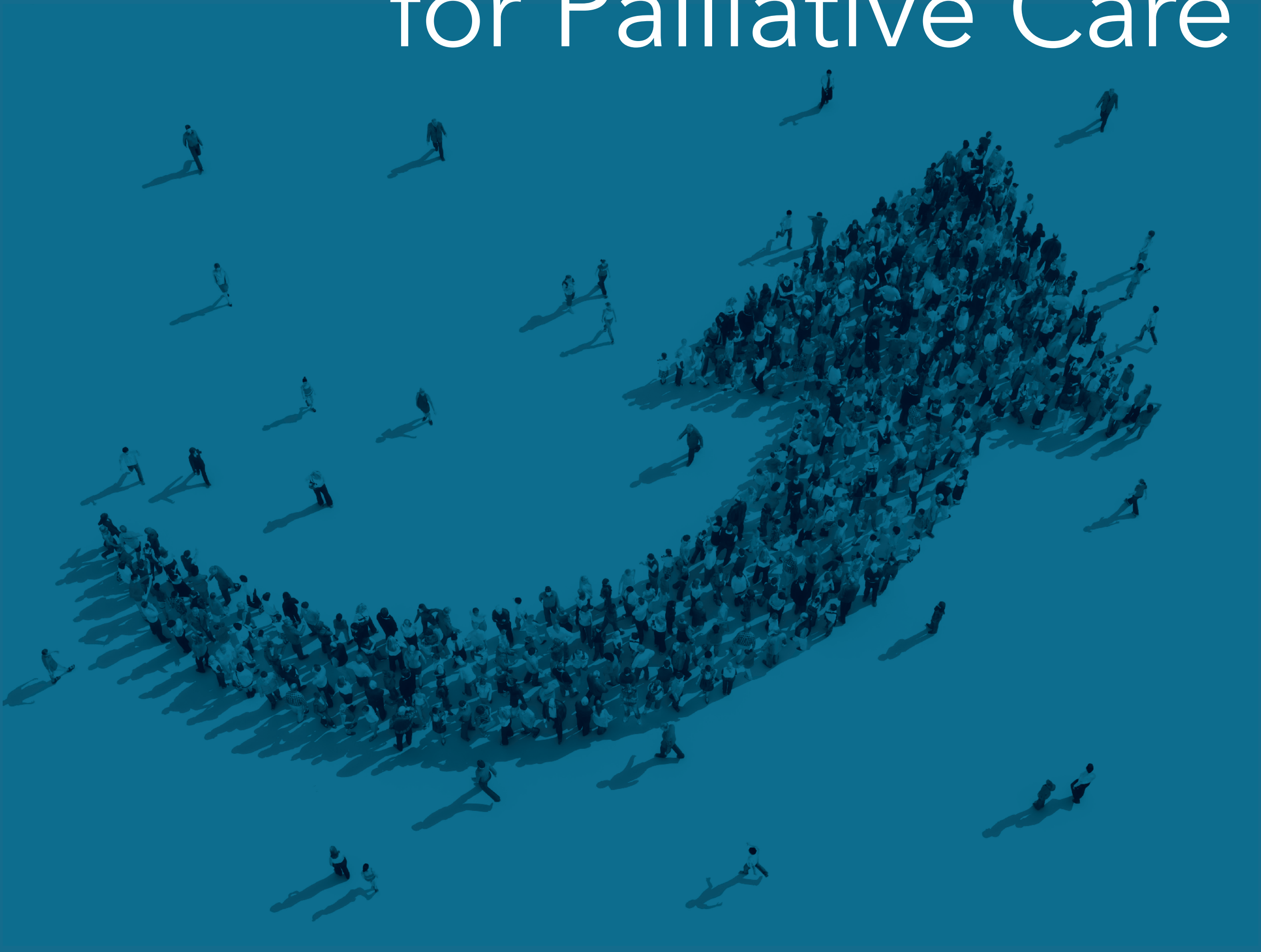
Netherlands **Quality Framework** for Palliative Care



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palliactief

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The Netherlands Quality Framework for Palliative Care has been endorsed by the following organisations:

Patiëntenfederatie Nederland
samen de zorg beter maken

verenso
specialisten in ouderengeneeskunde

VGVZ
Vereniging van Geestelijk VerZorgers

v&vn
Beroepsvereniging van zorgprofessionals

Federatie Medisch Specialisten

NVPO
Nederlandse Vereniging Psychosociale Oncologie

nhg
nederlands huisartsen genootschap

Zorgverzekeraars Nederland

foreword

Walking through the woods of the Veluwe (a woodland area in the Netherlands) in late summer, you can hear tits, blackbirds and wrens claiming the territory again. While daydreaming, the last thing you would expect is a tree suddenly falling on your head. You feel safe.
In much more serious circumstances you assume that, when visiting the family doctor or a hospital, you will find a similar atmosphere. An atmosphere in which you are treated in a way that radiates serenity and quality, where there is a sense of security. Every person has an idea of what curative care is - care directed at life extension and fighting disease - and knows approximately what to expect from it, whether you are a patient, practitioner or policy maker.

How different this is for palliative care. Palliative care should be nothing else than the provision of good care to every patient with an incurable condition or frailty. In these modern times since Descartes, however, we have somewhat forgotten about multidimensional attention and its corresponding professionalism and we often think we are immortal. Only very recently awareness has developed that every person who becomes ill, may not only be cured of the disease, but may possibly also die from it. It is therefore reassuring to see that there are increasingly more guidelines exploring both these possibilities and formulating practice recommendations. But we are not there yet.

A surprising number of people are talking about palliative care; there are political debates about its quality, discussions about what the word means, whether it is generalist and/or specialist care, how to pay for it, the role played by informal caregivers and volunteers, and so on. This means that it is no simple task for many patients and their families to find their way in the healthcare sector when they are approaching the palliative care phase of their disease. High time, therefore, to talk less, do more, and streamline palliative care at a national and regional level, both in terms of content and of organisation. This will only succeed if we mobilise all expertise to define a quality framework in which we describe who does what, where and when. This will greatly benefit the sense of security of all citizens, and place the realities of disease and dying in a correct perspective.

The present Netherlands Quality Framework for Palliative Care is the result of the efforts of representatives of many scientific associations and organisations involved in giving or supporting palliative care. It provides an overview as complete as possible of the aspects we think are important for arriving at good-quality palliative care, and it also shows what patients, families, healthcare professionals and volunteers can expect as the best care in often difficult circumstances. It sets a framework in which personal care can be given, and, in addition, it helps to find a personified way in the many grey areas of evidence and consensus. The implementation of this quality framework will provide direction to healthcare-related and organisational questions, to further substantiation of this field by means of solid research and education and to the conditions for funding.

For us, as initiators, it is a great pleasure to offer you this Netherlands Quality Framework for Palliative Care: it is possible to collectively create a framework for such an important and sometimes also controversial subject in Dutch healthcare. The willingness to implement this framework is now of the utmost importance. We would like to thank all those who have contributed to the creation of this document. Let’s put this quality framework into practice!

Kris Vissers

Peter Huijgens

table of contents

introduction

BACKGROUND

At the start of the National Palliative care Programme (2014-2020) it was argued that palliative care in the Netherlands could be improved by, for example, imposing uniform quality standards and removing organisational and funding barriers. In 2015, Palliactief and IKNL joined forces to this end and launched the project "Netherlands Quality Framework for Palliative Care with appropriate financing".

The project aimed to link national organisations in the field of palliative care with scientific associations and umbrella organisations, health insurers, and government, in order to reach agreement on a broadly supported, unambiguous quality framework for palliative care with appropriate financing. By analogy with the national guideline procedure, the project was executed from 2015 to 2017 by a working group comprising mandated representatives of patients and their families, healthcare professionals and health insurers. In preparation for this project constraint analyses for palliative care were carried out in primary and secondary care settings.[1,2] In addition, the participating professional and umbrella organisations were kept informed at management level by means of two invitational conferences during the project.

To achieve a consistent quality of palliative care for patients with a life-threatening condition or frailty, and to embed and safeguard that care, the quality framework was developed on a tripartite basis (patients and their families, healthcare professionals and health insurers) in accordance with the requirements of the reference framework of the Netherlands National Health Care Institute. This will allow the framework to be proposed for inclusion in the care register after authorisation. A patients' version of the quality framework, a list of recommended and validated measurement instruments, and an implementation plan will also be drawn up to this end. In addition, at the initiative of the Netherlands Organisation for Health Research and Development (ZonMw), a project[3] was launched to develop a set of quality indicators for palliative care.

KEY QUESTION

Based on the values, wishes and needs of patients and their families, the working group formulated the following key question: "What do we, as representatives of patients and their families, healthcare professionals and health insurers, agree that the criteria for quality of palliative care in the Netherlands should be?" In this regard the quality framework is intended as a guiding rather than a normative model. In other words, it describes "when" and "what" but not "how". In principle, this question enshrines the field's responsibility to consider how the desired quality of palliative care can be achieved in the organisation or in daily practice.

DEFINITION

Both the mandated members of the working group and the palliative care community during the consultation rounds, extensively discussed the 2002 WHO definition of Palliative Care. Firstly, this definition was compared with a number of other definitions from the literature, particularly that of the National Consensus Project for Quality Palliative Care (2013). Unlike the WHO definition, this definition explicitly cites aspects of palliative care that are considered important, such as interdisciplinary collaboration, dignity, autonomy, access to information and the opportunity to make choices. Conversely, the WHO definition clearly puts more emphasis on the importance of early identification.

Secondly, the working group re-examined the concept of a life-threatening condition. The prevailing view is that this description does not sufficiently reflect the current diversity of the target groups within palliative care and particularly fails to include the concept of frailty.

Finally, it was regarded as a relevant aspect of the definition that palliative care in the Netherlands is delivered by generalists, who receive support from healthcare professionals specialised in palliative care when required.

The working party ultimately agreed to add the following important points for palliative care in the Netherlands to the WHO definition:

Palliative care as defined in the Quality Framework

(gemodificeerd WHO 2002)

Palliative care is care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices.

Palliative care has the following characteristics:

- care can be given concurrently with disease-oriented treatment;
- generalist healthcare professionals and, when required, specialist healthcare professionals and volunteers, work together as an interdisciplinary team in close collaboration with patients and their families, and tailor treatment to the stated values, wishes and needs of the patient;
- to ensure continuity, care is coordinated by a central healthcare professional;
- the wishes of patients and their families concerning dignity are acknowledged and supported throughout the illness or frailty, during the process of dying and after death.

GENERALIST VERSUS SPECIALIST

In the Netherlands, palliative care is delivered by generalists, who are supported by healthcare professionals specialised in palliative care, when required. A consequence has been that the responsibilities are divided among generalist, specialist and expert. A more detailed interpretation – based on the international literature – is given in the glossary of terms.

In 2016, at the initiative of national palliative care programme ZonMw Palliantie, a description of the competences required of generalist care professionals was compiled in the "Educational framework for Palliative care 1.0"[4]. A similar description of the qualifications required of healthcare professionals specialised in palliative care is not yet available.

In the first round of consultations with the palliative care community, participants were therefore asked whether it would be desirable to include these requirements for palliative care specialists in the quality framework. The responses clearly showed that indeed there is a need to draw up a set of qualifications for specialists in palliative care, and that the quality framework is viewed as the right place for such criteria. Due to the additional time that this would entail, they are not included in the current version of the quality framework, but this will be followed up within the scope of this project.

STRUCTURE

The quality framework includes ten domains. Each domain consists of an introduction, one or more standards, and a number of criteria. The introduction provides a broad outline of the domain, and the standards indicate best practice and are supported by criteria. Special attention should be paid to the domain of "Structure and process", since a number of topics relevant to palliative care are described, including identification, shared decision-making, advance care planning, the individual care plan, and the coordination and continuity of care.

IN CONCLUSION

As the process continued it became apparent that a clear understanding of the terminology used was advisable. A glossary of terms has, therefore, been added to this quality framework in Appendix 1. Justification of the content development of the quality framework, and further information on the questions posed in the first round of consultations are described in Appendix 3.

Publication of the quality framework and the accompanying glossary of terms is expected to be an important step forward for palliative care, but not the final step. How the quality framework is received in daily healthcare practice will depend largely upon the extent of support for its implementation. The implementation plan will, therefore, be designed in analogy to the development of this quality framework.

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1. Knelpuntenanalyse Palliatieve zorg in de eerstelijn, IKNL / Palliactief 2017.
2. Rapport 'Palliatieve zorg in Nederlandse ziekenhuizen', IKNL / Palliactief 2015.
3. ZonMw-project 'Op weg naar een systeem om kwaliteit van palliatieve zorg inzichtelijk te maken'.
4. Onderwijsraamwerk palliatieve zorg 1.0 als onderdeel van de Kennissynthese Onderwijs palliatieve zorg (2016).

overview

WHO IS THIS DOCUMENT INTENDED FOR?

The Quality Framework for Palliative Care aims to provide various target groups with an insight into what a representative body of patients, friends and family, healthcare professionals and health insurers believe that the quality of palliative care in the Netherlands should be.

This document is intended for the various healthcare professionals involved in caring for palliative-stage patients. They include carers, nurses, general practitioners and medical specialists. The quality framework is intended to serve as a guide for daily healthcare practice by making it accessible to these healthcare professionals in a number of different ways. It is supported by guidelines and, whenever possible, by assessment instruments. At the same time, this quality framework offers tools to healthcare executives and managers to develop their missions and visions regarding care for palliative-stage patients, and to determine their quality policy for palliative care. The ambition of IKNL and Palliactief is to make practitioners feel supported by the quality framework in developing and implementing palliative care, enabling them to provide high-quality, safe and effective care for all palliative-stage patients, at the right time and in the right place.

GUIDING VERSUS NORMATIVE

At the start of development of the quality framework, a deliberate decision for a certain language and tone was made to guide healthcare professionals and institutions and provide them with tools to deliver the best possible palliative care. However, feedback from both consultation rounds repeatedly suggested that the quality framework should be less non-committal in nature. These suggestions were acted upon by adopting a more normative tone in some areas.

The standards indicate best practice within a domain, taking into account recent findings and evidence. The associated criteria are conditions required to achieve the desired standard. If, in the context of specific individual care and individual patient and family circumstances, certain criteria are considered less relevant in achieving the standard, these can be adjusted if there are valid arguments and in consultation with the patient.

CORE VALUES AND PRINCIPLES

The quality framework comprises a number of domains, which together cover the entire spectrum of care for palliative-stage patients and their families. They can be read separately, though, in order to gain an insight into the most appropriate procedure with regard to a certain aspect of care. However, all these domains are based on the information described in "Core values and principles". To understand the other domains, this domain should always be read.

CONNECTIONS BETWEEN DOMAINS AND GLOSSARY OF TERMS

The digital version of the quality framework is available at Pallialine.nl. In this version, the terms mentioned in the quality framework are linked with the definitions included in the glossary of terms. It is possible to click through to related guidelines and assessment instruments, within each domain.

CLOSE READING

To enhance readability, "he" and "patient" are used throughout the text. Occurrences of "he" in this text can also be read as "she" and "patient" can equally be replaced by terms such as "client", "resident" or "guest". If the patient is not legally competent, "patient" can be read as "legal representative". "Healthcare professional" in this document includes all members of the professional groups involved in palliative care. In general, it has not been specified which of these healthcare professionals should carry out the measure being described in a criterion. This has been done in order to be able to choose the healthcare professional that is best equipped, on the basis of his own capabilities, to meet the needs of the patient.

quality framework

table of contents

core values and principles

introduction

Palliative care is care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature. During the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices.

Palliative care has the following characteristics:

- care can be given concurrently with disease-oriented treatment;
- generalist-healthcare professionals and, when required, specialist healthcare professionals and volunteers, work together as an interdisciplinary team in close collaboration with patients and their families, and tailor treatment to the stated values, wishes and needs of the patient;
- to ensure continuity, care is coordinated by a central healthcare professional;
- the wishes of patients and their families concerning dignity are acknowledged and supported throughout the illness or frailty, during the process of dying and after death.

The core values listed below describe the baseline values of good care for palliative-stage patients and their families. The principles below describe the attitude and behaviour of healthcare professionals required to attain these core values.

core values

Every person is unique. Care is therefore given with respect for the autonomy of the patient, and it is tailored to the individual patient, respecting his views on individuality and quality of life. Care can only be given if patients and their families are prepared to accept it.

The relationship between a healthcare professional and patients and their families is based on mutual respect, integrity and dignity. The environment in which care is given is arranged in such a way that the patient feels safe, seen and heard.

Care is tailored to the personal, interpersonal, cultural and ideological values, standards, wishes and needs of the patient and his family in relation to life, illness and dying.

The healthcare professional is aware of the huge impact that approaching death has on the patient and his family. The healthcare professional is aware that this may influence how people see themselves and their lives, how they behave, how they take stock, and how they reassess their values.

core values and principles

principles

The patient or his legal representative has control over his own care and decides which healthcare professionals and family members will be involved in his care, and how. Care and attention is tender and loving, and always focused on both patient and family.

All care is provided in a manner that:

- offers safety and security, does not judge, force, discriminate or intimidate;
- gives space for self-realisation;
- poses no unnecessary risk or distress;
- offers continuity;
- prevents unnecessary duplication or repetition;
- guarantees privacy and confidentiality;
- conforms to national laws and regulations.

Effective communication, combined with shared decision-making and advance care planning, forms the basis for the provision of care in which patient and family are the primary focus.

Care is of a multidimensional nature and focuses on the welfare of the individual, in physical, psychological, social as well as spiritual dimensions.

The care offered should be aligned as much as possible with the values, wishes, needs and circumstances of the patient and family.

Together with the patient and family, the physical, psychological, social and spiritual dimensions should be proactively assessed and documented for situations in which:

- normal, everyday attention is enough;
- there is a need for guidance or treatment;
- crisis intervention is necessary.

In principle, palliative care is interdisciplinary. Healthcare professionals and volunteers form a personal and dynamic team in close collaboration with the patient and his family. When required, generalist healthcare professionals seek advice or support from healthcare professionals specialised in palliative care.

Care is given on the basis of the best available evidence (evidence-based care). If there is a lack of evidence, care is given on the basis of consensus (experience-based care).

Healthcare professionals and volunteers are aware of the emotional impact that providing palliative care may have on them. They reflect on their own attitudes and actions, and are conscious of their personal balance. In doing so, they take care of themselves and their colleagues.

structure and process
identification

introduction

Early identification of the palliative care phase – and subsequently adjusting the goal of care – requires the healthcare professional to approach the patient in an essentially different way. This is a type of care in which quality of life and death are take the lead, and benefits and disadvantages are weighed against each other accordingly. This is in contrast with treatment in which burdens and adverse effects are accepted because cure is the intended goal of care. This change in goal of care should be identified and explicitly stated.

standard

Patients in the palliative care phase are identified at an early stage.

structure and process
identification

criteria

1 To this end, healthcare professionals should ask themselves the "surprise" question: "Would you be surprised if this patient died within the next 12 months?" If they can answer this question with "no", then this identifies the stage as being one in which the patient's situation could change due to rapid deterioration.

2 In patients with a life-threatening condition or frailty, the surprise question should in any event be asked if the illness or frailty worsens, complications occur, or functionality deteriorates. If there is reason to do so, the conversation about the palliative care phase should take place earlier in the disease process, for example if a diagnosis of dementia has been made.

3 Asking oneself the surprise question by the healthcare professional is guaranteed. This can be done by the physician in charge or other healthcare professionals. Posing the question can also be prompted by questions from the patient or family. If a healthcare professional other than the physician in charge answers the surprise question in the negative, this is discussed with the physician in charge. The surprise question is not intended to be directed at the patient or his family.

4 It is important to identify not only the last year of the palliative care phase, but also the often gradual transition from disease-oriented treatment to more symptom-oriented treatment, and the end-of-life stage.

5 The patient and family are not arbitrarily confronted with the scenario of the patient dying within the foreseeable future. The treating physician explores the extent to which they are open to receiving this information, and whether they have the resilience to process it.

6 Following identification of the palliative care phase, the treating physician takes steps to initiate palliative care. This includes matters such as advance care planning, drawing up an individual care plan and coordination of care.

structure and process
shared decision-making

introduction

Shared decision-making is a method of communication primarily used for important decisions. During the process of shared decision-making, the healthcare professional, patient and family come to decisions that best suit the values, wishes and needs of the patient in that particular phase of his life. The reciprocal exchange of information is an essential part of this, focusing mainly on the way of sharing the information.

Shared decision-making requires a positive attitude towards the process itself, effective communication, weighing up the situation, the use of decision aids and the inclusion of values, wishes, needs and decisions in the individual care plan. Shared decision-making is the starting point for the process of thinking, planning and organising ahead (advance care planning), and perhaps for drawing up a living-will declaration. It should be regarded as the basis for the individual care plan.

standard

Shared decision-making is the continual process in which care is tailored to the personal situation and achievable values, wishes and needs of the patient and family.

structure and process
shared decision-making

criteria

1 Effective communication, attitude and exchange of information are essential pre-conditions to enable the patient, family and healthcare professional to decide on care that is tailored to the personal situation and achievable values, wishes and needs. When required, information should be available in other languages, possibly through an interpreter.

2 Effective communication with the patient and family takes place with respect for their desired degree of openness and honesty in the provision of information, and the way they choose to make decisions. The patient has a right to privacy. A patient's wishes concerning the degree to which information is shared with family and friends should be known to, and respected by, the healthcare professional.

3 The healthcare professional is aware of the attitude required to be able to support patients and their families in making their own choices and/or planning their lives. Healthcare professionals familiarise themselves with this attitude and act accordingly.

4 To deliver optimum care, it is important that the patient and his family are appropriately informed about the nature of the illness or frailty and its prognosis. This enables the patient to understand the consequences of his illness.

5 The healthcare professional furnishes the patient and his family with information about the available choices, their possible consequences and accompanying uncertainties and responsibilities. The healthcare professional asks the patient who and what is of value to him, and which values, wishes and needs are important to him when making choices at this stage of life. Important issues related to this include decisions on treatment (including whether or not to be treated), admission to hospital, place of care and dying, crisis situations, legal representation in the event of acute deterioration or legal incompetence, and end-of-life decisions.

6 The goals, wishes and needs of the patient may change over time and should be checked regularly in a multidimensional way. The patient and his family always receive an explanation about the situation at a particular moment and are given the opportunity to decide together whether they want to review and adjust the individual care plan.

7 Agreements resulting from the process of shared decision-making are documented in the individual care plan, signed by the patient or his legal representative.

structure and process
advance care planning

introduction

The process of thinking, planning and organising ahead (advance care planning) has a positive effect on the patient's welfare as well as on the quality of care (appropriateness), on his family (satisfaction) and on the health system (efficiency). The process can also contribute to the strengthening of the patient's autonomy with respect to the quality of the shared decision-making.

Advance care planning is a continuous and dynamic process of discussions on life goals and choices, and on which care is an appropriate fit, now and in the future. The healthcare professional can start these discussions early in the disease process, in the context of the patient's awareness of his own mortality.
Advance care planning, with shared decision-making as a guide, is therefore much more than a well-thought out living-will declaration and the appointment of a legal representative. Outcomes of the process are documented in the individual care plan.

standard

Advance care planning is to be raised in a timely and appropriate manner, preferably by the physician in charge or central healthcare professional, or by the patient and his family. The agreements made are recorded in the individual care plan. Advance care planning is repeated when necessitated by the patient's situation.

structure and process
advance care planning

criteria

1 Advance care planning is a standard part of palliative care.

2 To deliver optimum care, it is important that the patient and his family are appropriately informed about the nature of the illness or frailty, and the prognosis. This will enable the patient to understand the consequences of his illness. Possibilities for treatment (including whether or not to be treated) and the benefits and disadvantages are weighed in the context of the values, wishes and needs of the patient.

3 The conversation with the patient and his family is to take place with respect for their desired degree of openness and honesty in the provision of information, the way they choose to make decisions and how this is shared. The concerns, fears, hopes and expectations of the patient and his family are discussed in a way that meets their capacity, culture, age, spirituality and social situation.

4 When the answer to the surprise question is negative, this could be an appropriate first time to all together think about the meaning of the last stage of life and the process of advance care planning.

5 Moments in the disease process that call for (updating of the) advance care planning include:

- when indicated by the patient, his family or by healthcare professionals or volunteers;
- in case of disease or frailty progression;
- at an early stage of diseases leading to cognitive impairment, such as dementia;
- when transitioning from disease-oriented to symptom-oriented treatment;
- in case of several hospital admissions in a relatively short period of time;
- when the benefits of disease-oriented or symptom-oriented treatment no longer outweigh the disadvantages;
- in case of functional or cognitive deterioration caused by illness or frailty;
- in case of admission to a nursing home or hospice;
- in case of severe physical, psychological or spiritual suffering.

structure and process
advance care planning

6 Advance care planning is a continuous and dynamic process in which the patient’s life goals and choices are the primary focus. The process follows a step-by-step approach focusing on the following points:

- introduction of the (sensitive) subject of the patient’s end of life;
- probing the need to talk about this;
- listing the subjects to be discussed on the basis of the four dimensions;
- reciprocal expectations about the course of the disease and death (prognosis);
- identifying goals and choices for this moment in time and in the future, for example, with respect to the care desired during the last stage of life;
- the (burdensome) role of the informal caregiver and/or the legal representative.

7 Subjects that should be covered in advance care planning include:

- philosophy of life and cultural background;
- decisions on treatment (including whether or not to be treated);
- admission to hospital;
- place of care and dying;
- crisis situations (including major bleeding, acute asphyxiation, refractory symptoms);
- living-will declaration;
- legal representation in the event of (acute) deterioration or legal incompetence;
- end-of-life decisions (including administration of fluids, nutrition, antibiotics, resuscitation, switching off ICD, palliative sedation, euthanasia, organ donation, deliberately stopping of eating and drinking);
- care after death.

8 The healthcare professional is committed to following wishes expressed earlier by the patient or his legal representative. For patients who can no longer communicate and who have not made their wishes known earlier, the healthcare professional checks whether:

- a legal representative has been appointed;
- there is a living-will declaration, or
- there are wishes that have been put in writing in some other way.

In such a situation, extra attention should be paid to explaining the process of decision-making to the patient’s minor children.

9 Agreements resulting from the process of advance care planning are recorded in the individual care plan, with the approval of the patient or his legal representative.

10 The process of advance care planning will be repeated regularly, in mutual agreement with the patient and his family. This provides for the possibility to review and adjust agreements made with respect to current and future support and treatment.

structure and process
individual care plan

introduction

The conversation with the patient and his family about the strategy that fits him and his situation best, is the basis of the dynamic individual care plan. The agreements made are recorded in this care plan, focusing on physical, psychological, social and spiritual well-being. Simple and short if possible, intricate and extensive when required. The patient can, from a personal perspective, use this documented, updated and monitored individual care plan to acquire more knowledge about his illness or frailty, take part in the decision on the strategy and treatment and get to work with it himself, if possible. This way, he can keep or increase self-management and control of his situation. For the healthcare professionals, the overview of goals and agreements is a means to promote continuity of care and to increase involvement of the patient and his family in the care process.

standard

Each patient in the palliative care phase has an individual care plan which is kept with the patient and is adjusted when necessary during the disease process. The individual care plan is the means to keep the patient, his family, healthcare professionals and volunteers aligned, and lists the agreements unambiguously and accessibly, and is always available, even during nights, weekends, in crisis situations and in the end-of-life stage.
If, in the context of specific individual care and individual patient and family circumstances, an individual care plan is considered unnecessary, it is possible to decide not to have one if there are valid arguments for it and in mutual agreement with the patient.

structure and process
individual care plan

criteria

1 When drawing up an individual care plan, the process of shared decision-making and of advance care planning – with the patient, his family and the physician in charge – is the primary focus.

2 The individual care plan is managed by the central healthcare professional who is the patient's first point of contact and who is responsible for the coordination and continuity of the provision of care.

3 The individual care plan does not only reflect the current situation and coordination of care, but also includes the agreements made with reference to the advance care planning.

4 For purposes of coordination of care, the physician in charge, the central healthcare professional and other healthcare professionals, informal caregivers and volunteers are recorded in the individual care plan, together with their respective tasks and responsibilities.

5 Regarding advance care planning, agreements are recorded concerning:

- wishes and needs regarding care;
- philosophy of life and cultural background;
- decisions on treatment (including whether or not to be treated);
- admission to hospital;
- desired place of care and dying;
- who will be present during the end-of-life stage;
- crisis situations (including major bleeding, acute asphyxiation, refractory symptoms);
- living-will declarations;
- legal representation in the event of (acute) deterioration or legal incompetence;
- end-of-life decisions (including administration of fluids, nutrition, antibiotics, resuscitation, switching off ICD, palliative sedation, euthanasia, organ donation, deliberate cessation of eating and drinking);
- care after death.

6 In the individual care plan, the values, wishes and needs of the patient regarding the four dimensions are recorded and linked to goals that are yet to be realised.

7 In the individual care plan, current and likely problems, actions to be taken and planned evaluations, all regarding four dimensions, are recorded and signed off by the patient. Following an evaluation, the individual care plan can be revised or adjusted.

structure and process
individual care plan

8 In the individual care plan, a section is dedicated to social and practical consequences of being ill and the approaching death, e.g. regarding financial consequences, insurances, notarial and legal aspects, position of partner and children, organ donation and funeral arrangements.

9 To enhance the patient’s own control, in accordance with the agreements made, the individual care plan document describes what:

- the patient wishes to do himself;
- will be done by his family;
- will be done by healthcare professionals or volunteers.

10 The family members, healthcare professionals and volunteers who have access to the individual care plan are documented in mutual agreement with the patient, and in accordance with privacy legislation.

11 The individual care plan is preferably accessible electronically to all involved. If not, a paper version is kept with the patient.

structure and process

interdisciplinary care

introduction

All current and potential questions about a patient can better be approached collaboratively than separately. This requires an interdisciplinary approach and calls for a good collaborative relationship among the disciplines. This will enable a methodical work approach that is based on the values, wishes and needs of the patient and his family in the physical, psychological, social and spiritual areas.

standard

The multidimensional approach of the patient and his healthcare requirements in the palliative care phase calls for knowledge and involvement of several disciplines working together in an interdisciplinary team. This team is formed by healthcare professionals and volunteers in close collaboration with the patient and his family.

structure and process
interdisciplinary care

criteria

1 The healthcare professionals and volunteers form a personal and dynamic team around the patient and his family that is available at any time. This team works on the basis of the individual care plan, with the central healthcare professional as the connecting link.

2 With input from the patient and his family, the team of healthcare professionals involved evaluates the well-being of the patient and the care provided at set times and, when necessary, ad hoc. The individual care plan is updated when required.
In primary care, this evaluation should preferably take place in a PaTz (Palliatieve Thuiszorg (palliative care at home)) group or in a similar multidisciplinary evaluation group.

3 In mutual agreement with the physician in charge, healthcare professionals specialised in palliative care will be involved when generalist palliative care professionals cannot meet the values, wishes and needs of the patient and his family.

4 A specialist palliative care team always consists of physicians and nurses specialised in palliative care and spiritual care givers and/or BIG*-registered psychologists and/or social workers.

5 If specialist evaluation of the patient takes place, advice is accompanied by a step-by-step plan for continuing treatment when signs or symptoms worsen

6 Involvement of existing and new healthcare professionals, informal caregivers and volunteers is continuously updated in the individual care plan. Their tasks and responsibilities are also recorded.

*BIG = Beroepen Individuele Gezondheidszorg (Individual Healthcare Professions)

structure and process
informal care

introduction

Informal caregivers play a key role in offering support and care to the patient, irrespective of whether he is living at home, or has been admitted to a hospital, nursing home or hospice. Optimal collaboration between healthcare professionals and volunteers and informal caregivers involves taking into account the different roles an informal caregiver can fulfil: as a family member, shadow patient, colleague healthcare provider or expert (e.g. on the patient's life). Which role is most prominent may differ from time to time and from situation to situation. Fulfilling an informal-care role may be a source of satisfaction, but is often physically and psychologically taxing. Informal caregivers need guidance, information, advice and support before and after the patient's death. Specific attention by the healthcare professionals and volunteers for the individual values, wishes and needs of the informal caregiver enables him to better fulfil his role and reduces the stress he may experience.

standard

The informal caregiver is recognised by the healthcare professionals and volunteers as the family member who plays an important role in caring for the patient and is actively involved in this. Based on his specific values, wishes and needs, the informal caregiver is also supported and guided, and is provided with information. One or more family members may have this role.

structure and process
informal care

criteria

1 The informal caregiver and his responsibilities are listed by the patient and his family in mutual agreement with the healthcare professional. Furthermore, which family member will act as the patient’s legal representative will also be discussed. These agreements are recorded in the individual care plan by the physician in charge or the central healthcare professional, and are evaluated during the disease process and adjusted when required.

2 In his role as a caregiver, the informal caregiver is informed about the situation of the patient and how he can best support him. To support the informal caregiver in planning and offering care, he is provided with information and relevant support options tailored to his needs (for example, use of home care, volunteers, respite care).

3 The healthcare professional pays specific attention to the strengths and strains, burden, values, wishes and needs of the informal caregiver in his role as a family member, and provides support to prevent or reduce any overload.

4 The informal caregiver is stimulated to self-care activities to reduce stress and increase his well-being and safety, to enable him to continue to care for the patient.

structure and process
coordination and continuity

introduction

Along with challenges brought about by the disease, a patient with a life-threatening condition or frailty and his family are faced with the task of staying in charge of their own lives. This is made more challenging by a complicated and fragmented healthcare system, which requires fine-tuning between a number of different healthcare professionals, various healthcare settings and many diagnostic and treatment interventions. High-quality palliative care requires coordination and continuity of care and planning and organising ahead in full knowledge of the situation. Since a team of healthcare professionals is involved in palliative care, one person shall be designated as having primary responsibility and should carry out these tasks. This person, who is designated the "central healthcare professional", is the point of contact for the entire team and for the patient and his family.

standard

The healthcare professionals form a personal and dynamic team around the patient and his family that is available at any time. Available facilities and expertise are effectively used and called in. Any transfers required must take place seamlessly. This team works on the basis of the individual care plan, with the central healthcare professional as the connecting link.

structure and process
coordination and continuity

criteria

1 For palliative care to really be available and effectively and efficiently usable, it will have to meet a number of conditions:

- the care is tailored to the patient and his family and the situation;
- it is clear who is the physician in charge;
- it is clear who is the central healthcare professional;
- it is clear how the central healthcare professional can be reached by the patient and his family;
- an individual care plan is used;
- healthcare professionals can respond in time to patient-reported worsening of symptoms, and interventions are documented;
- availability of care is guaranteed, anywhere, 24 hours per day, 7 days per week;
- multidisciplinary evaluation takes place;
- the healthcare professionals involved are working together as an interdisciplinary team;
- the healthcare professionals involved are responsible for informing the central healthcare professional at the information handover;
- specialised palliative care teams are available to support the healthcare professionals involved;
- volunteers are used when necessary;
- work is done in accordance with protocols, guidelines and care paths.

2 A central healthcare professional is available for every patient. In principle this is a BIG-registered healthcare professional with clear tasks and responsibilities with regard to palliative care, and coordination and continuity of care.
In mutual agreement with the patient and his family, the tasks of the central healthcare professional are carried out by the physician in charge or are delegated to another team member (specialised in palliative care).
It may be necessary to change to another central healthcare professional due to changes in the patient's situation or the location in which he receives care.

structure and process
coordination and continuity

3 The central healthcare professional is the first point of contact for the patient and his family and for other healthcare professionals, and he makes sure that:

- retention of control by the patient and his family is stimulated, as far as possible and/or desired;
- the individual care plan is realised, adjusted and complied with;
- task allocation between healthcare professionals, informal caregivers and volunteers is clear;
- continuity of care is arranged;
- required multidisciplinary evaluation, other consultations or referrals are arranged;
- the community services involved in caring for the patient and his family are clearly documented and updated;
- appropriate support, home care, informal care and aids are arranged and coordinated;
- there is attention for support of informal caregivers and volunteers;
- agreements made are compatible with the patient's healthcare service indication; and:
- if agreements and healthcare service indication are not in agreement with each other, possible solutions are discussed with the organisations involved.

4 The individual care plan is the means to keep the patient, his family, healthcare professionals and volunteers aligned, and lists the agreements unambiguously and accessibly, and is always available, even during nights, weekends, in crisis situations and in the end-of-life stage. It is therefore preferable that the individual care plan is accessible electronically to all involved. If not, a paper version is kept with the patient.

structure and process
network

introduction

A palliative care network is a formal and sustainable partnership of independent organisations involved with palliative care in a specific region. The collaboration within a network region should be focused on a complete, coherent and sufficient provision of palliative care of sensible quality. The palliative care network plays a role in informing healthcare professionals about expertise available in the region, so that patients and their families can receive appropriate care in a timely manner. The network coordinator has a central role here because he initiates, advises and facilitates with respect to continuous improvement of quality and accessibility of palliative care in the region.

standard

The organisations involved in a region work together effectively and efficiently to provide for the wishes and needs of patients with a life-threatening condition or frailty, and their families.

criteria

1 The responsibility for a good organisation of palliative care in the region lies with the organisations participating in the network, healthcare professionals and others involved. It is the task of the network to connect, coordinate, inform, signal and facilitate.

2 For a well-functioning care network, there should be binding agreements and protocols regarding education, documentation, direction and control, task allocation, quality assurance, and handling of complaints and problems between healthcare providers and individuals.

3 Agreements have been made within the network between generalist and specialist providers of palliative care concerning collaboration, transfer and referral procedures. The goal is to guarantee continuity of palliative care, regardless of where the patient is living.

4 For patients with needs that surpass the abilities of the generalist healthcare professional, specialist consultation is available 24 hours per day, 7 days per week.

5 Agreements have been made about the availability of respite care within a network region.

6 All necessary information is available, accessible and transferable. ICT plays a key role in this.

structure and process
expertise

introduction

All healthcare professionals in the Netherlands are expected to be able to provide palliative care for patients and their families, and to request specialist support whenever required. Every healthcare professional involved in providing palliative care at a generalist, specialist or expert level shall, therefore, receive appropriate and continuing training and education to guarantee the quality of care.

Volunteers play an important part in the provision of palliative care in many organisations. They can only take part in the provision of palliative care after a certified basic training. They also have their own quality framework.[1]

standard

Both healthcare professionals[2] and volunteers are qualified for the care they provide, and they can prove that they are keeping their knowledge up-to-date with relevant continuing education.

criteria for healthcare professionals

1 As relevant to his position, the healthcare professional is skilled and knowledgeable with respect to the four dimensions of palliative care (physical, psychological, social and spiritual), shared decision-making and advance care planning. He has taken note of other important aspects of care, such as organisation, end-of-life care, loss and bereavement, culture, ethics and law. The healthcare professional maintains the expertise and skills described for his position.

2 As relevant to his position, the healthcare professional is able to distinguish between disease-oriented treatment, symptom-oriented treatment and the end-of-life stage. He is also able to anticipate and identify problems on time, and he is able to provide and organise the appropriate care before and after death (continuity of care).

3 The healthcare professional should be aware of his own qualities and limitations as well as those of direct colleague healthcare professionals with respect to expertise and skills related to palliative care. This allows the healthcare professional to call in specialised palliative care to add expertise and skills and thus increase the effectiveness of the requested care.

4 The healthcare professional is able to ask himself the question "Would you be surprised if this patient died within the next 12 months?" If the answer is negative ("No, I would not be surprised"), then he is able to discuss this with the treating physician.

5 Following identification of the different stages characterising the course of the disease, the treating physician is able to have the complicated conversation about the diagnosis and the likely course, and knows that it is important that a family member is with the patient during this conversation.

6 As relevant to his position, the healthcare professional is able to take a multidimensional and functional case history. Whenever possible, he uses (validated) measurement instruments to do this.

7 Together with the patient and his family, the healthcare professional is able to clarify what is still important to the patient, what the patient wants to realise and what his achievable wishes and goals are.

8 The healthcare professional is able to have the complicated conversation with the patient and his family about the patient's approaching death and the time after death, and during this conversation he is able to pay attention to the values, questions, worries and needs involved. In addition, he is able to respect the right (not) to want to know.

9 As relevant to his position, the healthcare professional is able to provide optimal information to the patient and his family, taking into account intellectual powers, culture, coping style and language.

structure and process

expertise

additional criteria for healthcare professionals with specific palliative expertise

10 Healthcare professionals specialised in palliative care have had a certified training in palliative care, and have relevant experience and skills. This allows them to fulfil the multidimensional needs of the patient and his family. They are also willing and able to collaborate as an interdisciplinary team (primary, secondary or transmural).

11 The specialised palliative care team has the expertise required to be able to provide advice and support in specific situations with reference to e.g. children, vulnerable older people or disabled people who are involved with patients in the palliative care phase.

12 Healthcare professionals specialised in palliative care are educated and trained in self-reflection and in developing effective coping skills.

13 Expertise and skills of individual healthcare professionals and of specialised palliative care teams should not only be acquired but also kept up-to-date and recorded, for example in a discipline-specific register.

14 Healthcare professionals specialised in palliative care provide training (such as bedside training and discipline-transcending training) to other healthcare professionals to enhance the development of generalist palliative care.

15 Healthcare professionals specialised in palliative care are used for palliative care training in initial education and further education.

16 Healthcare professionals specialised in palliative care participate in initiatives to increase public awareness with respect to palliative care, to provide information or to increase the number of volunteers.

criteria for palliative care volunteers

17 As relevant to his position, the volunteer is knowledgeable and skilled in adapting to the patient, with attention for the four dimensions of palliative care and for collaborating with others. Required expertise and skills as laid out in a specific quality framework[1] are kept up-to-date.

18 Volunteers are educated and trained in self-reflection and in developing effective coping skills.

19 Volunteers are aware of their own values and convictions. Volunteers are able to stay within the limits of their own responsibilities, identify on time when their own expertise and skills are inadequate, and they are able to ask for support, guidance and/or training[1].

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1. Zicht op ‘Er Zijn’, Kwaliteitskader Vrijwilligers Palliatieve Terminale Zorg (2016).
2. Onderwijsraamwerk palliatieve zorg 1.0 als onderdeel van de Kennissynthese onderwijs palliatieve zorg (2016)

structure and process
quality and research

introduction

Quality management is based on principles of continuing evaluation and improvement. Organisations strive for the best quality palliative care for patients with a life-threatening condition or frailty. Organisations participate in audits and quality projects and aim to participate in research to achieve this goal. Participation in research is dependent on the capacity of the organisation and varies from contributing to data collection to initiating research projects. Participation by an organisation in external accreditation programmes contributes to the development of structured programmes for quality improvement, including evaluation of patient care and patient satisfaction research.

standard

Providers of palliative care strive for the best quality palliative care, both in experienced quality of care and support offered to all patients and their families, healthcare professionals and volunteers, and in organisation of care.

structure and process
quality and research

criteria

1 Care facilities go through a plan-do-check-act (PDCA) quality and performance improvement cycle for all parts of palliative care, including satisfaction with and effectiveness of care provided, organisation, education and team commitment.

2 Depending on their possibilities, providers of palliative care are prepared to participate in research or initiate this themselves to gain insight in the wishes, needs and experiences of patients and their families, and to be able to evaluate the quality of care delivered and/or implement new interventions.

3 Actions for quality improvement may be based on satisfaction research among patients, families and staff members as well as on bottlenecks resulting from regular and systematic measurements, analyses and evaluations of care processes and outcomes. The provider of palliative care translates the findings to policies for daily practice

4 Actions or notifications to improve quality of palliative care are a part of the daily routine. They are reported and have an influence on daily practice. This process is guided by appointed quality staff whenever possible.

5 Care facilities offering palliative care strive to use benchmarking to compare themselves with other care facilities in order to improve quality of care and the organisation.

6 Palliative care providers strive for relevant levels of education for all of their healthcare professionals, in relation to their position. The organisation provides opportunities for acquiring new knowledge and insights in palliative care.

7 In order to guarantee the quality of palliative care, care is provided on the basis of professional, authorised and registered guidelines, protocols and care pathways, supported by (validated) measurement instruments whenever possible. The palliative reasoning method, shared decision-making, advance care planning and regional and transmural collaboration agreements are part of the palliative care process.

8 There are policy agreements on triage of referred patients and reported crisis situations within 24 hours.

9 A specialist palliative care team organises supervision and peer to peer coaching for the team members involved and, at least once a year, organises a joint evaluation of the quality of care provided, including quality measurement and quality improvement, policy and staffing.

10 There is a pronounced willingness to involve volunteers in palliative care. Organisations using volunteers dispose of policy agreements, protocols and procedures to guarantee the quality of the volunteer supply. This might include: recruitment and selection, support and guidance, supervision and performance reviews.

11 An experienced healthcare professional with relevant training acts as a coordinator for the volunteers within an organisation. This coordinator is responsible for enhancing the quality of care provided by the volunteers.

physical dimension

introduction

Ensuring physical wellbeing and high-quality management of physical symptoms of the patient with a life-threatening condition or frailty is the basis of palliative care. This enhances psychological, social and spiritual quality of life and should be an integral part of the palliative care plan.

Symptom management complies with the current guidelines for palliative care as much as possible, while paying attention to effectiveness, efficiency and medication safety. The goal of treatment is to lower the symptom burden to a level acceptable to the patient. With this regard, the patient's (physical) wellbeing should be assessed regularly, using (validated) measurement instruments whenever possible.

Symptoms tend to present simultaneously, which complicates assessment and treatment. This calls for a multidimensional and interdisciplinary approach for which help from healthcare professionals specialised in palliative care can be called in when necessary.

Frequently occurring symptoms in palliative care include pain, anorexia and cachexia, obstipation, weakness, shortness of breath and death rattle, nausea and vomiting, fatigue, delirium (and agitation), depression, challenging behaviour in dementia, itching, dry mouth, coughing, anxiety, oedema, sleep disorders, incontinence and urine retention, diarrhoea and hiccups. There should also be attention for skin- and wound care.

standard

The physical symptoms of a patient with a life-threatening condition or frailty should be treated in accordance with current guidelines and insights from which can be derogated based on expertise and knowledge and to tailor the treatment to the individual patient. The resources this requires (such as medication, syringe drivers or a high-low bed) should be available in sufficient quantities.

physical dimension

criteria

1 The goal of symptom management is to appropriately and safely reduce the symptom burden to a level acceptable to the patient.

2 Assessment and treatment of mostly multiple simultaneous symptoms requires a multidimensional and interdisciplinary approach. Help from healthcare professionals specialised in palliative care is called in when necessary.

3 The healthcare professional, together with the patient and his family, assesses the values, wishes, needs and habits important to increasing or maintaining physical wellbeing such as:

- food and drink;
- exertion and relaxation;
- self-care and (physical) care;
- mobility;
- rhythm of day and night;
- privacy;
- intimacy and sexuality.

4 In order to deliver optimum care, it is important that the patient and his family are appropriately informed about the nature of the illness or frailty and the prognosis by the treating physician or the central healthcare professional, in mutual agreement. This enables the patient to understand the consequences of his illness.

Treatment options (including whether to receive or forego treatment) and their benefits and disadvantages, including discontinuation of medication no longer thought useful are then weighed in the context of the patient's values, wishes and needs.

5 The healthcare professional, together with the patient and his family, identifies and assesses the current symptom burden and anticipates any likely symptoms. He evaluates physical functioning, using (validated) measurement instruments whenever possible, and determines nature, severity and possible risks in this domain. In mutual agreement with the patient and his family, appropriate and any necessary anticipatory interventions are discussed, recorded and carried out. The advice should preferably be accompanied by a stepped care plan for continuing treatment in case of worsening signs or symptoms.

6 Treatment of symptoms and side effects can consist of non-pharmaceutical, pharmaceutical and invasive interventions, whether or not supported by complementary care. The effect of the treatment on the wellbeing of the patient should be evaluated regularly and revised whenever necessary.

physical dimension

criteria

7 Informal caregivers and/or family and volunteers are sufficiently trained and supported to enable them to provide physical care to the best of their abilities and in accordance with their responsibilities. They know how to act in emergency situations.

8 The healthcare professional pays specific attention to fables, facts and barriers with respect to the use of medication, and especially opioids and sedatives, such as:

- risk of addiction;
- respiratory depression;
- hastening death, also in relation to euthanasia, physician-assisted suicide and palliative sedation;
- any other alleged side-effects.

9 Agreements resulting from the care process are recorded in the individual care plan.

psychological/psychiatric dimension

introduction

Psychological symptoms such as anxiety and despondency often occur in patients with a life-threatening condition or frailty. They have a negative effect on the quality of life. Psychological symptoms can cause physical symptoms such as nausea, shortness of breath and sleeplessness. On the other hand, physical symptoms can worsen anxiety and despondency. Undertreatment of pain can also lead to worsening of psychological symptoms.

Regular assessment of the psychological condition of a patient is an important part of palliative care and all healthcare professionals involved with palliative care should have knowledge of dealing with and treating the psychological aspects of this care. Providing information to the patient, his family, involved healthcare professionals and volunteers, and attention for legal representation are essential parts of the treatment plan. In case a psychiatric condition is suspected, specific screening is carried out, using (validated) measurement instruments whenever possible, and when required, a specialised healthcare professional will be involved in the care.

standard

The healthcare professional, together with the patient and his family, pays attention to the psychological consequences of a life-threatening condition or frailty and the presence of any psychiatric symptoms. The goal is to increase the psychological wellbeing of the patient and his family by improving aspects such as coping. The healthcare professional operates in accordance with current guidelines and insights.

psychological/psychiatric dimension

criteria

1 Healthcare professionals have had specific education and have basic skills to recognise and possibly treat common psychological and psychiatric symptoms and conditions (such as anxiety, depression, delirium, (complicated) grief, loneliness, hopelessness, hallucinations, suicidal thoughts and withdrawal symptoms in case of addiction).

2 The healthcare professional, together with the patient or legal representative and his family, assesses values, wishes and needs that contribute to increasing or maintaining cognitive and emotional psychological wellbeing, including regaining perspective on life and striving for a good balance. Issues that can play a role here include:

- coping with (accepting) the current situation;
- finding and maintaining a balance between strengths and strains;
- values and choices;
- respect and personal identity;
- regaining a sense of purpose in life;
- risks and barriers for psychological wellbeing;
- caregivers burden.

3 The healthcare professional identifies, assesses and evaluates the nature and severity of any signs, symptoms and risks experienced by the patient and his family with respect to emotional and cognitive functioning, using (validated) measurement instruments whenever possible. He discusses these with the patient and his family and takes appropriate and preventive measures in mutual agreement. When required, the healthcare professional will consult an expert.

4 Assessing and treating the psychological condition of the patient also includes:

- effectively communicating with the patient or legal representative and his family;
- informing them about the disease or condition or frailty, symptoms, possible treatments and side-effects;
- providing safe and applicable advice and measures, tailored to the patient, his care needs, his legal competence and coping strategies;
- informing healthcare professionals and volunteers, in mutual agreement with the patient or legal representative, when necessary.

5 The healthcare professional assesses, together with the patient and his family, the support needed with respect to cognitive functioning (understanding, remembering, thinking, following conversations, planning and organising, orientation in time, place and person, taking initiatives).

psychological/psychiatric dimension

6 The healthcare professional responds adequately to psychological distress and psychiatric conditions, taking into account the choices made by the patient or legal representative. Treatment is aimed at comfort and based on clinical and psychological examination of the patient, current guidelines and insights, and may consist of non-pharmaceutical and pharmaceutical interventions, supported or not supported by complementary care.
The effect of the treatment on the wellbeing of the patient should be evaluated regularly and revised when necessary.

7 In cases of a psychiatric condition such as depression, suicidal thoughts, anxiety or delirium, resulting from a life-threatening condition or frailty or an additional psychiatric disease, the healthcare professional should consult an expert when necessary.

8 Agreements resulting from the care process are recorded in the individual care plan.

social dimension

introduction

A life-threatening condition or frailty not only has consequences for the patient as an individual, but also affects his social functioning because of the patient's changing roles and responsibilities.
In addition, a life-threatening condition or frailty affects not only the patient, but also his family, in the broadest sense of the word. Children, partners, parents and other family members, colleagues, friends, neighbours, employers, and also healthcare professionals and volunteers are affected by the situation of an individual patient.

The coping process of the patient and his family (which may have an asynchronous course), changing roles and responsibilities, communication with family and friends, possible financial worries and the conversation about goals, wishes and needs that are still to be realised, all fall within the domain of social aspects of care. This social context may affect care and the nature and manner of decision-making by the patient. In order to be able to provide good care, insight in this context is required for healthcare professionals.

standard

Together with the patient and his family, the healthcare professional reflects on their social circumstances, in order to enable that their goals, wishes and needs are met, strong points can be utilised, and the wellbeing of the patient and his family can be increased. The patient as well as his family experience appropriate attention and support in interacting with one another.

social dimension

criteria

1 Together with the patient and his family, the healthcare professional assesses what is important to them with respect to social wellbeing. This assessment may include the following:
- family structure and function: (changing) roles and responsibilities, patterns of communication, coping, achieving closure, and decision-making;
- strengths and vulnerabilities: finding a balance between strength and strain, resilience, presence of social and cultural support networks, effect of disease or frailty on intimacy, prior experiences with disease, disability and loss;
- making choices and establishing priorities for everyone participating in the social network, school, work (including legal framework for leave of absence), and wishes for how to spend time and take part in recreational activities;
- living conditions: changes in financial security, geographic location and suitability of living environment, possible use of aids, transportation, and adjustments in the home;
- estimating healthcare needs and availability of care in time and manpower, and availability of professional care in the vicinity, contact with peers, financial support, use of volunteers, respite care (e.g. community services in the region).

2 The healthcare professional identifies, assesses and evaluates the nature and severity of concerns, problems and risks experienced by the patient and his family with respect to social wellbeing, using (validated) measurement instruments whenever possible. The healthcare professional discusses the findings with the patient and his family, and after mutual agreement takes appropriate and preventive measures. An expert is called in when necessary.

3 The healthcare professional supports both the patient and his family:
- to understand the different ways of dealing with disease, loss, grief and bereavement;
- to provide emotional and social support;
- to discuss goals, wishes and needs of everyone:
- in the process of decision-making;
- in communication with each other and communication with healthcare professionals and volunteers;
- to find solutions for financial problems.

4 Together with the patient and his family the healthcare professional assesses the social and practical needs arising from winding up one’s life, such as re-establishing lost contacts, carrying out last wishes, drawing up living-will declarations and other legal and notarial affairs, and arranging the funeral.

social dimension

5 Together with the patient and his family, the healthcare professional discusses the feasibility of the various goals, wishes and needs, and whenever necessary refers to the appropriate organisations for help with both identified social needs as with maximising personal strengths.

6 The agreements resulting from the care process are recorded in the individual care plan. The perspective of the patient and his family guides the evaluation and revision of the agreements made.

spiritual dimension

introduction

Spirituality plays an important role in how people deal with disease or frailty, how they experience inner peace and acquire insights into what has value in their lives. Confrontation with death and physical, psychological and/or social limitations have an influence on how purpose and meaning are experienced, and often lead to a re-evaluation of one's life story. This may lead to enrichment, but it may also be accompanied by spiritual distress. The time and space needed by an individual to face the reality of the diagnosis and to relate it to what has meaning and value in his life, varies. This process leads some to growth and transformation, others to existential crisis and despair, and most to a combination of both.

standard

The patient and his family experience attention being paid to what is important to them and receive appropriate support for spiritual[1] and existential concerns and needs.

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[1] Whenever "spiritual" is mentioned in the criteria, it also means "religious" or "meaning".

spiritual dimension

criteria

1 Attention for spirituality is a fundamental part of patient- and family-oriented care that honours the dignity of all concerned.

2 The healthcare professional is aware of his own values and beliefs, acknowledges his own spirituality as part of his professional role and does not impose his personal values, spiritual and existential beliefs on patients, families or colleagues.

3 Healthcare professionals have had specific education, are able to assess spiritual needs and have the (basic) skills for providing spiritual care.

4 In communication with the patient and his family, respect is shown for their spiritual beliefs, practices and rituals.

5 The healthcare professional pays attention to the patient's life story is able to recognise what made the patient find and what made him lose purpose and meaning. The healthcare professional pays attention to values, wishes and needs with regard to the spiritual wellbeing of the patient and his family, and assesses which aspects they want healthcare professionals to take into account in the care they provide.

6 The healthcare professional pays attention to what touches and moves the patient and his family in the confrontation with disease and loss, is able to recognise spiritual distress or existential crisis and to map those more precisely, using (validated) measurement instruments whenever possible. Subjects that may concern the patient and his family include:

- anxiety, grief, resignation, anger and resistance with regard to experiencing purpose and meaning;
- looking for meaning in the past (life story), the present (having a purpose or experience meaning, even when you are ill) and the future (life closure and death);
- existential questions and questions about the meaning of life, questions about identity, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy, a need for rituals;
- the most valuable things for a person such as the relationship with oneself, family, culture, ethics, morality and life itself;
- ideological and philosophical considerations and foundations; faith, belief, the relationship with the transcendent or godly and nature;
- barriers and risks for spiritual wellbeing.

In mutual agreement with the patient and his family, the healthcare professional takes appropriate and preventive measures. Regardless of where the patient is, an expert is called in whenever desired or required (e.g. in a crisis situation).

spiritual dimension

7 The patient and his family are extended the courtesy to express their own faith or ideological beliefs and to meet who they want in this context. Whenever desired, they receive (professional) support for customs and rituals that are important to them.

8 In mutual agreement with the patient and his family, it is decided what is to be included in the individual care plan, and thus should be brought to attention in transferral of care, with respect to spiritual wellbeing and spiritual needs of the patient and his family.

end-of-life care

introduction

Care of the patient at the end of life can be qualified as intensive care, in which both recognition and acknowledgement of the approaching death of the patient by the healthcare professionals as well as optimal communication on this subject with the patient and his family are essential. Attention to the values and wishes of the patient, a plan for optimal symptom management during this stage and attention to care immediately after death all reduce anxiety and bring peace for all involved. It is, therefore, important that specific agreements are recorded in the individual care plan or in the End-of-Life-care pathway and that they are available, e.g. electronically, to the patient.

standard 1

Patients at the end of life are identified at an early stage. The individual care plan is updated accordingly, or the End-of-life care pathway is started.

end-of-life care

criteria

1 Indications for identification of the end of life are:

- the patient no longer leaves his bed;
- the patient is semi-conscious;
- the patient can only take small sips;
- the patient can no longer swallow tablets.

It is possible that these symptoms have been present for some time even though the patient was not dying, or that they are not clearly present while it is nevertheless clear to the healthcare professionals involved that the patient will die within a few days. It is, therefore, emphasised that a (multidisciplinary) professional evaluation is decisive for identifying the patient at the end of life.

2 Care for the patient at the end of life requires time and attention for physical, psychological, social and spiritual processes as they develop at the end of life. Agreements are also made with respect to accessibility and availability of the healthcare professionals involved in case of changes in one of the four dimensions.

3 The healthcare professional is aware of the values, wishes and needs of the dying patient. The concerns, anxieties, hopes and expectations of the patient and his family at the end of life are honestly addressed and, if so desired, discussed in an open atmosphere. This is done in a way appropriate for the patient’s culture, age, spirituality and social situation.

4 The healthcare professional discusses, if this has not been done earlier, with the patient or the legal representative and/or family what is important to them at life closure, such as:

- attention for the meaning the patient attaches to winding up his life in dignity and individuality, and the choices and decisions this entails;
- preferred place of care and dying;
- physical, psychological, social and spiritual wishes and needs;
- saying farewell properly and carrying out rituals;
- wishes and needs with respect to the dying process and the involvement and support of family, and practical issues just before and after death.

5 Current and likely signs and symptoms and possibilities to manage these are discussed with the patient or the legal representative and/or family. The required aids and medication are (proactively) arranged.

6 The healthcare professional informs the family about what they can expect in this stage and how they can support the patient, in a way that is appropriate for their culture, age, spirituality and social situation. During the dying process the healthcare professional gives advice about position, administration of fluids and nutrition (including cessation), and recognising signs of imminent death.

7 The healthcare professional pays attention to the strengths and strains of the patient and his family, and provides support to prevent or reduce any overload. Volunteers are involved whenever necessary.

8 Before the patient's death, a conversation takes place with the patient and his family about the imminent loss and (anticipatory) grief, and which reactions may be expected. The patient and his family can already be supported during the last stage of life with regard to bidding farewell in a meaningful way. Possibilities for professional support are also discussed. When the family member has a different family doctor than the patient, the relative's family doctor may be informed by phone about the patient's imminent death, if required and with approval of the family member.

9 When appropriate, the treating physician has a conversation before the patient's death about sensitive issues such as post-mortem examination, organ and tissue donation, or donation of the body to science.

10 When there is an indication to start palliative sedation, the implications must be discussed properly with the patient or the legal representative and/or family, especially when it concerns continuous palliative sedation. When required, help from a healthcare professional specialised in palliative care can be called in.

11 The agreements resulting from the care process, including a plan for good symptom management, are recorded in the individual care plan or the End-of-life care pathway, which are regularly evaluated and updated when required.

12 All healthcare professionals involved, especially the treating physician in secondary or primary care, are notified by the physician in charge as soon as possible about the patient entering the end-of-life stage or the patient's demise. Personal contact by phone preferably precedes a written message.

end-of-life care

standard 2

Care after death is delivered with respect and honours the dignity, culture and ideological and philosophical beliefs of the patient and his family.

criteria

1 The family members experience sufficient room to bid farewell to their loved one in a way that is appropriate to them. They are asked whether they want to give the last care to their loved one. If they wish, they can be supported by healthcare professionals while providing the last care

2 The family is given the opportunity to perform ideological or culture-specific rituals. If desired, they can be supported in this.

loss and bereavement

introduction

Bereavement includes all physical, emotional, cognitive, spiritual, existential and behavioural reactions that occur around the imminent death or after the loss of a loved one. The patient and his family often already experience feelings of bereavement during the disease process, at which stage it concerns mourning of loss of health and functional autonomy and anticipatory grief about the imminent death.
Surviving relatives usually do not know which (acute) responses may follow the loss of a loved one. Their own (cultural) background may give expectations and opinions about how to behave or what to feel, and approximately how long this grieving process should last; however, this process differs from person to person, and bereavement may vary in duration and form.

The bereavement process for surviving relatives usually follows a natural, uncomplicated course. A problematic (complicated) process of dealing with grief, however, may have far-reaching consequences. Inadequate coping with loss manifests itself by avoiding the loss, by being continuously preoccupied with that loss or by being incapable of giving a new meaning to life, sometimes lasting for many years after the death of a loved one. The reality of the loss is not accepted. Such a manifestation of complex grief requires attention, guidance or a (specific) intervention.

In recent years, more attention has been given to manifestation of loss and bereavement in healthcare professionals after the death of a patient. A bereavement process in healthcare professionals manifests itself differently than in family members, and is socially less well recognised and acknowledged. Nevertheless, repeated loss of patients may be a factor in the development of, for example, overload, empathy-fatigue and burn-out in a healthcare professional and, therefore, requires structural attention by means of peer to peer coaching or supervision.

standard

The patient, his family, healthcare professionals and volunteers experience appropriate attention for loss and (anticipatory) grief. Professional guidance should be available and accessible when necessary or desired. Special attention is given to surviving relatives who are dependent on the patient.

loss and bereavement

criteria

1 Before death, a conversation takes place with the patient and his family about the imminent loss, the importance of bidding a proper farewell, (anticipatory) grieving and reactions that may occur. Possibilities for support, such as contact with peers or (professional) guidance, are also discussed. When required, and with the approval of the family member concerned, his family doctor will be informed by phone about the imminent death of the patient.

2 The family members experience sufficient room to bid farewell to their loved one in a way that is appropriate to them. They are asked whether they want to give the last care to their loved one. If they wish, they can be supported by healthcare professionals while providing the last care.

3 After death, time and attention are given to the family and friends to offer comfort and support in dealing with their loss. This attention is appropriate for the social, cultural and spiritual rituals and customs of the patient and his family.

4 The healthcare professional pays attention to the way in which surviving relatives respond to the loss of their loved one. These can be physical, emotional, cognitive, spiritual, existential and behavioural responses. The healthcare professional evaluates whether there is enough attention and support available from the immediate surroundings, assesses potential (risk factors for) problems in coping with loss (complicated grief) and takes appropriate or preventive measures.

5 A few weeks after the death of their loved one, surviving relatives are given the opportunity to talk with the healthcare professional, usually the physician in charge or the central healthcare professional, about how they are doing, how they are looking back on the period of disease and dying and on the care provided. This conversation may also make the surviving relatives feel supported in the way in which they are dealing with the loss of their loved one and with their grief. If there are signs of complicated grief, the surviving relatives are advised to contact their own family doctor or, in mutual agreement with the surviving relatives, the healthcare professional may also contact the family doctor directly.

6 Healthcare professionals and volunteers provide support regarding loss and (complicated) grief to the surviving relatives, healthcare professional(s) and volunteers, based on good mutual relationship and current protocols, guidelines, and other relevant documents.

loss and bereavement

7 Experts such as spiritual caregivers, social workers, psychologists, psychiatrists and bereavement counsellors are available for referral in situations of (imminent) complicated grief.

8 Structural attention is paid to education, support, supervision or peer to peer coaching with regard to coping with (repeated) loss and bereavement by the healthcare professionals and volunteers.

culture

introduction

Culture is a broad concept. Cultural identification – whether you feel or want to/can feel at home in the culture – is determined by ethnicity, country of origin and by descent, religion, socio-economic class, age, gender and sexual orientation.

On the one hand, culture is regarded as the total of learned and shared convictions, values and way of life of a specific group of people, generally transferred from generation to generation. On the other hand, culture can also be regarded as a system of meanings that is continuously moving, as a constant process of adaptation, mostly as a response to interaction with others.

Culture is a part of the way people give meaning to their being ill, suffering and dying; it plays a role in the process and substance of decision-making about the type of care a patient wants to receive, who has to provide it and under which conditions. Healthcare professionals, as well, have their own culture and specific professional culture, which is distinct from the social environment of the patient. It is the responsibility of all healthcare professionals involved with palliative care to have communication skills that enable them to offer appropriate care to patients and their families, while being aware of the cultural differences between themselves and others.

standard

The cultural background of the patient, his family and related community are recognised, acknowledged, and explored and respected during the care process.

criteria

1 Each healthcare professional and volunteer is aware of his own cultural background and reflects on how his own cultural values, professional culture, (pre)conceptions and expressions influence his image of patients, family and colleagues. The healthcare professional/volunteer tries to prevent that his value judgements interfere with his interaction with patients, family and colleagues.

2 When assessing healthcare needs, the healthcare professional maps the cultural background of the patient and his family with specific attention to:

- habits, customs and rituals;
- the meaning people give to life, disease or frailty, and death;
- to what extent and in which manner people derive strength and support from their culture.

The healthcare professional is also aware that opinions may differ between the patient and his family.

3 The patient and his family receive support from the healthcare professionals involved, in a manner which is appropriate for their cultural background. When required, experts or organisations with knowledge of the respective cultural background are called in.

4 Healthcare professionals are aware of the community services available in their own region, including (multi)cultural centres and healthcare - or patient organisations.

5 Language barriers can lead to loss of quality in effective communication. In these situations, the healthcare professional is expected to make use of telephone interpreting. In an emergency, for lack of a colleague healthcare professional available to act as interpreter, or at the explicit request of the patient and his family it is possible to deviate from this with consent from the patient and his family. In that case, healthcare professionals should be aware of the potential implications for the patient and his family when acting as an interpreter during difficult conversations.

6 The agreements resulting from the care process, are tailored to cultural needs, preferences, customs and rituals. Things of importance to the patient and his family are recorded in the individual care plan.

7 Every healthcare professional and volunteer is willing to continue to develop his sensitivity and competence by means of education, supervision and/or peer to peer coaching.

ethical and legal

introduction

Ethical care and legal principles are linked to professional provision of care. Healthcare professionals should be able to recognise moral dilemmas. Palliative care, in particular, may confront healthcare professionals and volunteers with moral dilemmas. They should therefore have access to ethical and legal expertise when providing care and have the opportunity to deepen their insights by having moral deliberations.

standard 1

The healthcare professional recognises, acknowledges and explores complicated ethical issues that may occur when caring for patients with a life-threatening condition or frailty.

criteria

1 Healthcare professionals and volunteers recognise moral dilemmas. These may result from applying the ethical principles of professional provision of care, namely:

- respect for the individual and his autonomy;
- doing good;
- doing no harm;
- justice and equal allocation of resources.

2 Healthcare professionals and volunteers are sensitive to the context and the relation where moral questions arise. They are capable to reflect on this with others who are involved (patient, family, colleagues) from their different perspectives.

3 Moral dilemmas experienced by the patient, his family, healthcare professionals or volunteers are recognised, acknowledged and explored with the goal of finding a solution and preventing further problems. When required, this is done in collaboration with the specialised palliative care team. Possible issues are: renouncing or discontinuing further treatment, do-not-resuscitate policy or euthanasia. The outcomes of these are recorded in the (medical) file. When required and if possible, a moral deliberation is held and led by a moderator.

4 In case of differing insights or complicated or conflicting moral dilemmas, an ethicist or ethical commission is called in or legal support is sought.

ethical and legal

standard 2

Current law and regulation, acknowledged medical-care standards and professional guidelines are the frameworks within which the values, wishes and needs of the patient or legal representative and his family are respected.

criteria

1 Palliative care is carried out within the frameworks of current law and regulation, existing professional ethical codes and available guidelines and care standards for all disciplines involved.

2 The healthcare professional knows and acts in accordance with legal or otherwise regulated aspects of palliative care, including issues about:

- access to the medical file or provision of personal medical information;
- informed consent;
- living-will declaration;
- investigation into legal competence;
- deliberately stopping of eating and drinking;
- role and responsibilities of legal representatives;
- organ donation;
- palliative sedation;
- euthanasia.

3 Whenever relevant, the healthcare professional discusses with the patient and his family how legal, professional or personal fundamental boundaries obstruct the realisation of goals, wishes and needs.

4 The patient and his family are advised by the healthcare professional to ask for professional advice when drawing up or updating legal or financial documents such as a will, guardianship and parenthood papers.

ethical and legal

5 The healthcare professional is committed to following wishes expressed earlier by the patient or his legal representative. For patients who can no longer communicate and who have not made their wishes known earlier, the healthcare professional checks whether there is a living-will declaration, whether wishes have been put in writing in some other way and whether a legal representative has been appointed.

6 The healthcare professional supports the legal representatives and guides them to understand the legal and ethical basis of represented decision-making. This includes complying with the known wishes and preferences of the patient, represented evaluation of the situation and acting in the interest of the patient. In such a situation, extra attention should be paid to explaining the process of decision-making to the minor children of the patient.

recommendations

The quality framework is expected to play an appropriate role from now on. The working group sees fit to propose a number of recommendations on how the quality framework can be used and put to practice, from the perspective of the patient and his family, the healthcare professional, the volunteer and the health insurer.

IMPLEMENTATION

Considering the experience with development of this quality framework, it is recommended to similarly plan implementations in dialogue with patients, healthcare professionals and health insurers and to do this in phases over a period of at least 3 years. A coordination group could be created for this purpose, with a mandated representation of the parties involved in the development of the quality framework. It also seems appropriate to pay attention to both the generic implementation and the implementation within specific disciplines. For the generic implementation, the quality framework can be made available on for example Pallialine.nl and via the app "Palliarts". Appropriate implementation tools can be used within the specific disciplines. A supplement to the quality framework can be developed for specific target groups.

PUBLIC AWARENESS

Awareness of palliative care among citizens is an important condition for effective implementation of the quality framework. The organisation of a public campaign seems desirable to achieve this goal. Attention could be focused on issues such as the meaning of palliative care, shared decision-making, advance care planning and the importance of the individual care plan.

INDIVIDUAL PALLIATIVE CARE PLAN

The Netherlands Ministry of Health, Welfare and Sport has stated that in 2020 every citizen will be ensured of good palliative care in the right place, at the right time and by the right healthcare professionals. In order to achieve this objective, the goals, wishes and needs of the patient should be known to all healthcare professionals involved. The coordination of care this requires, however, appears to be one of the most important obstacles in the executed constraint analyses. A digital individual palliative care plan is an essential tool to overcome this obstacle and reach the desired goal. It is, therefore, strongly recommended to give priority to its development and for it to be available to the patient.

EDUCATION

With the objective of providing all healthcare professionals with good basic knowledge of palliative care, it is important that educational institutions (vocational education at intermediate and higher levels, university, and other certified training) include education on palliative care and its desired quality as a structural element in the curriculum.

HEALTHCARE PROVIDERS

Healthcare professionals should be supported when providing palliative care, so that patients and their families can experience high-quality palliative care. It is, therefore, necessary for healthcare providers to make palliative care part of their mission and vision and to visibly put it into practice.

REGISTRATION AND RESEARCH

In order to provide insight in the quality and added value of palliative care and enable focused improvement, data collection and research still offer a lot of potential. This also allows healthcare providers to benchmark themselves to other comparable institutions. The development of a national palliative care registration database could be a good starting point for this.

HEALTH INSURER

It is desirable to give healthcare providers time to integrate the standards and criteria set in the quality framework in a sustainable way. It is therefore recommended to draw up reimbursement criteria for palliative care over an extended period of time and in dialogue with healthcare providers.

IN CONCLUSION

It is to be expected that the spin-off of the Netherlands Quality Framework for Palliative Care will exceed the recommendations made above. In countries neighbouring the Netherlands it has become apparent that implementing quality standards successfully, has led to e.g. shortages of labour resources, high frequency of burn-out among healthcare professionals in palliative care and lagging technological developments. This should be anticipated at an early stage.

attachments

A1 Glossary of terms

ADVANCE CARE PLANNING
Advance care planning is a process of thinking, planning and organising ahead. With shared decision-making as a guide, advance care planning is a continuous and dynamic process of conversations on current and future choices and goals in life, and on which type of healthcare is appropriate in that regard, now and in the future.

ANTICIPATORY GRIEF
Anticipatory grief is a form of grief that may occur when time allows anticipation of the death of a loved one. This form of grief can be experienced from two different perspectives: the perspective of the patient who grieves about loss of health and the perspective of family, friends and formal/informal healthcare providers.

AUTONOMY
Autonomy is one of the four ethical principles in medical ethics according to Beauchamp and Childress (1979). Autonomy is the right or the ability of a person to determine himself what is to happen to him. In healthcare in Western countries, autonomy has priority over all other ethical principles and cannot be pushed aside, unless this autonomy infringes on the autonomy of others. If a patient is unable to act and think autonomously, a healthcare professional should use the principle of "doing good".

BEREAVEMENT
Bereavement includes all the physical, emotional, cognitive, spiritual and behavioural responses that follow the loss of a loved one with whom there was a meaningful relationship, or after the loss of something that was considered important. Bereavement, as an undefined period, should ultimately lead to normalisation in dealing with the loss suffered.

CARE AFTER DEATH
Care after death is a part of loss and bereavement counselling and includes care and support offered – in the context of palliative care – to the surviving relatives of the deceased patient by the healthcare professionals involved. Immediately after death, the needs of family and friends in terms of practical, psychosocial and spiritual aspects are addressed adequately to enable them to live through the period of bereavement and coping with loss.

CARE-ETHICS APPROACH
Care ethics adds the relational aspect to the ethical principles of professional care provision. Care ethics assumes that the attitude and actions of individuals are determined by the combination of intellectual, emotional, practical and social abilities and needs. According to care ethics, a correct moral judgement or a correct decision cannot only be derived from general principles, but it depends on a specific and single concrete situation. This care-ethics approach has been integrated into the quality framework.

CARE STANDARD
A care standard describes the standard to which multidisciplinary patient-centred care to chronically-ill patients must comply. A care standard is also disease-specific. Organisation of care and relevant quality indicators are also described in a care standard.

CENTRAL HEALTHCARE PROFESSIONAL

The central healthcare professional is the main point of contact for the patient and his family and for the entire team of healthcare professionals involved. This appointed first responsible person is in principle a BIG-registered healthcare professional with concrete tasks and responsibilities in the areas of palliative care, coordination and continuity of care. In mutual agreement with the patient and his family, the tasks of the central healthcare professional are carried out by the physician in charge or delegated to another team member (specialised in palliative care).

COMMUNITY SERVICES OVERVIEW

A community services overview provides an overview of institutions, practices, activities and organisations in the areas of wellbeing, healthcare, assistance and (social) services.

COMPLEMENTARY CARE

Complementary care is a form of care supplementing regular palliative care, with the objective to enhance the patient's wellbeing. Aromatherapy, massage and aqua care are just some of the forms of complementary care.

COMPLICATED GRIEF

Complicated grief involves serious problems with adjusting to the loss. The surviving relative shows physical, emotional, cognitive, existentially-tinted or behavioural responses that are classified as very serious or protracted and severely limit his social or professional functioning. Complicated grief is formally called Persistent Complex Bereavement Disorder (PCBD) in the diagnostic handbook of psychiatry (DSM 5).

CONTINUITY OF CARE

Continuity of care means that there is an uninterrupted coherence of all elements that make up the entire care process. Continuity includes a minimum of:

- personal continuity: a permanent healthcare professional in every separate care setting who knows the patient and follows him;
- team continuity: communication of relevant patient information and collaboration between healthcare professionals within one care setting in order to ensure that care seamlessly fits together;
- transmural continuity: communication of relevant patient information and collaboration between healthcare professionals from different care settings in order to ensure that their care seamlessly fits together.

COPING

Coping includes the way in which someone responds behaviourally and cognitively as well as emotionally to circumstances that require adaptation.

Coping is a process that consists of many separate components and that changes continually, depending on new information and results of previous behaviour.

COPING STRATEGIES

Coping strategies are different ways in which people deal with stressors (such as a life-threatening condition or frailty). Depending on the personality and type of situation, people use different coping strategies that may change over time. In one certain coping strategy, several mechanisms may be used. A commonly used classification is:

- actively addressing: the problem is analysed and solved;
- seeking social support: seeking comfort and understanding from others, solving the problem together with someone else;
- avoidance: the problem is denied and avoided;
- palliative reaction: one focuses on other issues than the problem. In extreme cases, this may lead to addictions;
- depressive response pattern: worrying, blaming oneself, doubting oneself;
- expression of emotions: the problem leads to frustration, tension and aggression;
- reassuring thoughts and wishful-thinking: one tells oneself that the problem will correct itself or that things are a lot more difficult for others.

CORE VALUES OF PALLIATIVE CARE

Core values (also called basic values) are the most important values to strive for in care. Autonomy and dignity are examples of core values.

CRITERION

A criterion is a condition which a specific aspect of care must meet to obtain the desired standard.

CULTURE

On the one hand, culture is regarded as a total of learned and shared convictions, values and way of life of a specific group of people, generally transferred from generation to generation. On the other hand, culture can also be regarded as a system of meanings that is continuously moving, as a constant process of adaptation, usually as a response to interaction with others.

Cultural identification – whether you feel or want to/can feel at home in the culture – is determined by ethnicity, country of origin and by descent, religion, socio-economic class, age, gender and sexual orientation.

DECISION AID

Decision aid is an intervention to help patients and their families to choose between options, by providing information about options and outcomes relevant to the health of the patient.

DISEASE-ORIENTED PALLIATION

Disease-oriented palliation intends to maintain or improve the quality of life by treating the underlying disease. Extending life may also be a goal, provided that the quality of life is acceptable to the patient and that the patient regards this extension as desirable. In practice, disease-oriented palliation and symptom-oriented palliation are closely intertwined. Disease-oriented palliation never excludes symptom-oriented palliation and they are often applied concomitantly, so that they can reinforce each other to improve the patient’s quality of life.

EFFECTIVE COMMUNICATION

Effective communication is a structured process between patient and healthcare professional, in which bilateral information exchange and equality – with respect for the dependent position of the patient – form the basis. Effective communication is, for instance, essential for the method of shared decision-making. Empathic abilities and specific communication techniques must be available for such a process, for example, about how to ask questions, active and reflective listening, dealing with functional and emotional silences and displaying verbal and non-verbal communication.

END-OF-LIFE CARE

End-of-life care is care in the last days (up to 7 days) of life.

END-OF-LIFE CARE PATHWAY

The End-of-life care pathway is an instrument for providing appropriate care in the last days of life and is started the moment the team of healthcare professionals expects the patient to die within a few hours or days. The End-of-life care pathway is a healthcare file, checklist and evaluation instrument in one and serves as a tool to guarantee the quality of care, collaboration between healthcare professionals and the communication with the patient and his family.

END-OF-LIFE STAGE

The end-of-life stage comprises the last days (up to 7 days) of life. An irreversible "physiological" process has been started, as a result of which death is imminent.

ETHICAL PRINCIPLES

The following four ethical principles are central to the principle-based approach in ethics (Beauchamp & Childress, 1979):

- respect for the individual and his autonomy;
- doing good;
- doing no harm;
- justice and equal allocation of resources.

On the basis of these generally accepted starting points, the principle-based approach strives at arriving at an independent judgement about what is to be done in a concrete situation, from an ethical point of view.

EXISTENTIAL CRISIS[1]

An existential crisis is a stagnation in the spiritual process. The spiritual process sometimes does not flow in a natural way because confrontation with the end of life becomes so intense that a patient experiences anxiety- or panic attacks or exhibits signs of depression. This is known as an existential crisis. Characteristic for such a process is that the patient experiences feelings of anxiety and panic, powerlessness and meaninglessness.

FAMILY

Family is defined as the people who are closest to the patient with respect to care, emotional involvement and knowledge. Family may be blood relatives or relatives through marriage or partnership, but may also be friends. The patient determines who is to be regarded as his family.

FRAILTY

Frailty is a process of accumulating physical, psychological and/or social functioning deficits. This frailty increases the likelihood of negative health outcomes, such as functional limitations, hospital admission and death.

GUIDELINE

A guideline is a document with recommendations for supporting healthcare professionals and healthcare users, intended to improve the quality of care, based on scientific research and complemented with expertise and experiences of healthcare professionals and healthcare users.

HEALTHCARE PROFESSIONAL

In the quality framework, a "healthcare professional" is the formal care provider.

INDIVIDUAL CARE PLAN

The individual care plan is a dynamic set of agreements by the patient and healthcare professional(s) with regard to care and self-management. These agreements are based on the individual values, wishes and needs and situation of the patient. These agreements are listed after a joined decision-making process. The individual care plan is the result of the process of advance care planning.

INFORMAL CARE

Informal care consists of support and care provided by informal caregivers and volunteers.

INFORMAL CAREGIVER

An informal caregiver provides care to a person in need of help, not as a healthcare professional but as a member from the patient's immediate surroundings. This care provision flows directly from the social relationship. Informal care transcends the usual help that may be reasonably expected from family and friends.

INFORMED CONSENT

Within the context of the Netherlands medical treatment agreement act, informed consent is: permission granted on the basis of specific information, by the patient or his legal representative or person authorised in writing by the patient, to carry out an examination or a medical treatment.

INTERDISCIPLINARY COLLABORATION

In interdisciplinary collaboration, the various disciplines formulate a common goal and use a common language, accessible and understandable to all concerned. They also regard the qualities and perspectives of others as complementary and valuable. In effect, the professionals involved surrender part of their autonomy as it were. Interdisciplinary collaboration goes further than multidisciplinary collaboration. In case of multidisciplinary collaboration, several disciplines are involved, but each discipline works from its own perspective, with its own specialised language and its own logic and attempts to achieve its own goals. Professionals maintain their autonomy and work more or less in parallel.

LEGAL COMPETENCE

Legal competence is described in ethics as the individual ability to make decisions independently. Legal competence is understood, as long as the contrary has not been demonstrated. Several approaches of legal competence can be distinguished in literature, with different criteria. The cognitive approach is the best known, and with regard to this, legal competence is dependent on the presence of sufficient cognitive abilities in the patient. A patient is completely legally competent if he meets four criteria. These criteria are:

- being able to make a choice known;
- understanding relevant information;
- realising and appreciating the meaning of the information concerning his own situation;
- logical reasoning and using the information in considering treatment options.

LEGAL REPRESENTATIVE

A legal representative is authorised by law to make decisions in the area in which the patient is not legally competent. The legal representative acts on behalf of the legally incompetent patient and looks after his interests as well as possible.

The following people can (in this order) act as representatives:

- a curator or mentor, appointed by a judge;
- a person authorised by the patient, in writing;
- the spouse, registered partner or other companion in life;
- the parent, child, brother or sister.

LIFE-THREATENING CONDITION
A life-threatening condition is defined as a high risk of death, a negative effect on quality of life and daily functioning, and a heavy burden caused by symptoms, treatments and/or stress. Examples of life-threatening conditions are cancer, organ failure, dementia and neurodegenerative conditions.

LIVING-WILL DECLARATION
A living-will declaration is a written document intended to, in case of legal incompetence, influence any decisions about medical treatment and care in the future, to give indications about the actions of others after the author's death, or to make a request for euthanasia or help with suicide known. A distinction can be made between a negative and a positive living-will declaration. In the negative version, someone indicates that he refuses a certain treatment, for example, reanimation. Negative living-will declarations are binding for the healthcare professional. In the positive version, someone indicates that a certain situation is desired, for example, active termination of life (euthanasia). Positive living-will declarations do not have the same weight as negative ones. When someone requests a treatment, the healthcare professional may forgo the treatment based on medical considerations or statutory regulations. In the document, or in a separate written authorisation, the patient may designate a representative who makes decisions for him at a time he is no longer capable of this himself. It is advisable to update a living-will declaration regularly.

LOSS
Loss is losing a loved one with whom there was an existing relationship or of something which is considered important.

MEASUREMENT INSTRUMENT
Structured tools, based on the outcomes of scientific research, that help the patient as well as the healthcare professional to increase insight in the problems of the patient and/or his family, to support decision-making about the use (or non-use) of interventions and evaluation of the outcomes.

MORAL DELIBERATION
In moral deliberation, a dilemma of one of the participants is discussed by a group of healthcare professionals using a structured discussion method, facilitated by a moderator (an ethicist or professional trained for that purpose). In moral deliberations, all perspectives are mapped in order to make a balanced decision. Moral deliberation contributes to clarification of the situation discussed (the case), to professionalism of healthcare professionals, and to the manner and the culture of collaboration.

MORAL DILEMMA
There is a moral dilemma when several values are applicable at the same time while prescribing opposite actions.

MULTIDIMENSIONAL CARE
Multidimensional care pays attention to (lack of) wellbeing in the physical, psychological, social as well as spiritual dimension of the patient.

PALLIATIVE CARE

Palliative care is care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social and spiritual nature. During the illness, palliative care aims to preserve patient autonomy, access to information and the opportunity to make choices.

Palliative care has the following characteristics:

- this care can be given concurrently with disease-oriented treatment;
- generalist -healthcare professionals and, when required, specialist healthcare professionals and volunteers, work together as an interdisciplinary team in close collaboration with patients and their families, and tailor treatment to the stated values, wishes and needs of the patient;
- continuity of care is coordinated by a central healthcare professional;
- the wishes of patients and their families concerning dignity are acknowledged and supported throughout the illness or frailty, during the process of dying and after death.

PALLIATIVE CARE EXPERT

The palliative care expert is qualified by means of a certified education in palliative care[2], work experience and substantial deepening and broadening of knowledge and skills, and specifically has knowledge of and skills in complicated palliative care and crisis situations. For a palliative care expert, palliative care is the sole focus of work. The palliative care expert is preferably embedded in a specialised palliative care team.

PALLIATIVE CARE GENERALIST

Every healthcare professional as a generalist has basic knowledge and basic skills in palliative care.[3] As relevant to his position, he integrates core values, principles, methods and procedures of palliative care in care for a patient with a life-threatening condition or frailty. This not only entails non-pharmaceutical and pharmaceutical interventions for symptom management, but also effective communication with the patient, his family and other healthcare professionals involved, concerning identifying the palliative care phase, shared decision-making and advance care planning. The palliative care generalist knows his own limitations and consults a palliative care specialist, if necessary.

PALLIATIVE CARE NETWORK

A palliative care network is a formal and sustainable partnership of independent organisations involved with palliative care in a certain region. The networks are initiated to enhance coherence in interdisciplinary network care. The goal is to contribute to the highest possible quality of life and death, and is based on the values, wishes and needs of the patient and his family.

PALLIATIVE CARE PHASE

Based on the definition of palliative care – as it is used in the quality framework – in certain conditions the palliative-care phase may start many years before the expected death. For pragmatic reasons, the quality framework defines the palliative care phase as the last stage of life, in which the healthcare professional expects the patient to die within the next 12 months.

PALLIATIVE CARE PRINCIPLES
Principles are the ground rules every healthcare professional will want to follow in order to achieve target core values. For example, effective communication is an important principle to ensure patient autonomy and dignity.

PALLIATIVE CARE SPECIALIST
The palliative care specialist is qualified by means of a certified education in palliative care[4] and has specific knowledge and skills in more complicated palliative care. The palliative care specialist usually has a position in a discipline in which palliative care is frequently part of daily practice, but not the main focus. The palliative care specialist is preferably embedded in a specialised palliative care team; he knows his own limitations and consults a palliative care expert when required.

PALLIATIVE REASONING
Palliative reasoning is a methodology for decision-making with regard to symptom management in the palliative care phase. The methodology consists of four phases: 1. map the situation; 2. summarise problems and policy, and develop a proactive policy; 3. make agreements on policy evaluation; 4. adjust the policy when required, and continue to evaluate.

PATIENT
In the quality framework "patient" refers to patient/client/resident/guest. If the patient is not legally competent, it refers to the legal representative.

PaTz
PaTz, the Dutch abbreviation for "Palliatieve Thuiszorg" (palliative care at home), is a methodology to improve quality, collaboration and transfer around palliative care at home. General practitioners and district nurses meet six times a year to evaluate and discuss patients in the palliative care phase and to record them in a palliative care register. They draw up a care plan together, based on the wishes of the patient and those close to him. Early palliative care, development of expertise and supporting each other are central during the discussions. The PaTz group is guided by a palliative care specialist.

PDCA QUALITY AND PERFORMANCE IMPROVEMENT CYCLE
The PDCA quality and performance improvement cycle is a cycle of actions (Plan, Do, Check, Act) focused on continuous quality improvement. The cycle implies that care processes can be improved by introducing and trying small changes at a time ("rapid cycle improvement").

PHYSICAL DIMENSION
The physical dimension of palliative care explores, examines and treats physical symptoms and uses appropriate and (validated) measurement instruments whenever possible. Treatment of symptoms is multidimensional and can consist of non-pharmaceutical and pharmaceutical interventions, which may or may not be supported by complementary care.

PHYSICIAN IN CHARGE
The physician in charge is the physician who has final responsibility as to the substance of healthcare provision (diagnostics, treatment and continuity of care) to the patient. The person fulfilling this position can vary during the disease process.

PROTOCOL
A protocol offers step-by-step directions for how to act in daily

practice. Freedom of action is limited in a protocol. In a protocol, the care process, the different steps to be followed and the clinical decision moments are established in detail.

PSYCHOLOGICAL/PSYCHIATRIC DIMENSION

The psychological/psychiatric dimension of palliative care includes care related to the psychological/psychiatric wellbeing of the patient and his family, including issues of self-esteem and insight in adapting to having a disease and to its consequences. This form of care supports patients when expressing their emotions and feelings about the illness, and at the same time provides the possibility to improve the psychological and emotional wellbeing of patients and their families. In case of specific psychological or psychiatric signs or symptoms, it is likely that interventions will be required that go further than the usual psychosocial support.

NETHERLANDS QUALITY FRAMEWORK FOR PALLIATIVE CARE

The Netherlands Quality Framework for Palliative Care describes, from the patients' perspective, what the quality of care for patients and their families should be in the Netherlands. The quality framework consists of several domains (demarcated areas) describing the various dimensions of palliative care. One or several standards have been included for each domain, with criteria listed below them. A standard can be described as the best practice within a domain, taking into account recent insights and evidence. A criterion is the condition which a specific aspect of care must meet to obtain the desired standard.

QUALITY INDICATORS

Quality indicators are a set of measurable elements of practice. There is proof or consensus that they can be used to evaluate quality of care and changes therein. These quality indicators can be used internally to further improve quality and externally to provide information about choices to patients and insurers. Quality indicators may relate to structure, process or outcomes of care.

QUALITY OF LIFE

Quality of life can be defined as the dynamic perception of the patient and his family of their position in life in the context of the culture and value system in which they live and with respect to their goals, expectations, standards and interests. Quality of life is what the patient says it is.

RELATIVES

Blood relatives and persons linked to someone through marriage or partnership are all considered relatives.

REPRESENTED DECISION-MAKING

Represented decision-making refers to decisions made by the legal representative.

RESPITE CARE

Respite care is a temporary and complete taking-over of care with the objective to give the informal caregiver a break. It is a collective term for facilities that temporarily, professionally or voluntarily take over the informal care and therefore give respite.

RITUAL

A ritual stems from culture, religion or meaning, and is a succession of acts in a certain sequence and in a specific place. Rituals are characterised by the emphasis on form (exact execution of an act is important) and repetition (it is only a ritual if it is performed several times) and have a symbolic and often also practical meaning.

SELF-MANAGEMENT

Self-management is dealing with a life-threatening condition or frailty in a way that the condition gets a place in daily life in as good a way as possible. Self-management means: being able to determine the degree of control of one's own life and to have a voice in how the available care is being deployed, in order to achieve and maintain the optimum quality of life.

SELF-REALISATION

Self-realisation is striving to develop one's possibilities and the realisation of one's personal essence.

Self-reflection

Self-reflection is the investigation of impact and effect of experiences, in which both the professional and personal position (arising from the past, culture, norms and values or inexperience) are considered with reference to healthcare provision to patients with a life-threatening condition or frailty. Self-reflection is regarded as an intellectual and emotional process that leads to more insight in one's own actions, (self)knowledge and self-image in order to apply this in future actions. Self-reflection may be an individual process as well as a group process.

SHADOW PATIENT

Informal caregivers may exhibit tensions or (imminent) overload. As a result of this, they may become patients themselves. It is a challenge for the healthcare professional to recognise any signals from the "informal caregiver as shadow patient".

SHARED DECISION-MAKING

Shared decision-making is the process during which healthcare professional and the patient discuss the type of care best suited for the patient and during which all options, advantages and disadvantages, preferences and circumstances of the patient are taken into consideration.

SOCIAL DIMENSION

The social dimension of palliative care includes a wide range of facilities and activities that help the patient and his family to shape their daily lives. In case of palliative care, for example, this refers to provision of information, advice, support and strengthening self-reliance.

SPECIALISED PALLIATIVE CARE TEAM

A specialised palliative care team is a multidisciplinary team (formed on the basis of the four dimensions of palliative care) of healthcare professionals who are specialised in palliative care and who work together in an interdisciplinary manner.

SPIRITUAL CARE[5]

Care that recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in a compassionate relationship, and moves in whatever direction need requires.

SPIRITUALITY[6]

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.

STANDARD
The standard indicates best practice within a domain, taking into account recent findings and evidence.

SURPRISE QUESTION
If the answer to the surprise question – "Would you be surprised if this patient died within the next 12 months?" – is negative, this identifies the patient as being at a stage in which his situation can change through quick deterioration. Making clear agreements and thinking ahead are now given even greater priority. The surprise question is not intended as a "hard prediction" of the last year of life; it is mainly a way of ensuring that patients in need of palliative care are recognised on time and that all healthcare professionals involved with one patient are aware that they need to start anticipating the care to come.

SYMPTOM MANAGEMENT
Symptom management relates to the process of analysis and symptom treatment, to the evaluation of the effect and adjusting the treatment plan when required. Aspects of optimal symptom management are: a multidisciplinary approach, a systematic approach in accordance with the model of 'palliative reasoning' and clear documentation and reporting.

SYMPTOM-ORIENTED PALLIATION
Symptom-oriented palliation primarily aims to maintain or improve quality of life by alleviating the signs and symptoms of the underlying disease and preventing them if possible, in combination or not with disease-oriented palliation. When maintaining quality of life is no longer possible, symptom-oriented palliation is directed at the best possible quality of dying.

TERTIARY HEALTHCARE
In tertiary healthcare, academic centres offer top-level clinical care.

TRANSFORMATION
Transformation is a profound, long-lasting process of change.

TREATING PHYSICIAN
The treating physician is the person who is responsible for treating the patient within his field of expertise. The treating physician is not necessarily the physician in charge.

VALUES, WISHES AND NEEDS
Values, wishes and needs of the patient and his family are central starting points in healthcare. From the values, wishes and needs of the patient and his family, the goals with regard to advance care planning can be derived.

VOLUNTEER
A volunteer in palliative care is a person who, in an organised context, unpaid and without obligation, spends time, attention and support with the intention of improving the quality of life of a patient with a life-threatening condition or frailty and his family. At the start of the deployment of the volunteer, there is no personal relationship between the patient and the volunteer.

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1. The guideline for Spiritual care is currently being revised. The definition of an existential crisis – as it will be used in the guideline – will be adopted in this glossary of terms.
2. What these courses are has not yet been specified.
3. This is described in the Onderwijsraamwerk palliatieve zorg (educative framework for palliative care) 1.0 which is part of the Kennissynthese onderwijs palliatieve zorg (knowledge synthesis in palliative care education) (2016
4. What these courses are has not yet been specified
5. The guideline for spiritual care is currently being revised. This definition of spiritual care, translated into Dutch, will be included here. The Dutch version will also be used in this glossary of terms.
6. The guideline for spiritual care is currently being revised. This definition of spirituality, translated into Dutch, will be included here. The Dutch version will also be used in this glossary of terms.

A2 Overview of associations involved

STEERING GROUP	
ActiZ	Organisation of healthcare entrepreneurs (VV&T)
IKNL	Integraal Kankercentrum Nederland | Netherlands Comprehensive Cancer Organisation
KNMG	Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst | Royal Dutch Medical Association
LHV	Landelijke Huisartsen Vereniging | National Association of Family Doctors
NHG	Nederlands Huisartsen Genootschap | Dutch College of General Practitioners
NFU	Nederlandse Federatie van Universitair Medische Centra | Netherlands Federation of University Medical Centres
NPCF	Patiëntenfederatie Nederland | Dutch Patient Federation (previously NPCF, Nederlandse Patiënten en Consumenten Federatie, Dutch Patient and Consumer Federation)
NVAVG	Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten | Netherlands Society of Physicians for Persons with Intellectual Disabilities
NVPO	Nederlandse Vereniging voor Psychosociale Oncologie | Dutch Association for Psychosocial Oncology
NVZ	Nederlandse Vereniging van Ziekenhuizen | Dutch Hospital Association
Palliactief	Nederlandse vereniging voor professionele palliatieve zorg | Dutch Association for Professional Palliative Care
RK - FMS	Raad Kwaliteit Federatie Medisch Specialisten | Council Quality of Care – Dutch Association of Medical Specialists
SONCOS	Stichting Oncologische Samenwerking | Foundation for Oncological Cooperation
V&VN	Verpleegkundigen & Verzorgenden Nederland | Dutch Nurses and Caregivers
Verenso	Vereniging specialisten in ouderengeneeskunde | Dutch Association of Elderly Care Physicians and Social Geriatricians
VGVZ	Vereniging van Geestelijk VerZorgers | Dutch Association of Spiritual Caregivers
ZN	Zorgverzekeraars Nederland | Netherlands Organisation of Health Insurers

SOUNDING BOARD GROUP	
Agora	Centrum voor beleidsondersteuning in palliatieve zorg | Centre for Policy Support in Palliative Care
AHzN	Associatie Hospicezorg Nederland | Dutch Hospice Care Association

EPZ	Expertisecentra Palliatieve Zorg - bestuur | Palliative Care Expertise Centres – Management
KNGF	Koninklijk Nederlands Genootschap voor Fysiotherapie | Royal Dutch Society for Physical Therapy
LMK	Patiëntenbeweging Levenmetkanker | "Living with cancer" patients' movement
NIVEL	Nederlands instituut voor onderzoek van de gezondheidszorg | Netherlands Institute for Health Services Research
NPPZ	Nationaal Programma Palliatieve Zorg (Stuurgroep) | National Programme for Palliative Care (steering group)
SAZ	Samenwerking Algemene Ziekenhuizen | Cooperation of General Hospitals
Stichting Fibula	Platform netwerken palliatieve zorg Nederland | Dutch Platform for Palliative Care Networks
Stichting PAL	Stichting PAL Kinderpalliatieve Expertise | PAL Foundation for Paediatric Palliative Expertise
STZ	Samenwerking Topklinische Ziekenhuizen | Cooperation of Top-Level Clinical Care Hospitals
VPTZ	Vrijwilligers Palliatieve Terminale Zorg | Volunteers for Terminal Palliative Care
VWS	Ministerie van Volksgezondheid, Welzijn en Sport | Ministry of Health, Welfare and Sport
ZIN	Zorginstituut Nederland | National Health Care Institute
ZonMw	Organisation that stimulates health research and healthcare innovation

WORKING GROUP

FMS	Federatie Medisch Specialisten | Dutch Association of Medical Specialists
NHG	Nederlands Huisartsen Genootschap | The Dutch College of General Practitioners
NPCF	Dutch Patient Federation
NVPO	Nederlandse Vereniging voor Psychosociale Oncologie | Dutch Association for Psychosocial Oncology
V&VN	Verpleegkundigen & Verzorgenden Nederland | Dutch Nurses and Caregivers
Verenso	Vereniging specialisten in ouderengeneeskunde | Dutch Association of Elderly Care Physicians and Social Geriatricians
VGVZ	Dutch Association of Spiritual Caregivers
ZN	Zorgverzekeraars Nederland | Netherlands Organisation of Health Insurers

CORE GROUP

on behalf of Palliactief	Wim Jansen, Joep Douma
on behalf of IKNL	Birgit Fröhleke, Elske van der Pol, Manon Boddaert, Joep Douma

OTHER INTERESTED PARTIES

During the two invitational conferences during the project, the following groups, in addition to representatives from the above-mentioned groups, have been present. This way, they have demonstrated their involvement and interest for the project.

IGZ	Inspectie voor de Gezondheidszorg | Health Care Inspectorate
KWF	KWF Kankerbestrijding | Dutch Cancer Society
NFK	Nederlandse Federatie van Kankerpatiëntenorganisaties | Dutch Federation of Cancer Patient Organisations
NVA	Nederlandse Vereniging voor Anesthesiologie | Dutch Association for Anaesthesiology
NVK	Nederlandse Vereniging voor Kindergeneeskunde | Dutch Association for Paediatric Medicine Care Module Development Group Project Group for Quality Indicators Project Group for PTZ (terminal palliative care) District Nursing

PROJECT GROUP

The following people are involved in the project group on behalf of IKNL and Palliactief:

Manon Boddaert
Joep Douma
Floor Dijxhoorn
Maureen Bijkerk
Elske van der Pol
Chantal Pereira
Bo van Aalst

A3 Quality framework realisation process

CORE DOCUMENTS

This attachment describes in general how the quality framework was developed. The method of guideline procedure has been followed for developing the Netherlands Quality Framework for Palliative Care. In view of the form of the project, however, a few exceptions to this have been made.

After all organisations involved delegated a mandated member, the working group was formed (see attachment 2). The project group had then started an (inter) national literature inventory, using criteria that had been determined beforehand, looking for (quality) documents that could serve as the basis for the quality framework that was to be developed (see attachment 4). This has yielded the following core documents:

- Standards for providing quality palliative care for all Australians, PCA (2005).
- Quality standard end of life care for adults, NICE (2011).
- Hospice New Zealand standards for palliative care, Hospice NZ (2012).
- Clinical practice guidelines for quality palliative care, NCP (2013).
- Zorgmodule Palliatieve Zorg 1.0, CBO (2013) (including implementation documents).

The document Prezo Hospicecare, Stichting Perspekt (2015) was also added to the set of core documents, after approval by the working group. This is a shielded document and as a result of this, it did not come up during the literature inventory.

LAY-OUT OF THE QUALITY FRAMEWORK

Following the example of these core documents, the quality framework consists of several domains (a demarcated area) that describes the various dimensions of palliative care.

For each domain, all relevant standards and criteria from the core documents have been selected and presented to the working group. Each working group member has indicated which of these standards and criteria should be included in the quality framework. Using standardisation percentages, a decision was made to include, discuss or exclude each standard or criterion. The selected standards and criteria were then discussed with the working group and combined or adapted to the Dutch situation.

ROUND OF CONSULTATION 1

In order to test the standards and criteria using the guideline procedure, two rounds of consultation were held. The first round was held in the summer of 2016. The domains Structure and process (excluding advance care planning), Spiritual dimension and End-of-life care were presented for comments to organisations from the steering group and the sounding board group. In addition to the standards and criteria, three questions were presented to the rank and file. On the basis of the responses, the project group and the working group have formulated an answer to the questions posed.

QUESTION 1

The quality framework describes what the quality of care for patients and their families should be in the Netherlands. This care is provided by generalists,

and when required, with the support of healthcare professionals specialised in palliative care. Do you think it is desirable to include training requirements or qualifications for palliative care specialists in the quality framework?

The responses clearly showed that indeed there is a need to draw up a set of qualifications for specialists in palliative care, and that the quality framework is viewed as the right place for such criteria. There is a need for clarity in this area; the palliative-care generalist should know what to expect from a palliative-care specialist. Several organisations are already imposing requirements, and these should be unified on a national level. The working group agrees with the proposal of the project group to bring relevant parties together (in the context of training requirements) with the goal of listing multidisciplinary starting points for these qualifications. Because of the time this requires, they will be included as an attachment to the current version of the quality framework at a later point in time

QUESTION 2

The palliative-care phase will run a relatively uncomplicated course for most patients (60-70%). For the remaining 30-40 percent, it will be complicated and time-intensive (including multiple symptoms that are difficult to control, frequent re-admissions, social conflict situations, and psychiatric secondary diagnosis). For good quality palliative care, continuity and coordination of care and informed planning and organising ahead are important. In the present quality framework, these tasks lie with the 'central healthcare professional'. Is it desirable to name the discipline that carries out these tasks in the quality framework?

The majority of reactions from the rank and file indicates a wish to define who carries out the tasks of the central healthcare professional. On the basis of the responses from the first round of consultation, and in mutual agreement with the working group, it was decided to include the following in the quality framework:
For good quality palliative care, coordination and continuity of care and informed planning and organising ahead are important. Since a team of healthcare professionals is involved in palliative care, one person shall be designated who has primary responsibility and who carries out these tasks. This so-called central healthcare professional is the point of contact for the entire treatment team and for the patient and his family. In mutual agreement with patient and family, the tasks of the central healthcare professional are carried out by the physician in charge or delegated to another team member (specialised in palliative care).

QUESTION 3

The quality framework establishes that evaluations take place at fixed times in a multidisciplinary context to evaluate, organise and revise care when required. The PaTz project (palliative care at home) has been identified as a Good Example and could be a form of evaluation in primary care. The goal of the project is to enhance collaboration between family doctors and district nurses and to increase their expertise to improve the quality of palliative care at home A PaTz group consists of general practitioners and district nurses who meet about six times a year to discuss their patients in the palliative-care phase,

under guidance of a healthcare professional who is specialised in palliative care. Do you think it is desirable to include PaTz as such in the quality framework?

This question has also come up during a working conference on the bottle-necks or constraints in primary care. The round of consultation as well as the working conference showed that PaTz is preferred as a method of multidisciplinary evaluation in primary care. This will therefore be included as such in the quality framework.

ROUND OF CONSULTATION 2

The second round of consultation was held in the first quarter of 2017. The domains below were presented for commenting to organisations from the steering group and sounding board group:

Domain 1	core values and principles
Domain 2.3	advance care planning
Domain 3	physical dimension
Domain 4	psychological/psychiatric dimension
Domain 5	social dimension
Domain 8	loss and bereavement
Domain 9	culture
Domain 10	ethical and legal

FINALISATION OF THE FRAMEWORK

After processing the comments given during the rounds of consultation, the working group gathered for a last time to evaluate and approve the final results.

After authorisation by the organisations involved, the digital version of the quality framework will be made available on Pallialine.nl. In this version, concepts mentioned in the text will be linked to definitions as they are included in the glossary of terms and it will be possible within the various domains to click through to relevant guidelines and assessment instruments.
A patient version of the quality framework will be created together with the Dutch Patient Federation.

ESTABLISHMENT OF THE GLOSSARY OF TERMS

During the development of the quality framework it has become apparent that a clear understanding of the terminology used is desirable. For this reason, a glossary of terms has been added to the quality framework.

For each domain of the glossary of terms, terms have been identified for which clarification in a conceptual framework is important. Definitions of these terms have then been looked up in Dutch and international literature. For most of these terms, (inter)national definitions have been found that fit the starting points and contents of the quality framework. In case there was no definition available, or a definition appeared not to fit in the context of the quality framework, experts in the discipline concerned were consulted to formulate a definition or description of the concept in question on the basis of a consensus.

A4 Decision tree for literature inventory

The literature inventory was made using criteria that were listed beforehand. The decision trees below reflect the search process of the international and Dutch literature inventory for determining the core documents.

INTERNATIONAL LITERATURE INVENTORY

database: Google ↓

Query:
Quality Standard Palliative Care Hospice care
↓
(680.000 results)

Is it a guideline/(consensus) report/framework/standard describing requirements for palliative care?

🗑 ← no yes ↓

Was it published/revised after 2004 and written in English and from a western country and with a national scope?

🗑 ← no yes ↓

Does it focus on a specific population/caresetting/profession and/or are there little/no references?

🗑 ← yes no ↓

Does the abstract meet the following criteria:
- Does it cover the entire scope of palliative care?
- Is it applicable to Dutch healthcare?

🗑 ← no yes ↓

Results:

- Standards for providing quality palliative care for all Australians, PCA (2005).
- Quality standard end of life care for adults, NICE (2011).
- Hospice New Zealand standards for palliative care, Hospice NZ (2012).
- Clinical practice guidelines for quality palliative care, NCP (2013).

NATIONAL LITERATURE INVENTORY

database: Google ↓

Query:
Kwaliteitstandaard palliatieve zorg hospicezorg ↓
(28.000 results)

Is it a guideline/(consensus) report/framework/standard describing requirements for palliative care?

🗑 ← no yes ↓

Was it published/revised after 2004 **and** with a national scope?

🗑 ← no yes ↓

Does it focus on a specific population/caresetting/profession and/or are there little/no references?

🗑 ← yes no ↓

Does the abstract meet the following criteria:
Does it cover the entire scope of palliative care?

🗑 ← no yes ↓

Results:

Zorgmodule Palliatieve Zorg 1.0, CBO (2013)