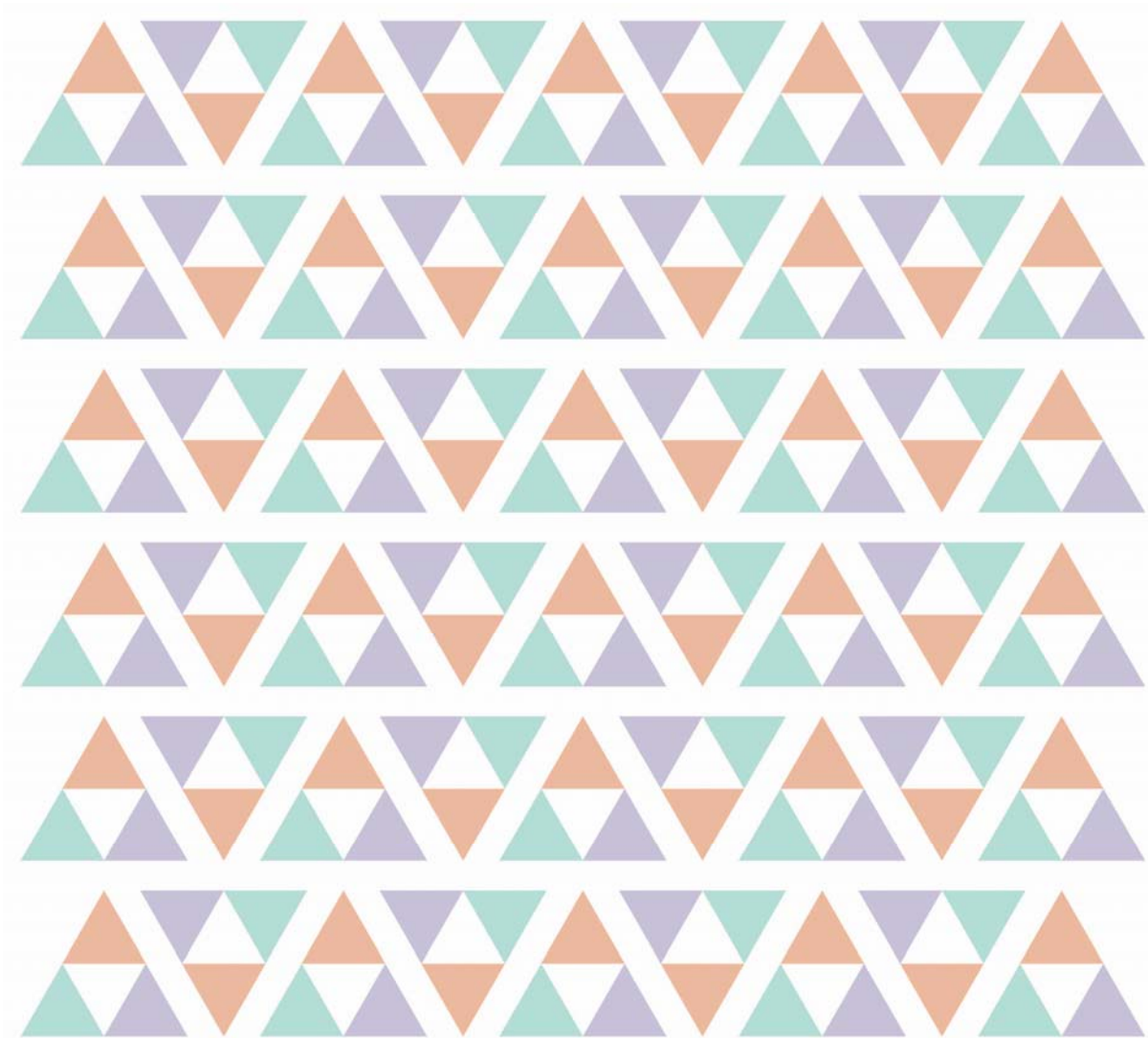




Framework for Palliative Care in Switzerland

A basis for defining palliative care for the implementation of the
«National Strategy for Palliative Care»

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Table of contents

1	Introduction	4
1.1	Objective and purpose of the framework	4
1.2	Intended audience	4
1.3	Development process	4
2	Basic principles of the framework	5
2.1	National Guidelines for Palliative Care	5
2.2	The personal approach of palliative care	5
2.3	The degree of specialisation: three levels of palliative care	6
2.3.1	The «palliative care awareness» level	6
2.3.2	The «primary palliative care» level	6
2.3.3	The «specialised palliative care» level	6
2.3.4	The «support from attachment figures and volunteers» cross-cutting area	6
2.3.5	The «field- and group-specific care» cross-cutting area	6
2.4	The time aspect	7
3	Applying the framework: four areas of implementation	9
3.1	The «target group» area	9
3.1.1	General description	9
3.1.2	«Palliative care awareness»: «society» target group	10
3.1.3	Patients receiving primary palliative care	10
3.1.4	Patients receiving specialised palliative care	11
3.2	The «services» area	11
3.2.1	General description	11
3.2.2	Palliative care awareness: information, competence and advice at the end of life	12
3.2.3	Primary palliative care: planning ahead and relieving suffering	12
3.2.4	Specialised palliative care: Treatment and support for complex symptoms and unstable situations	13
3.2.5	The «support from attachment figures and volunteers» cross-cutting area	13
3.2.6	The «field- and group-specific palliative care» cross-cutting area	14
3.3	The «care structures» area	15
3.3.1	General description	15
3.3.2	Palliative care awareness: advisory and information facilities	15
3.3.3	Primary palliative care: primary outpatient and inpatient care facilities	15
3.3.4	Specialised palliative care facilities	16
3.3.5	The «support from attachment figures and volunteers» cross-cutting area	17
3.3.6	The «field- and group-specific palliative care» cross-cutting area	17
3.4	The «competencies» area	18
3.4.1	General description	18
3.4.2	Palliative care awareness: competence in offering advice and enabling people to deal with the end of life	19
3.4.3	Primary palliative care competencies	19
3.4.4	Specialised palliative care competencies	20
3.4.5	The «support from attachment figures and volunteers» cross-cutting area	20
3.4.6	The «field- and group-specific palliative care» cross-cutting area	21
4	Defining the transitions between palliative care levels	21

1 Introduction

1.1 Objective and purpose of the framework

The implementation of the «National Strategy for Palliative Care» by the Swiss Confederation and Cantons affects a range of very different areas: it involves care concepts and structures, financing schemes, measures for raising awareness, voluntary work and the specific qualifications of care professionals. Furthermore, a distinction is made between different levels of specialisation with regard to the facilities, services and competencies concerned.

The objective of the «Framework for Palliative Care in Switzerland» is to provide a basis for defining palliative care in Switzerland. The intention is for this to serve as a common thread running through all the areas covered by the «National Strategy for Palliative Care» by providing a defining description of the field of palliative care in Switzerland. Better coordination of the concepts and definitions used to date is needed to ensure clear guidance and mutual understanding. In an international context, as yet, no task of this kind has been carried out.

The «Framework for Palliative Care in Switzerland» aims to establish a common basis for the various activities within the scope of the «National Strategy for Palliative Care» and to place them in an overall context.

The first part of this document describes the fundamental principles on which the framework is based. The second part applies these principles to the implementation of the framework in four areas: «target groups», «services», «care structures» and «competencies». A list of reference documents which examine these aspects in greater detail is provided for each area. These lists are related to the current status of the work being carried out and must be adapted and supplemented on an ongoing basis.

1.2 Intended audience

The «Framework for Palliative Care in Switzerland» is a working tool for all persons and institutions involved in the implementation of the «National Strategy for Palliative Care» at national and cantonal or regional level.

1.3 Development process

The idea of drawing up a framework was developed by the specialist association palliative ch at its spring retreat in 2013. At the time, fears were expressed over the possibility that a lack of agreement and coordination could cause ongoing work and projects to become lost in a metaphorical «Bermuda Triangle» and fade into non-existence. A «Bermuda» taskforce was subsequently set up with the aim of preventing this.

In consultation with the project management committee for the «National Strategy for Palliative Care», the decision was taken to develop a «Framework for Palliative Care in Switzerland» within the context of moderated workshops. Three workshops took place between August and November 2013. The participants included representatives from the Federal Office of Public Health FOPH, the State Secretariat for Education, Research and Innovation SERI, the Swiss Conference of the Cantonal Ministers of Public Health GDK, the Swiss Association for Palliative Medicine, Care and Support palliative ch and OdA-Santé, a national umbrella organisation for health professionals (see publication details for a list of members). The content of this project was based on intensive literature research into definitions and concepts of palliative care. The document was approved by the project management committee for the «National Strategy for Palliative Care» on 7 April 2014 and on 15 April 2014 by the operational committee of the «Dialogue on national health policy».

2 Basic principles of the framework

The «Framework for Palliative Care in Switzerland» is based on the principles listed below.

2.1 National Guidelines for Palliative Care

The document entitled «National Guidelines for Palliative Care» (FOPH & GDK, 2010) forms the basis for the «Framework for Palliative Care in Switzerland». The definitions used in these guidelines also apply to the framework. The most important points are summarised below:

- Palliative care comprises the care and treatment of patients with incurable, life-threatening and/or chronically progressive diseases.
- It includes medical treatments and nursing interventions as well as psychological, social and spiritual support.
- Palliative care treats the patient as a whole, i.e. it is considerate of the physical, emotional, social and spiritual dimensions.
- Palliative care focuses on the needs, symptoms and problems of affected patients as well as their attachment figures.
- Because of their different needs, a distinction is made between patients receiving primary palliative care and patients receiving specialised palliative care.
- Palliative care is delivered by an interprofessional team (health care professionals with or without a university degree, as well as other professionals with a background in social sciences or psychology, pastoral care or other occupations). Volunteers can be part of the interprofessional team and the palliative care, taking into account their qualifications and responsibilities.¹

2.2 The personal approach of palliative care

The framework is based on a personal approach. This means that, rather than the medical diagnosis, it is the needs and concerns of the people affected and their attachment figures that play the decisive or guiding role in ascertaining the patient's level of suffering and preparing a treatment plan.

The personal approach is based on a biopsychosocial understanding and translates it into a cooperative course of action for dealing with the challenges associated with the end of life. It can be divided into the following four areas of activity in palliative care (cf. Section 3.2.3):

1. Needs and issues relating to treating symptoms
2. Needs and issues relating to making decisions at the end of life, based on personal preferences
3. Needs and issues relating to the surrounding network/assistance
4. Needs and issues relating to support for attachment figures

The services required, suitable care structures and the competencies needed by professionals with different occupational backgrounds are determined by the complexity of the patient's needs.

¹ It is essential that they are adequately prepared and continuously monitored (supervision).

2.3 The degree of specialisation: three levels of palliative care

Based on the personal approach outlined above, this framework distinguishes between three levels of care. These relate to the degree of specialisation of palliative care competencies, facilities and services required to meet the needs of the people affected and their attachment figures in the best possible way. The three levels are as follows: palliative care awareness, primary palliative care and specialised palliative care. In addition to this, there are the cross-cutting areas of «field- and group-specific palliative care», which largely overlaps with the «specialised palliative care» level, and «support from attachment figures and volunteers».

2.3.1 The «palliative care awareness» level

The lowest, fundamental level is «palliative care awareness». This relates to society as a whole and to people's need for information, skills and advice on the issues of incurable illness, dying and death. At this level, the important thing is to ensure that people – regardless of whether they are specifically affected or not – can basically and proactively deal with the situation surrounding an incurable illness and the end of life and are given the support they need for this.²

2.3.2 The «primary palliative care» level

The second level is «primary palliative care». The basis for defining this level is the patients' general palliative care needs according to the «National Guidelines for Palliative Care» (cf. Section 3.1.3). The group comprises patients who are dealing with the end of life in a proactive way or have reached the final phase of their life due to the progression of an incurable, life-threatening and/or chronically progressive disease.

2.3.3 The «specialised palliative care» level

The third level is «specialised palliative care». This is based on the patients' specialist palliative care needs according to the «National Guidelines for Palliative Care» (cf. Section 3.1.4). This patient group is smaller in terms of numbers and includes patients who rely on the support of a specialised palliative care team. This may be because their medical condition is unstable, they require complex treatment or stabilisation of pre-existing symptoms, or their attachment figures start to show signs of reaching their breaking point. This results in other or special requirements in relation to the care structures, the necessary palliative care services and the competencies of care professionals.

2.3.4 The «support from attachment figures and volunteers» cross-cutting area

This area relates to attachment figures and volunteers, as members of society, who can be actively involved in all three levels of palliative care. Both attachment figures and volunteers often provide essential support services for people in palliative situations. Volunteers can also support attachment figures and help to relieve the strain on care professionals. At the same time, attachment figures and volunteers also rely on specialist support and guidance themselves.

2.3.5 The «field- and group-specific care» cross-cutting area

The «field- and group-specific palliative care» cross-cutting area takes into account the fact that patients receiving palliative care may have field-specific problems or needs in relation to particular diseases (e.g. in the case of oncological or neurodegenerative diseases, kidney disease, psychiatric disorders or addictions). There are also certain population groups, such as young children or elderly people (paediatric care, geriatric care), people with mental or physical disabilities or people living in particular circumstances (e.g. migrants, people with a low socioeconomic status), who have special requirements which need to be taken into consideration.

² Rather than focusing exclusively on the final few days of life, the «palliative care awareness» level encompasses the entire progression of an incurable illness. This is because the need for information is often greatest right at the start of the development of an incurable condition. Section 2.4 («The time aspect») elaborates on this.

Fulfilling the needs of these groups poses particular challenges for palliative care services, care structures and the competencies of care professionals. This cross-cutting area of care primarily comes under the «specialised palliative care» category, but it can also involve primary palliative care. Currently, however, specific definitions and basic principles for palliative care are only just being put in place for a few illnesses and care groups.

2.4 The time aspect

As a procedure for relieving suffering on a needs-oriented basis, palliative care can have a role to play throughout the entire progression of an incurable illness. There are various widely held views as to the point at which palliative care should be introduced during the development of an incurable condition and what the terms «palliative» and «at the end of life» mean in this context. In a clinical context, the terms «curative» and «palliative» still have a prognostic, i.e. temporal meaning: if treatment or patients are referred to as «palliative», this often implies that the person affected only has a few weeks or months left to live.

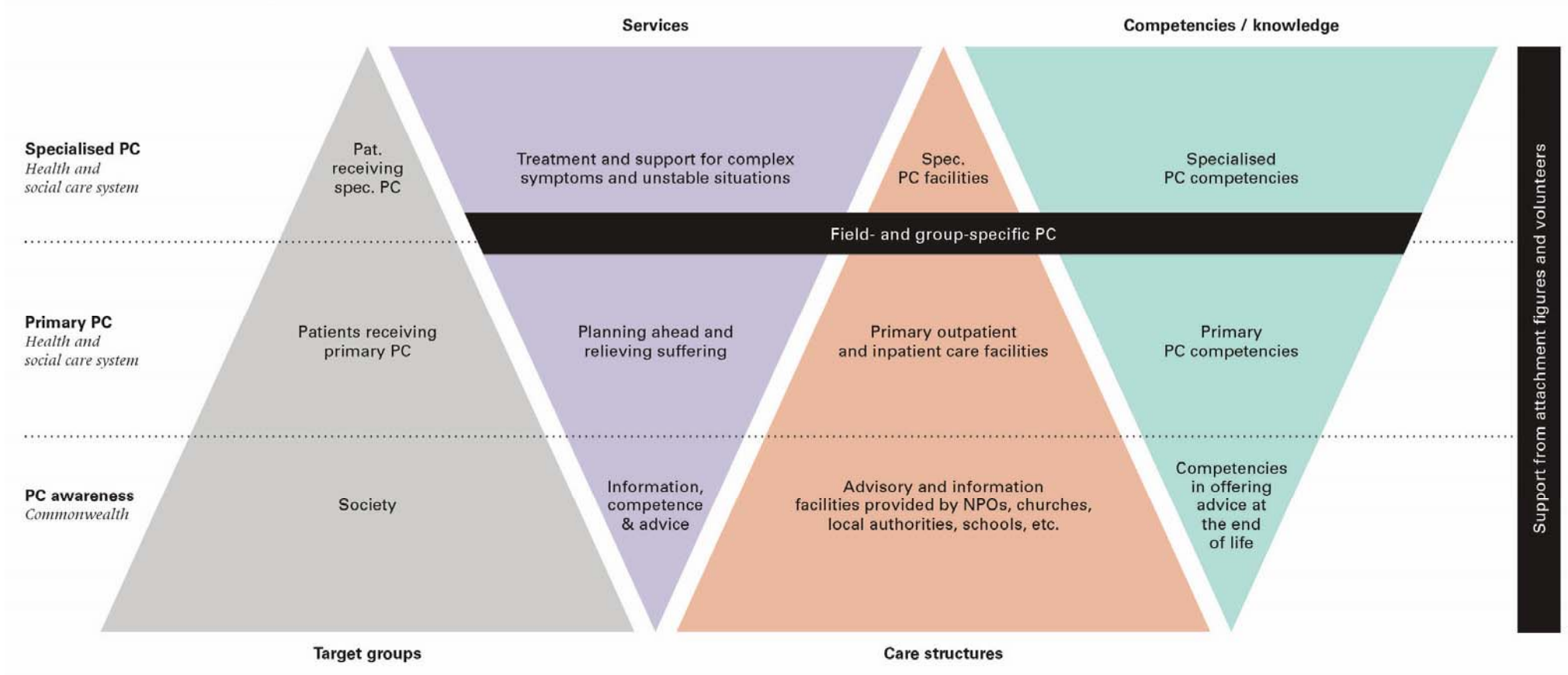
However, this approach is problematic in that there are no standard criteria or factors based on scientific foundations which would help to define the point in time when a situation changes from curative to palliative. The progression of an incurable illness can last from a few weeks or months to several years. The notion that there is a specific point in time when care turns from curative to palliative does not always apply. Although this change often occurs abruptly (when the patient is deemed «untreatable», i.e. all treatment options have been exhausted), in the case of chronically progressive diseases, for example, it tends to be described more as a shift towards palliation.

Curative and palliative care elements can be combined in a complementary manner during the progression of an illness. As a patient's condition deteriorates, the proportion of palliative care increases, depending on the needs of the person concerned. There are also phases over the course of an incurable illness when palliative elements take clear priority. This is often – but not exclusively – during the final phase of life. The work carried out within the scope of the «National Strategy for Palliative Care» focuses primarily on situations where palliative elements are predominant and the patient is preparing for the end of life.

Defining the precise time limits of this period is not a priority for the «National Strategy for Palliative Care», in which the needs of the person affected are the decisive factor. The framework therefore uses the terms «in a palliative situation», «remaining lifetime» and «at the end of life».³ It is important to bear in mind that the period of time in which palliative elements are prevalent can last for weeks, months and sometimes even years.

³ The definition of a «palliative situation» is derived from the patients' needs, as described in Section 3.1.

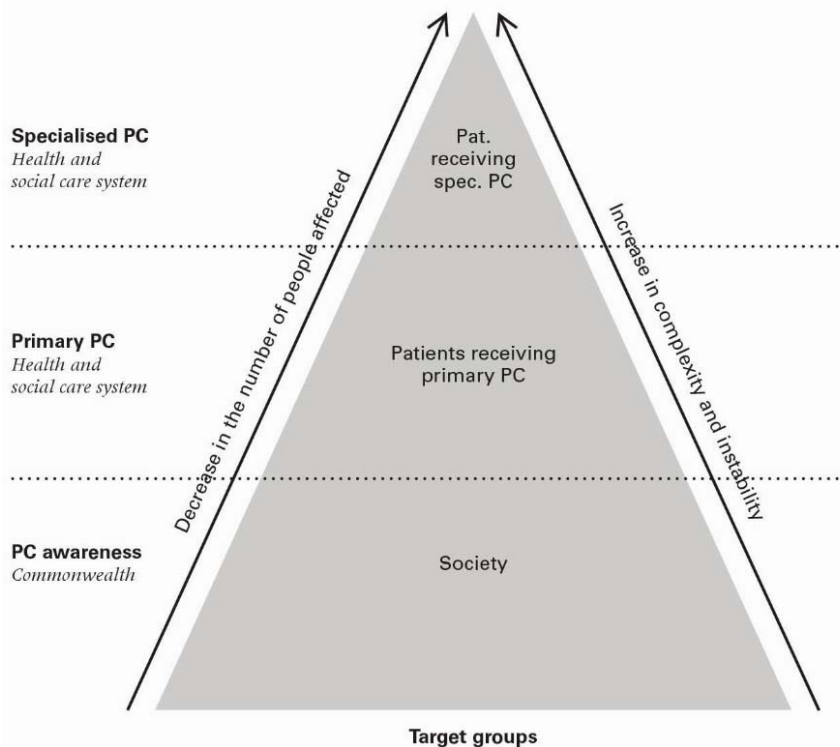
Framework Concept for Palliative Care in Switzerland



3 Applying the framework: four areas of implementation

The following section shows how the aforementioned fundamental principles are applied to four areas of implementation: target groups, services, care structures and competencies. Lists of reference documents which describe specific aspects of these areas in detail are also provided.

3.1 The «target group» area



3.1.1 General description

Palliative care focuses on the needs, symptoms and problems of affected patients as well as their attachment figures. At the «palliative care awareness» level, this relates to the needs of society for information, advice, and the ability to deal with the end of life.

The «primary palliative care» and «specialised palliative care» levels involve patients in palliative situations. Because of their different needs, a distinction is made between patients receiving primary palliative care and patients receiving specialised palliative care. The patients in the «specialised palliative care» category are distinguished by the instability of their condition and the greater complexity of their needs – not just in physical terms, but also in terms of psychological, social and spiritual requirements. Both patient groups may also require additional field- and group-specific elements in their care.

The transition between these two groups is fluid, meaning that a patient may belong to both groups during his or her lifetime, as his or her condition progresses. In addition to these two patient groups, patients' attachment figures are involved throughout the entire duration of care and treatment within the context of a partnership-based approach. Depending on the situation, they help design the patient's care or receive care themselves, for instance by receiving support and counselling during the grieving process.

Reference documents

National Guidelines for Palliative Care (FOPH and CMH, 2010)

<https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care.html>

Palliative care. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version)

<http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

3.1.2 «Palliative care awareness»: «society» target group

The target group «society» includes each and every individual member of the population. The needs of this target group can be summarised as follows:

- Integration of the end of life, dying and death in a normalised understanding of life; provision of knowledge and skills to deal with this normality
- Access to information on practical advance planning for the end of life (care, support and advisory options available, patient decrees and legal precautions, etc.)
- Specification of individual preferences with regard to making decisions and dealing with the end of life (e.g. for writing a patient decree within the framework of the Swiss law on the protection of adults)
- Advisory and facilitating support from specialists; help with advance planning
- Self-determination up to the end of life

Reference documents (in German and French)

Population survey concerning palliative care (GfK, 2009)

<https://www.bag.admin.ch/bag/de/home/service/publikationen/forschungsberichte/forschungsberichte-palliative-care.html>

Federal Council report on «Palliative care, suicide prevention and organised suicide assistance» (2011)

<http://www.ejpd.admin.ch/content/dam/data/gesellschaft/gesetzgebung/sterbehilfe/ber-br-d.pdf>

Pretest study of the key messages on palliative care (Dichter Research, 2012)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/sensibilisierung-zu-palliative-care/kernbotschaften-palliative-care.html>

Further reading

Gian Domenico Borasio (2014): Über das Sterben [About dying] (Swiss edition). C.H. Beck

3.1.3 Patients receiving primary palliative care

This group consists of patients who are dealing with the end of life in a proactive way or have reached the final phase of their life due to the progression of their incurable, life-threatening and/or chronically progressive disease. It is assumed that most patients requiring palliative care fall into this group.

In addition to the needs of the general population (cf. Section 3.1.2), the following requirements are also of primary importance for patients receiving primary palliative care:

- Specific evaluation and definition of individual priorities and needs with regard to planning the final phase of life
- Communication in order to enable decision-making and advance planning for medical, care-related and psychosocial issues
- Treatment of existing or expected symptoms and provision of information with the goal of preserving the patient's autonomy and strengthening his or her ability to make decisions
- Advance planning for emergency situations at home or in the patient's chosen environment
- Evaluation of the attachment figures' existing or possible breaking points, planning of alternative residence options, information about regional palliative care networks including volunteer assistance and support for attachment figures, assessment of the financing of the services required.

Reference documents

National Guidelines for Palliative Care (FOPH and CMH, 2010)

<https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care.html>

Formal voluntary work in palliative care. Recommendations for cantonal and local authorities and interested organisations (FOPH, CMH, palliative.ch, 2014, German/French/Italian)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/freiwilligenarbeit-und-palliative-care.html>

3.1.4 Patients receiving specialised palliative care

This patient group is smaller in terms of numbers and includes patients who rely on the support of a specialised palliative care team. This may be because their medical condition is unstable and/or they require complex treatment or stabilisation of pre-existing symptoms beyond the skills and capacity of their existing support network. Sometimes the symptoms or complex problems can be stabilised to the point where a return to the «primary palliative care» patient group may be possible.

The needs of patients in the «specialised palliative care» group include:

- Relief of extremely taxing symptoms, i.e. a combination of symptoms which have not improved as a result of previously conducted procedures and which seriously compromise the patient's quality of life
- Difficult decision-making processes, including the termination of life-extending treatments requiring an interprofessional palliative care team
- Intensive assistance required due to the patient's poor general condition, for instance in connection with determining outpatient or inpatient accommodation, special challenges associated with the care environment, or in the case of overlapping physical, emotional, social and spiritual suffering
- Intensive support for attachment figures exposed to a high degree of stress caused by the progression of the illness and other factors

Reference documents

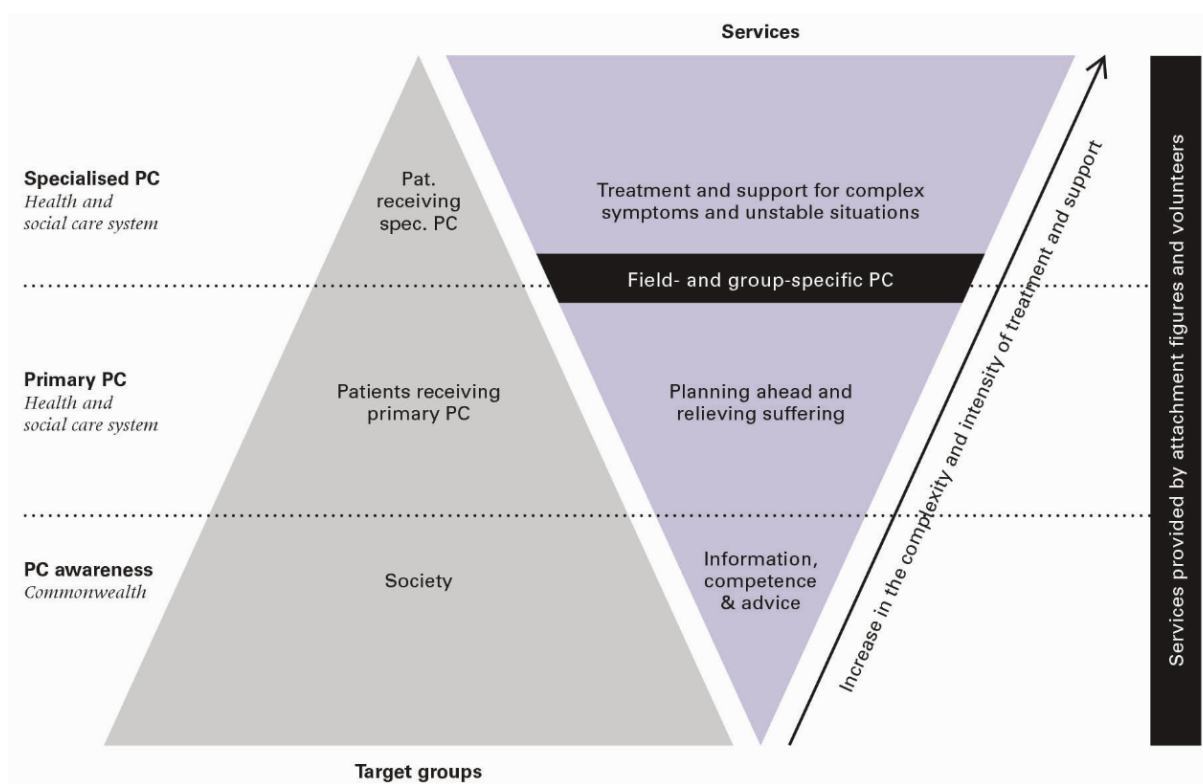
National Guidelines for Palliative Care (FOPH and CMH, 2010)

<https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care.html>

Indication criteria for specialised palliative care (FOPH and CMH, 2011, German/French)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/grundlagen-zur-strategie-palliative-care/spezialisierte-palliative-care.html>

3.2 The «services» area



3.2.1 General description

This area relates to the services which are required to fulfil the specified needs of the target groups at each of the three levels. The scope of palliative care services in terms of time, personnel and resources

increases as the levels progress from «palliative care awareness» up to «specialised palliative care»: the needs of the target group become increasingly complex and the treatment and support given to patients intensify. The patients' needs are not purely physical; psychological, social and spiritual aspects are also taken into account. The same applies to palliative care services, which is why they can only be provided by an interprofessional team (specialists in medicine, care, pastoral care, psychology, social work, physiotherapy, nutritional counselling and other occupations).

3.2.2 Palliative care awareness: information, competence and advice at the end of life

At this level, palliative care is aimed at providing suitable conditions to enable individual members of society to deal with the end of life. This requires encouragement, advice and the provision of information. The objective is to enable people to prepare for the end of life as they would for any other life event (e.g. entry into working life, the birth of a child, retirement and pensions, etc.), to think about their personal wishes and ideas with regard to the end of life and to record them in a patient decree, for example, and to accept dying and death as part of life.

Professionals in healthcare, social care and pastoral care, along with local authorities, are particularly well-placed to provide these services. Non-profit organisations which provide advice and raise awareness can also make a contribution at this level. Schools, religious institutions, cultural organisations and the media can also address the topic of palliative care and thus help provide information and stimulate debate.

Reference documents (German and French)

Federal Office of Justice: Overview of the new law on the protection of adults and patient decrees http://www.ejpd.admin.ch/content/ejpd/de/home/dokumentation/mi/2012/ref_2012-11-16.html

Further reading

Gian Domenico Borasio (2014): Über das Sterben [About dying] (Swiss edition). C.H. Beck

Steffen Eychmüller (2013): Lebensqualität in der letzten Lebensphase [Quality of life in the final phase of life]. In: Schulte, Volker/Steinebach, Christoph (Ed.): Innovative Palliative Care. Huber Verlag

International examples

Scotland: «Good life, good death, good grief» <http://www.goodlifedeathgrief.org.uk/>

Canada: «Speak up. Start the conversation about end-of-life care» <http://advancecareplanning.ca/>

NHS Greater Glasgow and Clyde: «My thinking ahead and making plans» <http://www.palliativecareggc.org.uk/index.php?action=cms.acp>

3.2.3 Primary palliative care: planning ahead and relieving suffering

At this level, palliative care services can be described using the «SENS structure», which comprises four areas:

- **S**ymptom management (physical, psychological, social and spiritual)
- **E**nd of life Decision-making based on individual preferences and advance planning for an impending crisis
- **N**etwork organisation, especially if the patient's own functions (physical, psychological or social) make self-determination acute or chronically impossible
- **S**upport for attachment figures who are also affected by the patient's illness

These palliative care services are provided by healthcare and social care professionals in cooperation with the patient and his or her attachment figures. Providers of primary care play a prominent role at this level, e.g. general practitioners or specialists involved in organising home care, homes for the elderly or nursing homes and acute care hospitals. The involvement of other occupations, such as pastoral care providers and psychologists, etc., is also important in ensuring that the needs of patients can be met in every aspect (physical, psychological, social and spiritual). Communication and documentation are the most time-consuming parts in the provision of these services. However, organising local networks, often with numerous participants, and instructing those affected on how to proceed in an emergency or in the event of complications also require considerable time and effort.

Reference documents

Eychmüller, Steffen (2012): SENS is making sense – on the way to an innovative approach to structure palliative care problems. *Therapeutische Umschau* 2012; 69 (2):87-90
Gold Standards Framework www.goldstandardsframework.org.uk
National Comprehensive Cancer Network USA Guidelines Palliative Care 2012 www.nccn.org

3.2.4 Specialised palliative care:

Treatment and support for complex symptoms and unstable situations

Services at the «specialised palliative care» level are also based on the practical elements of the «SENS structure». They are also largely in line with the «Indication criteria for specialised palliative care». The services for providing treatment and support for patients at this level are therefore more complex and intensive compared to primary palliative care. In some cases, the use of field- and group-specific palliative services (cf. Section 3.2.5) may also be required:

- Management of extremely taxing symptoms using measures which may include invasive procedures (e.g. invasive pain therapy, stent-assisted recanalisation, radiotherapy, etc.). The instability of the patient's condition and the difficulty of planning ahead mean that the treatment plan has to be adapted frequently, which poses a particular challenge.
- Making difficult end of life decisions, including with regard to the termination of life-extending treatments (e.g. intensive care) and how to proceed if a patient requests an assisted suicide
- Intensive support with organising the care network due to the patient's poor general condition and the high degree of coordination and communication required, and the provision of support for providers of primary care in particular (advice, training, information)
- Intensive support for attachment figures exposed to a high degree of stress caused by the progression of the illness and other factors

These services also require the involvement of an interprofessional team. The service providers from the various professions concerned need to have a sufficient level of specialist expertise in palliative care and specific expert knowledge⁴ (cf. Section 3.4).

Reference documents (German and French)

Indication criteria for specialised palliative care (FOPH and CMH, 2011)
<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/grundlagen-zur-strategie-palliative-care/spezialisierte-palliative-care.html>

3.2.5 The «support from attachment figures and volunteers» cross-cutting area

Attachment figures and volunteers can play a significant role in providing care and support for people at the end of their lives. Depending on the situation in question, attachment figures may be involved in organising care or receive support themselves from professional practitioners and volunteers, such as guidance in how to deal with the grieving process. If they are involved in organising care, they need advice and instruction (e.g. on medical or nursing matters) as well as support (e.g. acknowledgement in discussions and empathy). It is important to ascertain the limits of what these attachment figures can cope with at an early stage. It is essential to respect and understand these and to take proactive action accordingly, for example by engaging the services of volunteers.

Palliative care services provided by volunteers range from administrative and PR work to intensive psycho-social care and support for those affected and their attachment figures during and beyond their illness. Unlike attachment figures, volunteers do not usually provide services which fall under the responsibility of qualified professionals.

Reference documents

National Guidelines for Palliative Care (FOPH and CMH, 2010)
<https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care.html>
Formal voluntary work in palliative care. Recommendations for cantonal and local authorities and interested organisations (FOPH, CMH, palliative ch, 2014, German/French/Italian)

⁴ This does not necessarily mean that a more advanced level of training is required.

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/frei-willigenarbeit-und-palliative-care.html>

3.2.6 The «field- and group-specific palliative care» cross-cutting area

The services in this field- and group-specific cross-cutting area of palliative care must be defined on a case-by-case basis for each specialist field or each respective group, based on the needs of the patients concerned. This applies to:

field-specific palliative care services

- ...for people with psychiatric disorders
- ...for people with oncological diseases
- ...for people with dementia
- ...for people with neurological diseases
- ...for people with serious cardiovascular diseases
- ...for people with serious lung and respiratory diseases
- ...for pain therapy
- ...in the case of renal failure

group-specific palliative care services

- ...for paediatric care
- ...for geriatric care
- ...for people from an immigrant background
- ...for people with disabilities

The main service providers at this level are specialists in the fields concerned (e.g. geriatrics, oncology, paediatrics, care for the disabled, intercultural translation, etc.). However, primary care specialists who treat and support patients with field- or group-specific needs of this kind can also play a part in providing field- or group-specific palliative care (e.g. general practitioners). To fulfil the needs of these patients at the end of life in the best possible way, cooperation between providers of field- and group-specific palliative care services and specialised palliative care services is essential.

Reference documents

Palliative care. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version)

<http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

National Dementia Strategy 2014–2017 (FOPH and CMH, 2013) <https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie-2014-2017.html>

National Strategy against Cancer 2014–2017 and the National Cancer Programme for Switzerland 2011–2015 www.on-cosuisse.ch (German/French)

Medical treatment and care of people with disabilities. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version) <http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

Treatment and care of elderly persons dependent on care. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version) <http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

Recommendations on palliative care and psychological disorders (FOPH and CMH, 2014, German/French)

<https://www.bag.admin.ch/bag/de/home/service/publikationen/forschungsberichte/forschungsberichte-palliative-care/psychische-erkrankungen-und-palliative-care.html>

Publications by the European Association for Palliative Care (EAPC)

White paper defining optimal palliative care in older people with dementia (2013)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=PrBuOaKGIh4%3d&tabid=1616>

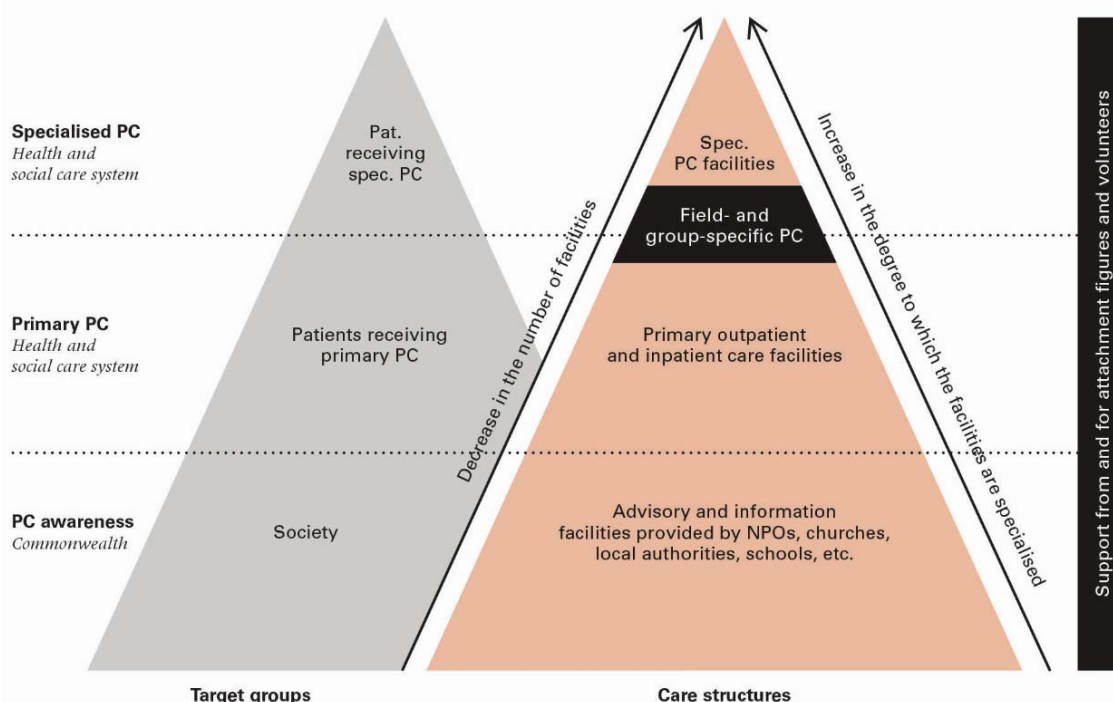
Palliative care for people with intellectual disabilities: Best practice guidelines and core standards

<http://www.eapcnet.eu/Themes/SpecificGroups/IntellectualDisabilities.aspx>

IMPACCT: Standards for paediatric palliative care in Europe (2007)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=ak11058QV3c%3d>

3.3 The «care structures» area



3.3.1 General description

This area specifies which supply structures need to be in place in order for the required palliative care services to be provided. At the «palliative care awareness» level, a readily accessible advisory and information programme is key. To provide optimum treatment and support for patients at «primary palliative care» level, well-developed primary palliative care for both inpatients and outpatients is essential. This requires, in particular, widespread integration into existing healthcare, social care and pastoral care facilities or, if need be, an expansion of these services. For the relatively small group of patients receiving specialised palliative care, fewer facilities are required but those which are needed are specialist in nature.

Reference documents

Care structures for specialised palliative care (palliative.ch, FOPH and GDK, updated in 2013, German/French)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/grundlagen-zur-strategie-palliative-care/spezialisierte-palliative-care.html>

3.3.2 Palliative care awareness: advisory and information facilities

At this level, readily accessible advisory and information facilities offered by non-profit organisations, local authorities or schools are essential. They provide advice on matters such as writing patient decrees, for example, as well as information on the support facilities on offer, the options available for dealing with the end of life and how to ensure self-determination

Reference documents

Federal Office of Justice: Overview of the new law on the protection of adults and patient decrees

http://www.ejpd.admin.ch/content/ejpd/de/home/dokumentation/mi/2012/ref_2012-11-16.html

Overview of cantonal and regional facilities: www.palliative.ch

3.3.3 Primary palliative care: primary outpatient and inpatient care facilities

The «primary palliative care» level involves care facilities for patients who are in a stable condition and do not require complex or specialist treatment or support (patients receiving primary palliative care). They can receive treatment and support from providers of primary services in acute inpatient care, long-term care (homes for the elderly, nursing homes and other institutions) or outpatient care (provided by

general or specialist medical practitioners, care services outside hospitals and outpatient clinics) in cooperation with practitioners in other occupations. These service providers must have appropriate basic knowledge of palliative care (cf. Section 3.4.3).

Reference documents (German/French)

Care structures for specialised palliative care (palliative ch, FOPH and GDK, updated in 2013)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/grundlagen-zur-strategie-palliative-care/spezialisierte-palliative-care.html>

Quality criteria for palliative medicine, care and support for inpatient treatment in long-term care institutions (List C)

http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/agqualitaet_kriterienliste_C_DE.pdf

Further reading (German)

Roland Kunz (2013): Interdisziplinäre Betreuung und Integrierte Versorgung [Interdisciplinary support and integrated care]. In: Schulte, Volker/Steinebach, Christoph (Ed.): Innovative Palliative Care.

3.3.4 Specialised palliative care facilities

The «specialised palliative care» level concerns the situation for patients who require specialised palliative care services. Specialised palliative care can also be provided within the context of hospital care, long-term care or outpatient facilities. A distinction is made between outpatient and inpatient care facilities. Specialised palliative care facilities are intended exclusively for the provision of palliative care and support for patients by an interprofessional team of experts with specialist palliative care expertise.

Inpatient facilities:

Inpatient facilities are geared towards patients who rely on ongoing support in the form of specialised palliative care. They include specialist palliative wards and palliative clinics. Most of these facilities have hospital status or are self-contained departments within acute care hospitals. There are also a few palliative wards in institutions providing long-term inpatient care or in specialised palliative care institutions with nursing home status.

These facilities only offer specialised palliative care, with treatment and support provided exclusively to patients who are in an unstable medical condition and require complex treatment or stabilisation of pre-existing symptoms. The care team is made up of specialists from various professions with proven, specific expertise in palliative care (cf. Section 3.4.5).

Outpatient facilities:

Palliative consultation services and mobile palliative care services support providers of primary or field- and group-specific palliative care by offering specialised palliative care expertise. The aim of this is to ensure that patients who are in an unstable medical condition and/or (occasionally) require complex treatment or stabilisation of pre-existing symptoms have access to specialised palliative care at their place of residence (at acute inpatient or long-term care institutions or at home). This should help, as far as possible, to avoid the need for transferrals or hospitalisation, which can be very stressful for terminally ill people and their attachment figures.

There are also outpatient care services such as day care/overnight care facilities and palliative outpatient clinics available for patients who are in a stable condition but still require complex treatment or stabilisation of pre-existing symptoms. These offer support and relief for all those affected and their attachment figures for a limited time. They ensure continuity of treatment and support within the palliative network and enable patients to remain at home while receiving the care they need.

Reference documents (German/French)

Care structures for specialised palliative care (palliative ch, FOPH and GDK, updated in 2013)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/grundlagen-zur-strategie-palliative-care/spezialisierte-palliative-care.html>

Quality criteria for issuing a quality label to specialised inpatient palliative care institutions (List A)

http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/agqualitaet_kriterienliste_a_de.pdf

Quality criteria for issuing a palliative care quality label to mobile consultation services within and outside hospitals (List B)

http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/AGQualitaet_Kriterienliste_B_DE.pdf

3.3.5 The «support from attachment figures and volunteers» cross-cutting area

The support services provided by attachment figures and volunteers are a key part of social involvement in palliative care. These include, in particular, formal voluntary work in palliative care or nursing and support provided by attachment figures. The facilities offered by regional associations and local networks are also important. These services are usually indispensable if a patient is being cared for at home. Volunteers also provide valuable services within inpatient institutions (e.g. nursing homes and palliative care wards and clinics). Not only do they support the people affected and their attachment figures, they also help the professional practitioners on site.

Reference documents (German/French/Italian)

Formal voluntary work in palliative care. Recommendations for cantonal and local authorities and interested organisations (FOPH, CMH and palliative ch, 2014) <https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/freiwilligenarbeit-und-palliative-care.html>

3.3.6 The «field- and group-specific palliative care» cross-cutting area

The «field- and group-specific palliative care» cross-cutting area covers the involvement of specialised palliative care structures within existing institutions or departments in specific specialist fields. This includes, for example, palliative care facilities for dementia patients in a nursing home or for people with disabilities in a sociomedical institution, or services offered by an oncology or geriatrics department. The difference between this area and the «specialised palliative care» level is that these facilities are not aimed exclusively at palliative patients. However, facilities of this kind which focus on the specific needs of this patient group at the end of life are still in need of further development. One possibility would be, for example, to define a person with specific skills to be responsible for resources for palliative care.

Support and treatment for these palliative patients is provided by professionals from the relevant specialist fields who have the necessary expertise in palliative care (cf. Section 3.4.6). In addition, patients with specialised palliative care needs (cf. Section 3.1.4) can also make use of the mobile facilities for specialised palliative care (mobile palliative services and consultation services). At the same time, this area also covers the integration of field- and group-specific competencies in primary and specialised palliative care structures.

Reference documents

National Dementia Strategy 2014–2017 (FOPH and CMH, 2013) <https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/nationale-demenzstrategie-2014-2017.html>

National Strategy against Cancer 2014–2017 and the National Cancer Programme for Switzerland 2011–2015 www.oncosuisse.ch

Medical treatment and care of people with disabilities. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version) <http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

Treatment and care of elderly persons dependent on care. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version) <http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

Guidelines on palliative care and psychological disorders (FOPH and CMH, 2014, German/French) <https://www.bag.admin.ch/bag/de/home/service/publikationen/forschungsberichte/forschungsberichte-palliative-care/psychische-erkrankungen-und-palliative-care.html>

Publications by the European Association for Palliative Care (EAPC)

White paper defining optimal palliative care in older people with dementia (2013)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=PrBuOaKGlh4%3d&tabid=1616>

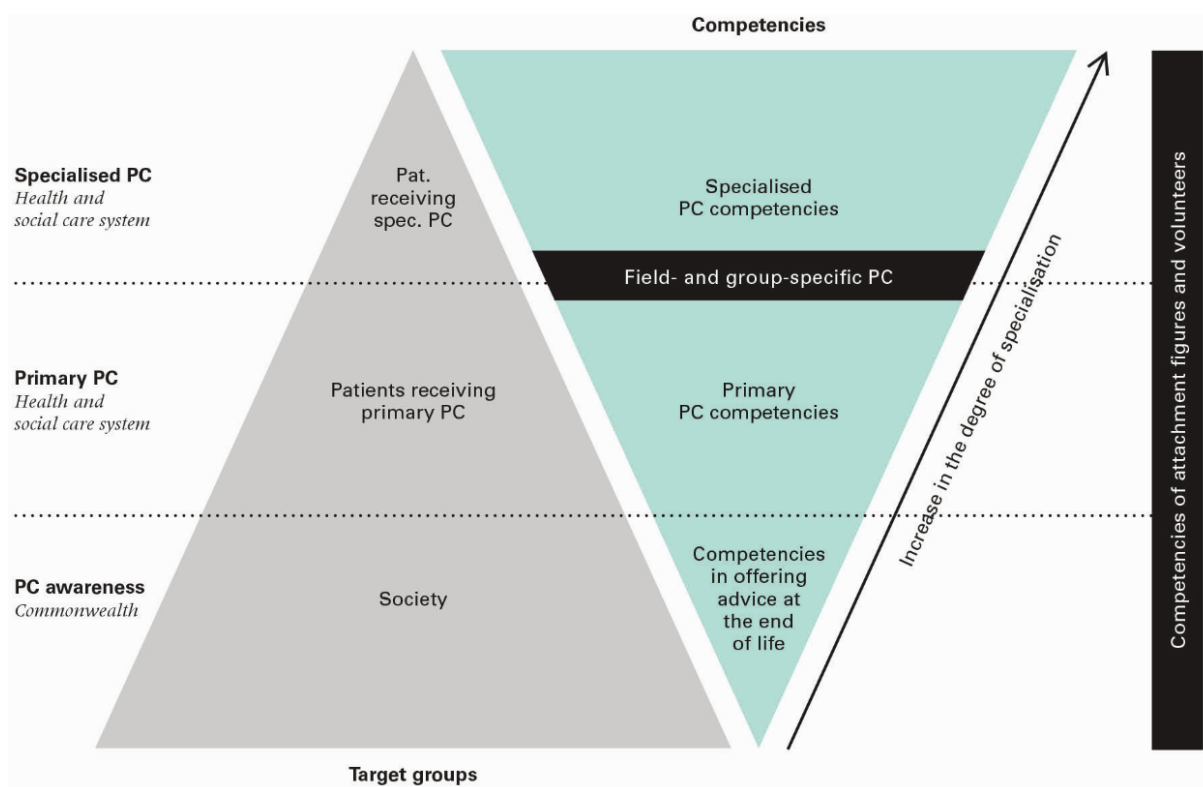
Palliative care for people with intellectual disabilities: Best practice guidelines and core standards

<http://www.eapcnet.eu/Themes/SpecificGroups/IntellectualDisabilities.aspx>

IMPACCT: Standards for paediatric palliative care in Europe (2007)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=akl1058QV3c%3d>

3.4 The «competencies» area



3.4.1 General description

This area outlines the competencies which healthcare and social care professionals should have in order to provide the palliative care services described. These competencies must cover all professional levels, including basic vocational training, advanced vocational training and higher education. The establishment of training standards – in all educational programmes essential for palliative care as well as further and advanced training – is a key requirement for ensuring the adequate provision of palliative care services. The more specialised the palliative care is, the more skills and in-depth knowledge are required.

To ensure that professionals involved in palliative care have the necessary specialist and general expertise in palliative care that is appropriate to their level, it is important to establish a common understanding of palliative care in training and education across Switzerland.

In terms of competencies, the «Framework for Palliative Care in Switzerland» differs from the competency levels defined by the European Palliative Care Association (EAPC). The EAPC's «palliative care approach» is applied more broadly here, so that it concerns the societal level («palliative care awareness») as well as the professional level of health and social care. In the Swiss framework, the competencies required at the «primary palliative care» level cover both the «palliative care approach», as a basis, and the «primary palliative care» level defined by the EAPC.

Reference documents

National Education Concept: «Palliative Care and Training» (FOPH and SERI, 2012, German/French/Italian)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/bildung-und-palliative-care/nationales-bildungskonzept-palliative-care.html>

<https://www.sbfi.admin.ch/sbfi/de/home/themen/berufsbildung/gesundheitsausbildungen/nationales-bildungskonzept.html>

Core competencies in palliative care: an EAPC White Paper on palliative care education (Gamondi/Larkin/Payne, 2013)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=XPrM1LNaSbo%3d&tabid=38>

3.4.2 Palliative care awareness: competence in offering advice and enabling people to deal with the end of life

Service providers at the «palliative care awareness» level (non-profit organisations, churches, local authorities, schools, etc.) must have sufficient expertise to offer people advice with regard to the end of life and to enable them to organise their final phase of life based on their own decisions. This includes, for example, knowledge about the facilities available, an acceptance of dying and death as part of life, communication skills and an understanding of how to keep a record of options, wishes and preferences for the end of life and substantiate them as appropriate (e.g. by means of a patient decree).

Reference documents

Patient decrees. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2013, updated version) <http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

Federal Office of Justice: Overview of the new law on the protection of adults and patient decrees (German/French/Italian) http://www.ejpd.admin.ch/content/ejpd/de/home/dokumentation/mi/2012/ref_2012-11-16.html

3.4.3 Primary palliative care competencies

Every professional who provides treatment and support for patients receiving primary palliative care should have primary palliative care competencies. These must be adapted for the training and education required for the various occupations concerned, based on the level at which individual professionals work (medicine, care, pastoral care, social work, psychology, etc.). These skills should be taught as part of regular, existing training programmes (e.g. undergraduate medical education, training to upper secondary level and tertiary levels A and B for health care professions).

Overriding objectives:

- To enable trainees, at a standard appropriate to their level, to recognise and empathise with the suffering of people with incurable, progressive diseases and to work out treatment and support targets in consultation with these people (shared decision-making). These targets are then to be implemented based on an interprofessional approach involving the resources available.
- To ensure that professionals involved in palliative care have both the practical skills required (technical expertise, social skills, self-competence and methodological skills) and the necessary personal and social-communicative skills (specifically communication skills, the ability to work in a team and the ability to cooperation).

Secondary objectives:

- To enable professionals involved in palliative care to work in an interprofessional and interdisciplinary team.
- To ensure that professionals involved in palliative care have in-depth technical, communication and social skills.
- To ensure that the professionals involved understand the multidimensional aspects of palliative care. Not only must they be aware of the different occupation-specific skills involved, but they must also respect these different competencies and accept their responsibility towards patients when working with others. This ensures an integrated approach to patient care, taking into account the physical, psychological, social and spiritual dimensions.

Reference documents

National Education Concept: «Palliative Care and Training» (FOPH and SERI, 2012, German/French/Italian)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/bildung-und-palliative-care/nationales-bildungskonzept-palliative-care.html>

<https://www.sbf.admin.ch/sbf/de/home/themen/berufsbildung/gesundheitsausbildungen/nationales-bildungskonzept.html>

Core competencies in palliative care: an EAPC White Paper on palliative care education (Gamondi / Larkin / Payne, 2013)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=XPrM1LNaSbo%3d&tabid=38>

Competencies of Health Professionals in Primary Palliative Care (Kompetenzen der Mitarbeitenden in Gesundheitsberufen in der Grundversorgung der Palliative Care, SBF/OdASanté)

<https://www.sbf.admin.ch/sbf/de/home/themen/berufsbildung/gesundheitsausbildungen/nationales-bildungskonzept.html>

Catalogue of competencies for primary palliative care (swisseduc/palliative ch, work in progress)

Recommendations of the European Association for Palliative Care (EAPC) for the Development of Undergraduate Curricula in Palliative Medicine at European Medical Schools (updated version, 2013)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=S1MI-tulutQ%3d&tabid=1717>

Steffen Eychemüller (2015): Palliativmedizin Essentials: Das 1x1 der Palliative Care für die Kitteltasche

Hans Neuenschwander, Christoph Cina (2015): Handbuch Palliativmedizin

3.4.4 Specialised palliative care competencies

A specialised palliative care programme is needed for people with complex symptoms and a generally unstable medical condition (patients receiving specialised palliative care). This calls for a wider range of competencies and specific expertise beyond the primary palliative care competencies on the part of the team providing support and treatment. These specific palliative care skills should build on the aforementioned primary palliative care competencies. They are taught within the framework of training and specialised further training courses and continuous professional development.

Reference documents

Competencies of Health Professionals in Primary Palliative Care (Kompetenzen der Mitarbeitenden in Gesundheitsberufen in der Grundversorgung der Palliative Care, SBF/OdASanté)

<https://www.sbf.admin.ch/sbf/de/home/themen/berufsbildung/gesundheitsausbildungen/nationales-bildungskonzept.html>

Competencies for Palliative Care Specialists (swisseduc/palliative ch, 2012)

http://www.palliative.ch/fileadmin/user_upload/palliative/fachwelt/E_Standards/Kompetenzkatalog_DE.pdf

A Guide for the Development of Palliative Nurse Education in Europe (EAPC, 2004)

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=e9JnEa7YZDM%3d>

The EAPC Task Force on Education for Psychologists in Palliative Care

<http://www.eapcnet.eu/LinkClick.aspx?fileticket=ru1x-wMhklq%3d&tabid=692>

3.4.5 The «support from attachment figures and volunteers» cross-cutting area

This area covers competencies which attachment figures and volunteers need to have in order to be able to perform their instrumental role in providing care and support for people at the end of life. These competencies include knowledge of the fundamental values and principles of palliative care, the necessary skills for supporting and caring for patients at the end of life and the relevant personal and ethical skills.

Reference documents

National Guidelines for Palliative Care (FOPH and CMH, 2010)

<https://www.bag.admin.ch/bag/en/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care.html>

Formal voluntary work in palliative care. Recommendations for cantonal and local authorities and interested organisations (FOPH, CMH and palliative ch, 2014, German/French/Italian)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/freiwilligenarbeit-und-palliative-care.html>

3.4.6 The «field- and group-specific palliative care» cross-cutting area

Field-specific palliative care is provided by primary care service providers and specialists who treat patients in palliative situations. These professionals are often involved in palliative care cases, but it is not one of the main elements of their work. Based on the aforementioned core competencies, they should have in-depth expertise in palliative care within their particular area of activity.

One aspect of this is that they should have field-specific competencies in dealing with specific, diagnosis-related needs (e.g. knowledge of the procedure for stopping dialysis). These competencies must be individually defined for each specialist field. Depending on the discipline and profession concerned, these competencies can be taught within the context of training and education (e.g. postgraduate medical education).

Another aspect of field- and group-specific competencies relates to the specific needs of certain target groups (e.g. people from an immigrant background). This is an issue which applies across all care disciplines and professions, which is why the relevant competencies should be taught right from the training stage.

Reference documents

Palliative care. Medical-ethical guidelines and recommendations (Swiss Academy of Medical Sciences, 2012, updated version)
<http://www.samw.ch/en/Ethics/Guidelines/Currently-valid-guidelines.html>

4 Defining the transitions between palliative care levels

A patient is considered to be in a palliative situation when the needs described in Section 3.1.3 (patients receiving primary palliative care) come to the fore. Another way of identifying whether a patient requires palliative care is to ascertain whether he or she is in the last few years or months of life. However, the key factor in determining the requirement for palliative care is the patient's needs from a somatic, psychological, social, organisational and spiritual perspective.

A patient's transition from primary to specialised palliative care depends on the complexity and instability of his or her needs. Complexity can refer to multidimensionality, unmanageability and the need for treatment and support from various different professions. A high degree of complexity also requires a high level of coordination, monitoring and support, and places great demands on communication. The degree of instability is reflected by the time and effort required for evaluating the patient's condition and by its unpredictability, which makes it necessary to alter the treatment plan frequently (several times a day in the case of a high degree of instability).

If possible, patients in palliative situations should receive care from the professional practitioners and volunteers they have requested and at the place they have chosen. «To-ing and fro-ing» between various institutions is to be avoided. If the needs of a patient who has hitherto been receiving primary palliative care become more complex and his or her medical condition becomes less stable, the first thing to do is to check whether specialised palliative care services can be brought in by a mobile palliative service. If this is not possible, for example because this kind of facility is not available or the care network is already at full capacity, it is recommended that the patient be referred to an inpatient institution for specialised palliative care.

Reference documents

Indication criteria for specialised palliative care (FOPH and GDK, 2011, German/French)

<https://www.bag.admin.ch/bag/de/home/themen/strategien-politik/nationale-gesundheitsstrategien/strategie-palliative-care/grundlagen-zur-strategie-palliative-care/spezialisierte-palliative-care.html>

Pallia10 CH: When should a specialised palliative care structure be implemented? (French)

http://www.vd.ch/fileadmin/user_upload/themes/sante_social/services_soins/pallia10_12-03-13.pdf