patient and his/her next of kin, and an appropriate location. For the latter of these aspects, the majority of respondents indicated a preference for home care.

1. Survey setup

The survey was designed to shed light on the problem of inappropriate end-of-life care from a variety of perspectives. Every person in the Netherlands who has had experience with end-of-life care, either as a patient, next of kin or care provider, could fill in an online questionnaire. The online questionnaire was brought to the attention of care providers and citizens via a variety of channels. The survey was supported by various patients' organisations, associations for the elderly and medical organisations. Potential participants were approached via e-mail, social media such as Twitter and Facebook, newsletters and a link on various home pages. The participating organisations were the Royal Dutch Medical Association (KNMG), Hematon, the Dutch Federation of Cancer Patient Organisations (NFK), the Federation of Patients and Consumer Organisations in the Netherlands (NPCF), the Dutch Patients' Association (NPV), the Dutch Association for Voluntary Euthanasia (NVVE), the Union of Catholic Senior Citizens' Associations (Unie KBO), Agora, Ambulancezorg Nederland (Sector Organisation for Ambulance Services in the Netherlands), the Haemato Oncology Foundation for Adults in the Netherlands (HOVON), Comprehensive Cancer Centre the Netherlands (IKNL), the Dutch College of General Practitioners (NHG), the Dutch Society of Cardiology (NVVC), the doctors' network Support and Consultation in Euthanasia in the Netherlands (SCEN), the Dutch Association of Elderly Care Physicians and Social Geriatricians (Verenso), the Netherlands Association of Spiritual Counsellors in Care Institutions (VGVZ) and the V&VN Dutch Nurses' Association. In addition, a paper questionnaire was sent to the homes of over 4,700 members of the Union of Catholic Senior Citizens' Associations (Unie KBO).

In the questionnaire, the respondents were asked about their experiences with end-of-life care and to indicate whether the care was appropriate or inappropriate. In addition, general questions were asked about end-of-life care, problems and solutions. The answers to the questions were coded in order to quantify them. To make the analysis as objective as possible, no code scheme was set in advance. The code scheme was created based on the respondents' answers.

2. Response

1,648 people took part in the survey: 91 patients, 593 next of kin, 349 doctors, 389 nurses and care workers, 100 spiritual advisors, 88 ambulance workers, 20 managers/policy officers, 15 healthcare volunteers and 28 other care providers. The

doctors and nurses worked in home care and in care/nursing homes, hospitals, hospices, other residential-care facilities and in the ambulance service. The respondents ranged from 23 to 88 years of age, 33% were male and all provinces of the Netherlands were represented amongst the respondents.

A particularly notable factor is that 45% of the participants and next of kin learned about the survey via the Dutch Association for Voluntary Euthanasia (NVVE) and 44% work/have worked in the healthcare sector. Wherever this may have influenced the results of the survey, this has been stated separately in the description of the results.

3. Results

Part 1. Summary: Appropriate end-of-life care

1. Definition and investigation of the problem

The respondents were asked the open question ‘What is appropriate end-of-life care?’ We have created the following summary from the most frequently given answers. The brackets display the percentage of patients/next of kin and the percentage of care providers (respectively) who gave this answer:

Appropriate end-of-life care:

- Complies with the wishes of the patient as much as possible (54% and 49%).
- Is based on decisions made following effective communication (20% and 26%), and preferably in consultation (26% and 7%) with the doctor and a well-informed patient (9% and 13%).
- Ensures sufficient care (6% and 10%) that is suitable to the patient's life (12% and 11%).
- Is provided by skilled (6% and 10%), committed (10% and 14%) and empathetic (11% and 5%) care providers who cooperate effectively (4% and 9%).
- Focuses on both the physical (8% and 11%) and the spiritual (11% and 17%) as well as on improving the quality of life (11% and 23%).
- Pays attention to the important role of the next of kin and the support provided to them (9% and 18%).

Most respondents indicated that the cause of inappropriate care cannot be ascribed to one group alone. Although doctors are seen as playing the leading role, the respondents also recognise the role played by nurses, patients, next of kin, the media, health insurers, the government and managers in the healthcare sector.

2. Cases

At the beginning of the questionnaire, based on open questions, respondents could describe experiences they have had with appropriate/inappropriate care. The patients and next of kin (hereinafter referred to as 'the public') described 429 cases of appropriate care and 309 cases of inappropriate care. The care providers described 582 cases of appropriate care and 486 cases of inappropriate care.

Most of the cases of both appropriate and inappropriate care related to cancer patients (64% and 58% in the cases of appropriate and inappropriate care respectively). Other frequently mentioned conditions were old age (18% and 21%), dementia (10% and 12%) and heart disease (10% and 12%). The age of the patients was quite evenly spread across the three categories of 65 years and under (30%), 66-79 years (30%) and 80 years and above (40%).

The respondents described why they considered the care to be appropriate or inappropriate. The aspects of care that were given as reasons are displayed in table 1. The cases experienced as appropriate care are described to the left of the dotted line in the table, while those experienced as inappropriate are displayed to the right. The aspects of the descriptions can be roughly divided into seven categories: medical treatment/decisions, supporting care, support and guidance, communication, location of the care, customisation, and an 'others' category.

Making the right treatment decision was a major aspect of end-of-life care. This was mentioned in approximately half of the cases of appropriate care and in nearly three-quarters of the cases of inappropriate care. Often, the decision involved either starting/continuing or forgoing/discontinuing a course of treatment intended to cure the patient or extend his/her life. In this regard, starting/continuing the treatment was often seen to be an inappropriate course of action (by 38% of the public and 49% of care providers). On the other hand, forgoing/discontinuing treatment was often stated as being an appropriate course of action (25% of the public and 32% of care providers). Incidentally, starting treatment designed to cure the patient or extend his/her life was more frequently considered to be an appropriate course of action among members of the public who work or have worked in the healthcare sector than the other groups (14% compared with 6%). In a third of the cases, other medical treatments and decisions were mentioned in addition to decisions regarding curative treatment. Treatment of symptoms was important (18-24%), such as pain relief or application of palliative sedation (deliberate reduction of consciousness in the final days of the patient's life). In addition, the application of euthanasia was often valued (11-14%), and the public in particular considered the non-application of euthanasia to be inappropriate care (17%). This percentage may be skewed by the respondents who learned about the survey via the newsletter of the Dutch

Association for Voluntary Euthanasia (NVVE). The members of the public who learned about the survey via the NVVE more frequently considered euthanasia to be appropriate care (24% compared to 6% amongst the other members of the public) or considered the refusal to conduct euthanasia to be inappropriate care (26% compared to 8% amongst the other members of the public).

The table shows that it is not only treatment decisions that determine whether end-of-life care is experienced as appropriate or inappropriate. Supporting care, such as good personal care and attention to psychosocial aspects, also frequently played a role (16-38%). In addition, support and guidance were mentioned in approximately half of the cases. The respondents described the importance of support and guidance for both the patient (18-43%) and for the next of kin (5-18%). In 39-50% of the cases, the respondents went on to describe the role played by communication between the care provider and the patient. Respondents reported the need for care providers who treated the patient with respect and compassion, who kept the patients well-informed and listened to their wishes and problems, and who consulted and made agreements with them regularly and in a timely manner.

Another aspect that was important to the respondents was the location of the care. This was a particularly important issue in the cases of appropriate care. Of these, the ability to be treated at home was the most highly valued aspect (27-30%). Staying in hospital was most frequently experienced as inappropriate (8-18%), although it was sometimes considered appropriate (5%).

A more general theme was providing care in accordance with the patient's wishes. This was mentioned as an important aspect in more than a third of the cases of appropriate care. Finally, care providers in particular reported that for appropriate care, good coordination and continuity of care was an important aspect.

Table 1: Characteristics of appropriate and inappropriate care

	Appropriate care		Inappropriate care	
	Members of the public n=429 %	Care providers n=582 %	Members of the public n=309 %	Care providers n=486 %
Medical treatment				
Active curative treatment* or diagnostics	53	58	69	75
'Overtreatment' (in cases of inappropriate care)	11	5	38	49
Forgoing curative treatment* or diagnostics	25	32	6	3
Other medical procedures and decisions	30	35	33	27
Effective treatment of symptoms (including palliative sedation)	18	24	-	-
Insufficient treatment of symptoms	-	-	14	20
Excessive treatment of symptoms†	-	-	5	1
Complying with a request for euthanasia or assisted suicide	14§	11	-	-
Refusing a request for euthanasia or assisted suicide	-	-	17	7
Care				
Supporting care	35	38	27	16
Good personal care	28	20	-	-
Insufficient or below-par personal care	-	-	26	12
Sufficient attention to psychosocial aspects	11	25	-	-
Insufficient attention to psychosocial aspects	-	-	1	4
Support and guidance	51	65	39	46
Support and guidance provided to the patient by care providers	38	43	-	-
Insufficient support and guidance provided to the patient by care providers	-	-	18	18
Support and attention provided to the next of kin by care providers	12	18	-	-
No support or attention provided to the next of kin by care providers	-	-	11	5
Support provided to the patient by the next of kin	8	5	-	-
No support provided to the patient by the next of kin or no next of kin present	-	-	2	9
Communication between practitioner and patient	39	47	50	49
Regular consultation and agreements made	15	23	-	-
Insufficient consultation and agreements	-	-	15	16
Care provider showed respect/empathy	15	10	-	-
Lack of respect/empathy from the care provider	-	-	14	4
Care provider shows interest in the patient and listens to him/her	9	12	-	-
Care provider does not show interest in the patient or does not listen to him/her	-	-	19	13
The patient is well-informed regarding his/her prognosis and treatment options	8	12	-	-
The patient is insufficiently informed	-	-	21	23

Table 1 (continued): Characteristics of appropriate and inappropriate care

Care	Appropriate care		Inappropriate care	
	Members of the public n=429 %	Care providers n=582 %	Members of the public n=309 %	Care providers n=486 %
Location	46	47	11	19
Able to stay at home (as much as possible)	27	30	1	1
Admittance to hospital	5	5	8	18
Admittance to a care/nursing home	9	7	2	1
Admittance to a hospice	6	8	-	0
Customised care	41	39	28	19
Care in accordance with the patient's wishes	41	39	-	-
Care not in accordance with the patient's wishes	-	-	28	19
Other				
Continuity and coordination of care	10	29	-	-
Insufficient continuity and coordination of care	-	-	14	27
Errors and complications	-	-	4	0
Other†	2	4	8	5

* Treatment aimed at curing the patient or prolonging his/her life.

† Resulting in, for example, side effects.

‡ Such as psychiatric treatment, patronisation, problems relating to euthanasia etc.

§ The percentage was higher among members of the public who were recruited via the NVVE (24%) and lower among non-NVVE recruits (6%).

|| The percentage was higher among members of the public who were recruited via the NVVE (26%) and lower among non-NVVE recruits (8%).

In summary, appropriate end-of-life care depends on many different aspects. With regard to treatment decisions, the survey found that the most common problem according to both members of the public and care providers is overtreatment that is oriented towards curing the patient or prolonging his/her life. This report will therefore go into greater detail on this aspect. Wherever we talk about overtreatment, we are referring to treatment oriented towards curing the patient or prolonging his/her life.

Part 2. Overtreatment

1. The most common forms of overtreatment

In order to examine the problem of overtreatment in depth, the 355 cases of inappropriate care that involved overtreatment were analysed separately. Overtreatment was reported in all age groups (slightly more often in the 80+ age group) and there were no conditions for which overtreatment was more frequently administered to any significant degree. Table 2 displays which types of treatment were seen as overtreatment in the cases of inappropriate care. The cases that the members of the public described related particularly to diagnostics (15%), admission to hospital (14%), operations (14%), preventive medication (10%), chemotherapy (9%), drip feeding (9%) and radiotherapy (8%). The care providers reported similar measures, although they more frequently mentioned chemotherapy (19%) and admission to hospital (17%), and rarely mentioned radiotherapy (1%).

The questionnaire also asked all care providers which types of overtreatment occurred most frequently (open question). 798 of these care providers mentioned 1-3 types of treatment. The answers matched the treatments reported in the cases of overtreatment. Chemotherapy (22%), diagnostics (18%), admission to hospital (14%), food and fluids (artificially administered or otherwise) (13%), preventive medication (11%) and operations (9%) were the most frequently reported aspects of care.

Table 2: The most common forms of overtreatment (cases)

	Members of the public n=117 %	Care providers n=238 %
Too much/too severe diagnostics	15	10
Go to hospital for admission or treatment	14	17
Operations	14	11
Chronic/preventive medication*	10	1
Chemotherapy	9	19
Food and fluids (drip feed, intravenous or otherwise)	9	8
Radiotherapy	8	1
Resuscitation	5	8
Intensive care treatment/artificial respiration	4	3
Antibiotics	3	3
Blood products	3	1
Rehabilitation	3	2
Other cancer treatments†	2	2
Dialysis	2	1
Other	3	2
Not specified	11	13

* Such as anti-hypertensive medication, cholesterol-reducing medication etc.

† Such as stem-cell transplantation, hormone therapy, immunotherapy etc.

2. Consequences of overtreatment

Overtreatment is frequently reported by the respondents as a reason why they considered the treatment inappropriate. The question also arises of what makes overtreatment a problem. What are the actual consequences of overtreatment? This survey offers an answer to this question. The respondents that described cases in which overtreatment was a factor were asked to describe its consequences. The answers to this question are displayed in table 3.

The most frequently given answers were reduced quality of life (41% and 39% of members of the public and care providers respectively), physical symptoms (31% and 23%) and being in unpleasant surroundings (18% and 27%), e.g. not being able to die at home or having to travel frequently to the hospital for treatment. The respondents also mentioned that overtreatment led to psychological issues in the patient (15% and 7%) and the next of kin (14% and 17%), such as feelings of fear, uncertainty and guilt. Overtreatment also resulted in a lack of realisation that the end was coming (7% and 10%), which made acceptance and closure difficult (8%).

Table 3: Consequences of overtreatment (cases)

	Members of the public n=105 %	Care providers n=238 %
Reduced quality of life or increased severity	41	39
Physical symptoms	31	23
Unpleasant environment*	18	27
Concern in the patient†	15	7
Concern amongst the next of kin‡	14	17
Patient/next of kin had no opportunity for acceptance/closure	8	8
Patient did not realise death was nearing	7	10
Anger/conflict	3	4
Accelerated the process of death or risked doing so	3	3
Patient took action him/herself	3	1
Lack of dignity and control	1	7
Death was not peaceful	0	4
Other	3	8

* Such as being unable to die at home, having to frequently travel to the hospital etc.

† Such as feeling afraid, unsafe, uncertain, lonely, regret, conscience-stricken etc.

‡ Such as guilt, fear, feeling overburdened etc.

3. Causes of overtreatment

In the cases featuring overtreatment, the respondents described what they thought the cause of the inappropriate treatment was. Table 4 shows that in the majority of cases of overtreatment, the doctor played a role in causing inappropriate care, a fact agreed upon by both the public and care providers. In a quarter of the cases, care providers stated that the patient or next of kin played a role, while the public rarely reported this. The public more frequently described a role being played by the nursing staff or care workers.

Table 4: Role of various players in overtreatment

	Members of the public n=117 %	Care providers n=238 %
Doctors	86	85
Nurses and/or care workers;	21	8
Patient and/or next of kin	5	24
Policy and management	2	0
Other care providers*	3	2
Not specified	19	10

* Such as physiotherapists, spiritual counsellors, social workers, doctor's assistants, psychologists etc.

Table 5 summarises the most frequently occurring causes of overtreatment in the cases. The most frequently mentioned causes of inappropriate care can be grouped into five categories: insufficient communication with the patient, decision-making problems, insufficient guidance, the tendency for doctors to continue treatment and insufficient cooperation between care providers.

Communication problems between care provider and patient

In half of the cases, the communication with the care provider (mostly the doctor) was insufficient. The main problem with the communication was insufficient provision of information by the doctor (30% and 34% amongst members of the public and care providers respectively). Often, there was a lack of clarity and honesty regarding the prognosis and expectations regarding the treatment, and disadvantages/side effects of the treatment were insufficiently communicated. In addition, insufficient information about possible palliative alternatives was sometimes given. In addition to the provision of information, respondents also reported too little consultation and too few agreements being made (14% and 11%), as well as care providers who do not listen to the patient enough (14% and 9%).

Decision-making problems

In more than a third of cases, problems directly related to decision-making were reported. Members of the public most frequently mentioned that the wishes of the patient were not sufficiently taken into account during the decision-making process (30%) or that the patient had to make a decision under pressure (from next of kin, the doctor, or a feeling of being against the clock) (10%). The care providers placed greater emphasis on problems faced by the doctor during the decision-making process, such as feeling pressured to treat by the patient or next of kin (10%).

Insufficient guidance and support from care providers

Insufficient support was reported as a cause of overtreatment in around a third of cases. This mostly related to doctors following protocols or routines and therefore paying insufficient attention to the patient's individual situation (21% and 16%). Less frequently occurring problems included insufficient evaluation and incorrect estimation of the patient's situation, lack of contact between care provider and patient, an insufficient bond of trust between the care provider and patient, and insufficient availability of the care provider.

Tendency of the doctor (and patient) to continue treatment

In a third of cases, the respondents said the doctor was too heavily oriented towards treatment. This was because, for example, the doctor focused only on curing the patient, even when the likelihood of a cure was slim (11% and 8%). Sometimes doctors did not seem to consider forgoing/discontinuing treatment to be an option: they were in 'treatment mode' (9% and 15%). Some respondents thought that doctors carried on administering treatment as they did not want the patient to lose hope (6% and 14%). In other cases, the doctors seemed to have unrealistic expectations regarding the treatment and seemed to avoid any conversations about death or discontinuation of treatment. Care providers reported more often than members of the public that the patient played a role in the overtreatment (19%). With regard to this issue, they said that patients chose to undergo treatment out of hope for a cure (8%) or due to a lack of acceptance that death was approaching (11%).

Insufficient cooperation and coordination

A frequently reported problem was the lack of cooperation and coordination of care (20% and 29%). Cooperation between care providers was sometimes insufficient (13% and 21%) due to a lack of consultation, coordination and continuity within primary care, between primary and secondary care, and between the doctor and nurses. In addition, respondents indicated that in some cases, the various practitioners, the patient and the next of kin were not always in agreement with each other (9% and

10%). Respondents also said that particular practitioners had an insufficient overview of the situation as their expertise was in a very specific area or they consulted too little with other practitioners and were therefore insufficiently able to recognise the disadvantages of the treatment for the patient (3% and 12%).

Other mechanisms

Less frequently occurring problems included a lack of knowledge of the patient's wishes, care providers paying insufficient attention to next of kin, and a less than satisfactory attitude displayed by the care provider. In 20% of the cases, care providers indicated that the patient had not made his/her wishes known, mostly because timely discussion of his/her wishes had not been discussed (advance care planning). In 12% and 11% of the cases, the care providers paid insufficient attention to the next of kin, resulting in them being insufficiently aware of the situation or feeling overburdened. Finally, some respondents stated that the care provider's attitude was not pleasant (12% and 6%): this was mainly due to an apparent lack of empathy or effort.

Table 5: Causes of overtreatment (cases)

	Members of the public n=117 %	Care providers n=238 %
Communication with the patient	50	54
Insufficient information from the care advisor	30	34
No agreements made or effective consultation conducted	14	11
Care provider did not listen enough	14	9
Decision-making	44	33
Too little consideration of the patient and his/her wishes	30	9
Patient put under pressure (by the doctor, next of kin or lack of time)	10	5
Doctor agreed with the patient's decision too easily	3	10
Patient had insufficient knowledge/guidance/time to process in order to make a decision	2	6
Doctor felt afraid/doubtful about making a decision	2	5
Guidance from care provider	39	29
Care provider strictly follows protocol or does not adjust to individual patients	21	16
Care provider incorrectly assesses the situation, does not evaluate or anticipate	9	8
Poor relationship between patient (or next of kin) and care providers	9	2
Care provider is insufficiently available	4	5
General: Insufficient guidance and support from care provider	5	3

Table 5 (continued): Causes of overtreatment (cases)

	Members of the public n=117 %	Care providers n=238 %
Tendency of the doctor to continue treatment	34	39
Doctor focuses on a cure instead of quality of life	11	8
Treatment mode*	9	15
Does not want patient to lose hope, wants to offer something	6	14
Doctor has unrealistic expectations	6	4
Doctor avoids difficult conversations	3	6
Cooperation and coordination	20	29
Insufficient cooperation between care providers	13	21
Patient, next of kin and care providers not in agreement	9	10
Care provider works too unilaterally and focuses too much on his/her own specialism, has an insufficient overview of the situation, or does not consult colleagues	3	12
Lack of direction, no clarity about who the primary practitioner is	2	6
Patient's wishes not known	9	20
Patient has not made his/her wishes known on time/at all	3	18
Doctor made no attempt to find out these wishes	6	8
Insufficient attention paid to the next of kin by care provider	12	11
Insufficient communication with next of kin	9	8
Next of kin overburdened or receiving insufficient attention	4	6
Poor attitude displayed by care provider	12	6
Other		
Insufficient quality of care (knowledge and skills)	9	12
Desired care or resources not available	6	3
Developments in and structure of the care at the management/policy level.	4	2
Problems between patients and next of kin	1	6
Cultural aspects†	1	2

* The term 'treatment mode' refers to the tendency of doctors to treat and to not consider forgoing or discontinuing treatment to be an option.

† The convictions or religious/cultural/personal beliefs of the doctor or patient obstruct appropriate care, or the language barrier is a problem.

4. Specific issues

As the cases did not leave room to go into great depth about possible underlying causes of overtreatment, the respondents were given the opportunity to do this in the second half of the questionnaire.

1. Social tendencies

One issue that was not evident in the first section of the questionnaire but was reflected by the second half is the way society deals with death. Two-thirds of the public and care providers (67% and 69%) agreed with the statement 'In society, it is predominantly accepted that illness must be fought and that discontinuing treatment is not an option'. Eighty-seven per cent of the public and 91% of care providers agreed with the statement 'Society should come to terms more with the fact that life is finite'.

Care providers stated that too much media attention is paid to new cancer treatments and to stories about people who survive serious illnesses against all odds. In addition, some care providers say there is too much media attention to negative stories about palliative care.

2. Lack of advance care planning

One of the most frequently stated factors contributing to appropriate care was the compatibility of the care with the patient's wishes. When a patient considers his/her wishes regarding end-of-life care and discusses these with the doctor, the likelihood is greater that the patient's wishes will be complied with. Discussing these wishes in advance in order to plan future care is known as advance care planning.

During the survey, the respondents were asked to indicate their preferred moment for patients and doctors to initiate a conversation about wishes relating to end-of-life care. The answers given were extremely diverse: 42% of the public and 18% of care providers indicated that the best time to do this is before the person becomes ill, 36% of the public and 44% of care providers expressed a preference for holding the conversation after or at the time of the diagnosis of a potentially life-threatening illness, and 22% of the public and 38% of care providers thought the best time to have this conversation is when a cure is no longer possible. Some respondents stated that the best time to have this conversation depends on the patient, as some people are more open to such conversations than others. Most members of the public would prefer the patient to initiate this conversation (90% of the public and 66% of the care providers), while the care providers saw this as being the doctor's responsibility (55% of the public and 80% of care providers). The majority of respondents also considered it an option that

the patient's next of kin or a nurse could initiate this conversation.

A survey conducted by the Royal Dutch Medical Association (KNMG) in 2013 found that 67% of KNMG panellists believe doctors wait too long to talk to patients about approaching death. In our questionnaire survey, we asked care providers to state possible reasons for this (members of the public were not asked this question). Nearly half indicated that the conversation is too difficult for the doctor (46%), with regard to both the subject matter and communication skills. According to a third of respondents, doctors find these conversations to be too emotionally difficult. Here, they mentioned two difficult aspects: having to give the bad news to the patient and then dealing with both the patient's emotions and the doctor's own emotions. Practical reasons were also given, such as lack of time (18%) or 'taking the easy way out' by continuing to treat rather than having to conduct a difficult and time-consuming conversation (5%).

According to some respondents, doctors do not always realise that discontinuing treatment is a viable option (9%). Doctors can also feel like they have got nothing to offer the patient if they are not actively treating them (13%). The latter aspect is particularly the case amongst doctors who have insufficient knowledge of palliative care, and therefore do not know what they can offer the patient with regard to palliative treatment.

The respondents mentioned that the patient or the next of kin sometimes do not want to talk about the end of life (10%), so the doctor does not have the conversation with them. However, the respondents also stated that doctors generally make the assumption that the patient does not want to talk about the end of life when he/she does not know whether this is actually the case. The doctors may therefore avoid a conversation about approaching death for fear of stripping the patient of all hope or being too upfront (15%). Furthermore, there is a feeling that death is a taboo subject (5%) and that patients or their next of kin may respond negatively to the issue (3%).

The respondents indicated that doctors can also have difficulty with the subject of death or maintain unrealistic hopes (12%). Finally, the respondents feel that sometimes doctors don't recognise when it is time to talk about the end of life (6%), or they wait too long for the 'right moment' (4%) or for absolute confirmation of the diagnosis or the incurability of the illness (5%).

3. Consultation and coordination

Thirty-two per cent of the public and 26% of care providers agreed with the statement 'Most GPs have a good overview of the care their patients receive'.

Eleven per cent of the public and 5% of care providers agreed with the statement 'If a patient is treated by multiple doctors, the doctors consult with one another effectively'. Evidently, both members of the public and care providers see a problem with regard to coordination of care.

The care providers were also asked to consider the statement 'The increasing level of specialisation in healthcare can result in overtreatment in the final stage of life'.

Three-quarters of care providers agreed with this statement.

Table 6: Statements

	Members of the public n=597 %			Care providers n=915 %		
	Agree	Neutral	Disagree	Agree	Neutral	Disagree
In society, it is predominantly accepted that illness must be fought and that discontinuing treatment is not an option.	67	20	13	69	17	14
Society should come to terms more with the fact that life is finite.	87	10	3	91	7	2
Healthy people do not want to talk about death with their doctor.	43	31	26	42	26	32
End-of-life care is often too heavily focused on survival and prolonging life, and not enough on quality of life.	84	9	7	80	12	8
Doctors often do not consult the patient enough before deciding on a course of treatment.	68	20	11	66	25	9
Most GPs have a good overview of the care their patients are receiving.	32	34	34	26	35	39
If a patient is treated by multiple doctors, the doctors consult with one another effectively.	11	28	60	5	23	72
The increasing level of specialisation in healthcare can result in overtreatment in the final stage of life*	-	-	-	75	15	10

* This statement was only made available to care providers.

Part 3. Solutions

In the questionnaire, the respondents were given the opportunity to suggest solutions to the general problem of inappropriate care. 1,326 of the 1,648 respondents obliged.

Firstly, the respondents were asked what doctors could do to improve end-of-life care (table 7). One-third of the respondents said that doctors could make more effort to find out the patient's wishes by listening better and actively asking about them. One in five respondents indicated that the provision of information to patients about their prognosis and the various treatment options could be improved.

Care providers in particular (17%) indicated that doctors' knowledge of palliative care and discontinuing treatment is lacking, and that doctors could improve this knowledge by means of further training. They indicated that adequate knowledge of the possibilities is necessary in order to inform patients of their options properly and to help patients more effectively if they choose to discontinue treatment.

Other frequently stated points for improvement addressed the issues of decision-making, guidance and cooperation. Some respondents indicated that doctors could involve patients more when making treatment-related decisions (12% of the public and 5% of care providers). Some respondents stated that patients will need guidance and sufficient time in order to do this (6% and 7%).

Doctors could be more involved with the patient and continually evaluate whether the care is appropriate (11% and 5%). Other respondents mention that doctors could conduct themselves with greater openness, respect and empathy (10% and 5%).

Doctors could make more time for their patients (7% and 8%) and could also show more attention to the wishes and well-being of their next of kin (6% and 5%).

Finally, some care providers stated that the cooperation between different doctors and between doctors and nursing staff could be better (3% and 4%). Doctors could also more frequently call upon colleagues' expertise via consults or structural consultation (3% and 8%).

**Table 7: Answers to the question:
‘What can doctors do to make end-of-life care more appropriate?’**

	Members of the public n=475 %	Care providers n=851 %
Communication with the patient		
Ask and listen to what the patient wants	32	28
Keep the patient well-informed	19	23
Maintain a respectful, empathetic and open attitude	10	5
More attention to shared decision-making		
Allow the patient (or the next of kin) to make the decision	12	5
Repeatedly give sufficient time and opportunity to make the right decisions	6	7
Make use of advance care planning	2	6
Giving effective guidance		
Be involved, actively offer assistance	11	8
Devote more time and attention to the patient	7	8
Acquire and maintain good knowledge of palliative care	5	17
Collaboration		
Better collaboration between care providers	3	8
Refer to or consult colleagues or experts	3	8
Be realistic		
Holistic approach	5	4
Make death an acceptable subject of discussion	5	4
Ensure realistic expectations regarding the treatment	3	5
Other		
Consult with and pay attention to the next of kin	6	5
Conduct euthanasia or give notification that it is not possible	7	1

Points for improvement were subsequently given by patients and next of kin (table 8). These mainly related to people having a more proactive attitude. Frequently stated answers included clear indication of wishes to both doctors and next of kin, and discussion of these wishes in a timely manner. When decisions have to be made, you must sometimes state your wishes clearly in order to ensure that doctors do not administer any unwanted treatments. This may also involve the patient having to ask for information in order to make a well-founded decision if the information provided by the doctor is not sufficient. Patients can also use other sources of information, but they must be prevented from focusing too greatly on success stories.

It helps when people can openly discuss death with each other and with the doctor, and what they expect from each other as the end of life approaches. Some respondents state that patients must be realistic and must not insist on active treatment for too long. Another factor in this regard is that patients sometimes cannot accept that they are going to die.

Some respondents said that patients should discuss things more thoroughly with their doctors and be more open to advice.

Finally, it was indicated that next of kin can play an important role in end-of-life care. For example, they are encouraged to be involved and support the patient in his/her wishes, but also to avoid pushing their own opinions on the patient. It is also important that they do not forget their own role and that they are given the chance to provide care themselves, e.g. by means of care leave.

**Table 8: Answers to the question:
‘What can patients and next of kin do to make end-of-life care more appropriate?’**

	Members of the public n=475 %	Care providers n=851 %
Discuss wishes		
Make your wishes clearly known	17	20
Advance care planning: discuss your wishes repeatedly and in a timely manner	12	9
Talk openly about death and your expectations	11	15
Discuss your wishes with your next of kin and make agreements	7	7
Keep well-informed and make well-founded decisions		
Actively ask the doctor for information	11	12
Think carefully before making a decision	6	5
Seek other sources of information	4	6
Open attitude		
Effective consultation with the doctor and openness to the available options	9	8
Discuss your concerns and fears with your doctor	4	6
Ask for and accept help and guidance	4	4
Be assertive		
Speak up about your wishes and be critical	8	5
Take charge or make decisions yourself	3	5
Acceptance		
Accept that death is approaching	6	7
Be realistic and know when to stop treatment	4	7
Role of next of kin		
Next of kin: let the patient decide and respect their wishes	9	7
Next of kin: be involved and empathetic	9	7
Next of kin: ask what the patient wants	5	4

APPENDIX

5

Results of online focus groups

The Steering Committee commissioned the EMGO Institute for Health and Care Research (EMGO+), the VU University Medical Centre (VUmc) and the Netherlands Institute for Health Services Research (NIVEL) to conduct five online focus groups with different categories of participants. In this appendix, you can find an overview of the results. You can find a more detailed description of the results at www.knmg.nl/passendezorg.

Three different groups took part: patients, senior citizens and next of kin (two focus groups); professional care providers (two focus groups) and people with Islamic backgrounds (one focus group). All participants were presented with discussion questions relating to five themes. The goal was to gain insight into mechanisms that result in overtreatment and to assess the interventions proposed by the steering committee.

In the opinion of the participants, continuing treatment for too long can rob people of a dignified death. This can be caused by many factors, such as doctors and patients not recognising soon enough that death is approaching. The systematic use of the 'surprise question' ('Would I be surprised if this patient died within a year?') is recommended as a way to improve this aspect. During the final stage of life, the patient's hopes are no longer on a cure, but on a 'good death'. Care providers can support this process.

According to many participants, social awareness for the end of life is currently helping to increase acceptance of the fact that life is finite. This trend can be further facilitated by the media and social organisations.

Consideration and discussion of end-of-life wishes are seen as a gradual process between the patient, his/her next of kin and the care provider, within which mutual trust is of great importance. Written declarations of intention make it much easier to instigate this discussion with doctors and next of kin. It would be useful if care providers could overcome their misgivings and talk about the subject of death at an earlier stage. Senior citizens and people with an Islamic background say it is important that the next of kin are involved in the communication and decision-making process. It is also important that this communication can be conducted in the participants' mother tongue.

The participants also think it is very important that the patient has one primary care provider who ensures cooperation and coordination. Professional care providers recognise that a number of unhelpful incentives are present in the system that can

result in overtreatment, but they are unclear about how these problems should be resolved. Some consider talking about death to be a standard part of their job, others believe that being able to bring up this subject of discussion can result in a more critical attitude towards the issue of continuing or discontinuing treatment. See also Appendix 4 for the research into the nature and scale of appropriate end-of-life care.

APPENDIX

6

Examples of what organisations are already doing, what activities they are going to intensify and what they want to do in the future

As indicated in the introduction to Chapter 5, the Steering Committee invites all parties to start implementing these interventions: if the cap fits, wear it. The basic principle is to dovetail with the working methods, activities and initiatives that are already part of current practice and to promote them in a wider sphere. Below are a few examples of what organisations are already doing, what activities they are going to intensify and what they want to do in the future:

The [V&VN Dutch Nurses' Association](#) will devote attention – via medical literature, the V&VN Academy and V&VN Magazine – to options that contribute to quality of life during the final stages and making them easier to discuss, as well as to the importance of recording these choices in the patient's file. The association will also take action such as bringing the importance of conducting and participating in multidisciplinary consultation on complex treatment decisions to the attention of the Nursing Advisory Boards (VARs) within the institutions.

The cancer patients' organisation [Levenmetkanker \(Living With Cancer\)](#) is working towards structurally implementing time for reflection at critical moments into the process of oncological care. This will ensure that the conditions for the patient's control – and therefore for appropriate care during the entire process – can be guaranteed to the greatest possible extent from diagnosis onwards, paying special attention to the timely discussion of choices and appropriate end-of-life care. This should preferably be conducted in the form of *Feel 'Free to Choose' (Kies Gerust)* conversations with the GP.

Via www.Thuisarts.nl, the [Dutch College of General Practitioners \(NHG\)](#) and the [National Society of General Practitioners \(LHV\)](#) will distribute as much targeted information as possible and expand upon this information wherever necessary. Video footage is also under consideration for patients with limited command of the Dutch language. The NHG guidelines for 'Information Exchange between GPs and Specialists with regard to Referrals' will be adjusted and expanded to include information exchange between GPs. Attention has also been paid to developing education in advance care planning and including a summary of the pros and cons of treatment options and the related decision-making tools in illness-related standards.

By means of a variety of projects, [the associations for the elderly](#) are going to promote the importance of ‘timely discussion of the end of life’ amongst their members and empower them in this regard. [The Union of Catholic Senior Citizens' Associations \(Unie KBO\)](#), [the Protestant-Christian Senior Citizens' Association \(PCOB\)](#) and [the Network of Organisations of Elderly Migrants \(NOOM\)](#) will use their own communication channels to do this (members' magazines, digital newsletters and websites). The Union of Catholic Senior Citizens' Associations (Unie KBO) and the Protestant-Christian Senior Citizens' Association (PCOB) have been actively involved in the development of a neutral do-not-resuscitate token, in conjunction with other organisations. Facilitators are also used to help get the discussion going during meetings regarding end-of-life matters. The Network of Elderly Migrants' Organisations (NOOM) has already developed methods for assisting elderly migrants in formulating their wishes for the future. The topic of ‘speaking about end-of-life care’ will be included in this process. The NOOM also provides training courses for healthcare providers on the subject of diversity during the final stages of life. In addition, the three associations for the elderly are working together on the ‘Meaningful until the End’ (*Van Betekenis tot het einde*) Coalition. The goal of this coalition is to promote timely discussion of end-of-life wishes. The associations for the elderly are also intensively collaborating on other interventions.

[The Netherlands Federation of Medical Specialists and the Federation of Patients and Consumer Organisations in the Netherlands \(NPCF\)](#) will implement the topics of ‘joint decision-making’ and ‘improved decision-making’ during the final stages of life into their projects titled ‘Deciding Together’ (Samen Beslissen) and ‘Sensible Decisions’ (Verstandig Kiezen). In addition, the Netherlands Federation of Medical Specialists will strive to include the option of ‘doing something different’ in the development of the guidelines if the treatment objective can no longer be achieved.

[The Dutch Association of Elderly Care Physicians and Social Geriatricians \(Verenso\)](#) will – via education and further training – ensure that attention is paid to the influence of cultural and personal beliefs on end-of-life care. Verenso will pass on its expertise in the field of advance care planning by developing a protocol and training courses, as well as by making advance care planning part of the quality reviews. Various parties will collaborate in order to develop a neutral do-not-resuscitate badge and set up an adequate distribution channel.

[The Netherlands Society of Physicians for Persons with Intellectual Disabilities \(NVAVG\)](#) will revise the ‘Medical Decisions regarding the End of Life’ guidelines. These guidelines will include opportunities to discuss the subject of appropriate care (‘Just because we can, doesn't mean we should’) with people with intellectual disabilities,

their next of kin and other people of importance. These guidelines for the Actions of Physicians for the Mentally Handicapped will address, amongst other issues, communication with and support of parents, the definition of appropriate care and what is required to achieve it, advance care planning, methods to make clear the patient's wishes (if possible), and the manner in which decision-making should take place if the subject of discontinuing curative or life-prolonging treatment is raised or if treatment is no longer medically viable.

[The Comprehensive Cancer Centre the Netherlands \(IKNL\)](#) will encourage adequate application of the guidelines for palliative care. IKNL also wishes to contribute to the further development of a National Transmural Agreement (LTA) by, amongst other methods, rolling out the Palliative Home Care (PaTz) project and by working with palliative-care consultants.

[The National Health Care Institute \(ZiN\)](#) greatly values effective collective decision-making by care professionals in dialogue with patients and their family. For this reason, ZiN explains its reasoning in the report titled 'Just because we can, doesn't mean we should'. ZiN also wants to make a contribution to appropriate end-of-life care. For this purpose, the institute is going to make it mandatory that every quality standard is accompanied by an information standard that explains which data must be recorded and transferred, and in what form. Furthermore, every quality standard must be accompanied by a patient's version or, if possible, a decision-making tool in order to adequately prepare patients to participate in shared decision-making. In order to focus guidelines not only on 'doing something' but also 'doing nothing' (i.e. 'doing something different'), ZiN will – via its Assessment Framework – continually and carefully consider whether the medical indications are described with sufficient clarity.

The powers of modern medicine are growing. Whereas a cancer diagnosis once almost certainly meant a death sentence, nowadays it is possible to live on for years, and sometimes even be cured. However, these improvements in treating illness and prolonging life also have a flipside. Some treatments are extremely invasive, while others have severe side effects and can have damaging consequences. When are medical interventions no longer useful? Do doctors and patients stop to consider the patient's quality of life after a planned course of treatment? Do they discuss the limitations that the treatment may cause with regard to everyday functioning? Do they discuss whether the patient even wants the treatment, or whether it is realistic? Or whether the doctor and patient both have the same goals?

Although all parties wholeheartedly agree that care providers must conduct this discussion in a timely manner with patients who are facing the prospect of death due to illness or a vulnerable situation, in practice, this conversation takes place far too infrequently. What is stopping us? In this report titled 'Just because we can, doesn't mean we should', a steering committee made up of representatives of patients, doctors, nurses, senior citizens and elderly migrants describe mechanisms that sometimes result in too little attention being paid to quality of life.

It also examines how we can work together in the Netherlands to ensure people receive appropriate end-of-life care. This will allow each of the organisations involved to support these common goals with their own objectives and capacities in mind.

The report *Just because we can, doesn't mean we should: Appropriate end-of-life care* was created by a steering committee set up by the Royal Dutch Medical Association (KNMG) that comprised representatives of the following organisations:



This report and supplementary information is available in PDF format via the web file 'Appropriate End-of-Life Care' at www.knmg.nl/passendezorg.

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