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Perspectives for practice and research

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Palliative care in Germany

Perspectives for practice and research

Foreword

Palliative care is not about healing, but about providing comprehensive care and support to those with incurable, life-threatening diseases. The intention is for palliative care to envelop patients and their families like a cloak (lat. pallium = mantle). Finding a satisfactory means of achieving this is a major challenge facing society.

The importance of palliative care is being recognised and accentuated increasingly in political debate. A broad consensus exists about the need for comprehensive, high-quality and evidence-based palliative care in Germany. This goal has not yet been achieved.

The present statement by the German National Academy of Sciences Leopoldina and the Union of German Academies of Sciences and Humanities examines this important issue in more detail. Taking as its starting point the needs and requirements of those affected, it identifies the deficiencies of the status quo – in an international comparison – while at the same time signposting the perspectives and options for action which will merit our attention in the years ahead.

If we are to ensure the long-term future of a comprehensive system of high-quality palliative care, it is essential for research to be intensified in this area, so that treatment plans can better meet the needs of the dying. It is to this end that the academies are presenting an interdisciplinary and wide-ranging research agenda for palliative care.

We would like to express our heartfelt thanks to the spokespersons and active members of the working group as well as to the reviewers who have helped prepare this statement or have provided feedback at the many meetings which have been held over the last two-and-a-half years.

Halle (Saale) and Berlin,



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of Sciences Leopoldina



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Summary and recommendations

When compared with other countries, Germany's provision of palliative care still leaves much to be desired; sustained commitment towards research in palliative care would be an important step towards addressing such shortcomings.

The aim of palliative care is to achieve or maintain the best possible quality of life for patients, their families and relatives in the face of life-threatening, incurable conditions. 'Palliative care' is used here as a generic term for any activities involving such individuals. The prevention and relief of suffering are key priorities. A prerequisite of this is the early recognition and accurate recording of all impairments, symptoms and areas of conflict at all physical, mental, social and spiritual levels.

In recent years, public discussion about the topic of life and death has gained in importance. In surveys, 54 percent of respondents reported having contemplated their own mortality. Thirty-nine percent claimed that the topic of life and death was an important or very important concern for members of their immediate circle.

The most common causes of death in Germany are cardiovascular disease and cancer, which account for more than 500,000 fatalities every year. Most of these afflicted people spend their final days suffering from physical symptoms such as pain or dyspnoea, and both they and their families can also be burdened with psychosocial or spiritual problems.

Patients with other severe diseases, such as neurological disorders (Parkinson's disease, dementia, multiple sclero-

sis, etc.) and lung diseases, as well as frail, older patients with a range of medical conditions, also require palliative care. Children and adolescents need special care depending on their developmental stage, on the prevailing spectrum of diseases and on their family circumstances.

There is also conjecture about the efficiency of palliative care, since health care research in this area is still in its early days, and there is a substantial need for studies focused on the field of palliative medicine. This statement will make recommendations about what has to be done in the light of both the need to catch up and the perceptible additional demands the future will bring.

These recommendations take into account the irrefutable entitlement we have to the best possible quality of life, and the specific care required by critically and terminally ill patients.

The statement makes three basic recommendations for the provision of:

1. a homogeneous, comprehensive level of high-quality care throughout Germany, which – in contrast to the present situation – is accessible to all those in need;
2. a commitment by every region in Germany to meet in full the actual costs of science-based palliative care in hospitals, care facilities and the home environment;
3. a package of care, scientifically proven and available to all those in need of it in Germany. This will necessitate the ongoing development of a body of evidence supporting the provision of palliative care in Germany.

Palliative care in Germany should attain at least the same level of excellence as is achieved by global leaders in the field (such as the USA, Great Britain and Sweden). This will require a paradigm shift so that palliative care becomes a science-based discipline, and a concomitant guarantee that appropriate support will be provided for research in palliative medicine.

Ensuring care provision and healthcare research should extend beyond palliative care for cancer patients. Explicit efforts should also be made to improve palliative care in the long term for patients with other medical conditions: those with multimorbidity, dementia and disabilities, patients from all age groups and social situations, care home residents, prison inmates, or the homeless.

Thus, in addition to the recommendation that a basic knowledge of palliative care should become an integral part of initial and advanced training courses for all professional groups involved in the area of palliative care, and that a reliable regulatory framework should be established for the voluntary sector, the following individual recommendations are formulated:

Recommendation 1: The development of an independent national palliative strategy

The strategy should incorporate:

- the nationwide standardisation of regulatory requirements for evidence-based palliative care, in order to ensure the provision of comprehensive, high-quality care throughout Germany;
- the establishment of a research agenda for palliative care;
- the development of nationally consistent quality assurance standards in palliative care based on research results (e.g. as a national palliative register);

- the integration of palliative care into the development of the National Cancer Plan, the National Dementia Strategy, the National Health Care Guidelines, the Disease Management Programme (DMP), and care strategies for other medical conditions.

Recommendation 2: Promoting specific methods and key issues in the area of interdisciplinary palliative care research

The integration into palliative care of different disciplinary perspectives and research approaches from the life sciences, the humanities and the social sciences. The basically interdisciplinary research approach should take into account the specific conditions arising from simultaneous physical and psychosocial changes, as well as changes in spiritual attitudes at the end of life.

Intervention studies with endpoints on issues relating to palliative medicine, with the aim of ensuring that a sufficient body of evidence exists on which to base guidelines concerning patient care.

Studies on the current and future role of medical technology in maintaining the autonomy and independence of palliative patients, and on how to counterbalance to some extent the anticipated, demographically caused care deficit.

Improving palliative medicine by carrying out basic research on systemic biological changes at the end of life and where chronic medical conditions have progressed to the terminal stage.

Recommendation 3:

Promoting the structures for interdisciplinary palliative health care research

Grants aimed specifically at young researchers to provide the necessary incentives to attract them to inter- or transdisciplinary projects.

The development of time-limited interdisciplinary research structures involving clinical scientists and basic researchers, as well as researchers in the fields of palliative nursing care and spiritual and psychosocial studies.

Recommendation 4:

Involving patients and their families in decision-making on the drawing-up of a research agenda

The involvement of patients and their families in the development of the research agenda for palliative care is essential if their palliative care needs are to be met. Their input, where appropriate, should serve to make palliative care more responsive to the needs of the recipient.

1 Introduction

“You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.”

CICELY SAUNDERS (1918 – 2005)¹

What began in 1967 with the founding of St. Christopher’s Hospice in Sydenham near London by Cicely Saunders, brought about positive, far-reaching consequences throughout the world for the care of the critically and terminally ill.² Considering more carefully than in the past the needs and wishes of those who could not be healed and whose lives were clearly limited by their illness, this developed from a programmatic postulate to become one of the core duties of nursing and medical care.³

Life-threatening illnesses and death present both the patients themselves and their relatives with complex and particularly burdensome challenges. The same is true of those charged with providing professional care and support for such people. That is why, in many respects, palliative care has become the forerunner of networked, multi-professional and multi-perspective thinking and approaches to looking after patients. In hardly any

other branch of medicine is there a comparable example of such close cooperation between different professional groups and specialist disciplines.

Taking as its starting point the needs and requirements of people with incurable and life-threatening diseases, this report aims to highlight the deficiencies of the status quo in terms of research and the provision of care, suggest approaches aimed at optimising the situation, and recommend measures designed to improve the care of patients and their families. This also applies to research in this particular field, the organisation and optimisation of structures, as well as processes in the field of social policy.

This statement formulates a research agenda with the objective of enabling scientific activities in the years ahead to contribute towards improving conditions for critically and terminally ill patients and their social circle. It concludes with concrete recommendations for action to be taken by elected officials and functionaries in political and social spheres.

¹ Dame Cicely Saunders was a nurse, social worker and physician. She is recognised as the founder of the modern hospice movement and of palliative medicine.

² Any reference to people in this text refers equally to men and women. In order to improve readability, we shall generally restrict ourselves to the masculine form, which is currently in wider use.

³ The care of the critically ill and dying is not a separate area of activity, but is one of the oldest and most fundamental core responsibilities of a medical stance which prioritises the needs of the patient, supports him, and attempts to alleviate his suffering (Ruppert, 2010, p. 10).

2 Basic principles of palliative care

2.1 Definition and goals

In this report, the term ‘palliative care’ is invariably used as a generic term to cover all activities involving people with incurable, life-threatening diseases.⁴ This is intended to take account of the special nature of this interdisciplinary area of healthcare in which many different professions are involved. ‘Palliative care’ is the term generally used in English. In our modern understanding, the use of the term ‘palliative medicine’ alone or as a synonym for palliative care would fall short of what is required (Bollig et al., 2010). Where, for instance, there are references to research in the text, then in the absence of any more precise specification – in keeping with the meaning of the broad concept of palliative care – this should be understood as encompassing not only the narrower field of healthcare research, but also all other activities relevant to palliative care, including basic research.

The definition of the World Health Organisation (WHO) published in 2002 forms the basis for the following report. The WHO defines this area of activity as follows: *“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identi-*

*cation and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”*⁵

Originally focused on care for cancer patients, today palliative care aims to provide patients with all forms of life-threatening and incurable diseases from every age group, irrespective of their social background, with wide-ranging care and support based on their requirements and oriented towards meeting their needs. Providing relief from distressing symptoms is a particular priority.

The target group for palliative care constitutes patients with advanced stages of cancer, end-stage cardiac, pulmonary or renal insufficiency, neurological medical conditions such as amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS), as well as patients who have suffered a stroke, have dementia, or are older with multimorbidity, if these conditions are responsible for physical or psychosocial problems and impinge upon their quality of life. Children and adolescents may also require palliative care for a large number of other medical conditions.

Palliative care encompasses more than just medical support for the dying patient. It should be integrated into the course of treatment for an incurable disease at an early stage (early integration). In this way, receiving palliative care does not mean that the patient has to be aware that he is dying. Conversely, not every ter-

⁴ During the writing of this report, such matters as terminology and boundaries with contiguous areas of care were discussed at length. A broad approach has been adopted. Consequently, the term ‘palliative care’ also encompasses all of the activities of the hospice movement. Moreover, ‘palliative care’ is the term which has prevailed to an increasing extent in the legislation and in the healthcare system since 2009, which is why it was chosen for the title of the report.

⁵ <http://www.who.int/cancer/palliative/definition/en/>; Status: 12 September 2014. The WHO has published its own definition of palliative care for children and adolescents (ibid.).

minally ill patient requires palliative care; dying is often, but not inevitably, accompanied by physical ailments or by psychosocial or spiritual problems.

A series of common values and attitudes apply in palliative care which are inextricably linked with the self-perception of those working in the field. Summarised in the *White Paper on Standards and Norms for Hospice and Palliative Care in Europe*, which was published in 2011, these have since met with a broad consensus in Germany, too, where they have been considered as norm-setting (Radbruch & Payne, 2011).

These common values and attitudes apply in principle to every form of medical, nursing and therapeutic activity, but acquire a special significance in the context of incurable or life-threatening diseases. The interdisciplinary and multi-perspective approach to treatment and support and the holistic view of the patient, his needs and those of his family, are especially worth emphasising in this respect. Palliative care aims to provide a robust support mechanism, able to initiate and maintain the services and assistance which are required every step of the way.

In the case of paediatric palliative care, the WHO definition must be extended to include, in particular, the role of the parents as primary carers, the need for respite care (e.g. through admission to an inpatient children's hospice), and the meaningfulness of providing care from the time the diagnosis is first established (Zernikow et al., 2008).

Common values and attitudes of central importance in palliative care are:

- **Dignity:** Special measures should be taken to protect the dignity of those entrusted to the care of the palliative care team for treatment and support, and such care should be provided in a

respectful, open and sensitive way. This includes exhibiting the highest possible level of acceptance in response to the individuality and needs of patients with severe diseases and at the end of life. Sensitivity should also be shown to the patient's religious, social, cultural and personal customs and observances.

- **Autonomy:** As in other areas of health-care, the value of each patient as an autonomous and unique individual should be recognised in palliative care. At every stage of treatment and support, but especially at the end of life, the wishes of the patient and/or of the designated decision maker⁶ who speaks for him should be respected and satisfied as far as possible. The patient and/or his designated decision maker should at all times be given the opportunity to make autonomous decisions on whether to consent to or refuse treatment and palliative care or support options. Thus the concept of a dialogue-based or participatory approach to decision-making is of especial importance for critically or terminally ill patients (van Oorschot et al., 2004).
- **Communication:** Communication skills are essential in palliative care, which supports people facing an existential crisis as a result of their incurable and life-threatening conditions. Consequently, empathy and heedfulness to the patient's present needs should be given even greater priority here than in other areas of medicine, nursing or healthcare. This applies both to communication with patients and their families and to communication within the teams made up of various professional groups providing treatment and support.

⁶ The patient's designated decision maker should be his advocate regarding treatment if the patient is incapable of making his own decisions (cf. German Civil Code (BGB) Art. 104 No. 2 re incapacity to form a contract, and BGB Arts. 630d Para. 2 Sent. 1, 630d Para. 4 re informed consent). Irrespective of this, the physician must always explain to his patients the treatment they are to receive as far as this is possible (BGB Art. 630d Para. 5).

- **A multiprofessional and interdisciplinary approach:** Palliative care is a prototype for integrated multiprofessional and interdisciplinary collaboration, as incurable and life-threatening diseases generally confront those providing treatment and care with multidimensional challenges. A broad spectrum of professions works together on behalf of the patient and his family, contributing expertise to providing them with care and support. As well as physicians and nurses with qualifications in palliative medicine and palliative care respectively, this can include physicians from other specialist fields, psychologists and psychotherapists, physiotherapists, religious/spiritual counsellors, social workers, wound managers, case managers, pharmacists, occupational therapists, music and art therapists, nutritionists and others besides. Volunteer staff also plays an important role in palliative care.
- psychiatric symptoms, e.g. confusion and perceptual disorders
- neurological symptoms, e.g. paralysis and speech disorders
- poorly healing or non-healing wounds

Patients receiving palliative care generally exhibit several symptoms concurrently, and can present complex clinical pictures. Sleep disorders, diurnal restlessness, epileptic seizures and spasticity are frequent symptoms in children and adolescents with life-threatening and incurable medical conditions. Foresight and forward planning to deal with potential acute crises, for instance the preparation of contingency plans, must go hand in hand with the treatment of symptoms.

2.2.2 Psychosocial support

Life-threatening diseases often put patients and their social framework under extreme pressure, resulting in a need for assistance which goes far beyond requiring medical or nursing care. It is not always possible for the sufferer to overcome or tolerate anxiety and uncertainties unaided. It is not unusual to encounter legal difficulties, financial uncertainty, problems with the organisation of everyday life, and even existential fear.

As part of their palliative care, patients and their social circle receive support in dealing with their illness. Family members, who often fulfil important care duties, are given essential information and assistance to help them in this role. Advice and assistance on social welfare rights is offered to help with financial concerns, lack of confidence in dealing with the authorities, and ignorance of their legal position. One element of psychosocial care is the provision of advice and welfare planning for the end of life; a comprehensive care plan (advance care planning) makes it possible to record the patient's wishes, for instance with an advance directive, a healthcare proxy or an enduring power of attorney. Children, adolescents and young

2.2 Key areas and measures

The following key areas and measures for palliative care have been developed in order to achieve the above-mentioned goals.

2.2.1 Symptom management

Symptom management comprises measures to alleviate or prevent the onset of afflictions which might have a negative impact on the patient's quality of life.

The most frequently occurring symptoms include:

- pain
- respiratory symptoms, e.g. dyspnoea
- gastrointestinal symptoms, e.g. nausea, vomiting, constipation and diarrhoea
- symptoms of cachexia, e.g. fatigue and weakness
- mental symptoms, e.g. anxiety and depression

adults related to the patient may have specific problems which necessitate special psychosocial support and counselling.

If children or adolescents require palliative care, there will be a need for measures and services over and above those already mentioned; examples include ensuring that the specific information and guidance provided is appropriate to the patient's age and developmental stage, and arranging for their parents and siblings to receive special support services.

2.2.3 Spiritual support

Another important mission of palliative care is to make allowance for the patient's spiritual needs. Given the imminence of their deaths, many patients and their families raise questions about the meaning of life. External and internal changes brought about by the disease and the grievances, anxiety and uncertainty associated with these can also be addressed in conversations with a religious/spiritual counsellor. Spiritual support is given at the request of the patient concerned and in a manner which is in keeping with his ideologies, religious affiliations and cultural background.

2.2.4 Bereavement services

The comprehensive approach adopted by palliative care also encompasses the mourning processes associated with incurable and life-threatening diseases. Grief reactions can be triggered as early as when the diagnosis is made, and also when the patient loses his abilities, experiencing a limitation of his quality of life as the illness progresses. After the death of a patient, it is important to continue to make counselling and support services available, and to provide ongoing assistance to family members – for instance, by supplying grief counselling after the death as well as through the medium of support groups, individual bereavement counselling, memorial services and get-togethers for family members.

3 The palliative care environment

3.1 Social sphere

3.1.1 Demographic factors

In 2011, there were 852,328 deaths in Germany (Federal Statistical Office, 2012a). This figure is anticipated to rise to more than one million per annum by 2038. The birth rate deficit experienced in Germany since 1972 is expected to rise even further, while at the same time there will be an increase in the average age of the population; in 2050, only one in eight Germans is expected to die before his or her 75th birthday. There is little doubt that nursing and medical care needs change with increasing age. Therefore, it would appear judicious to adapt healthcare and end-of-life care to take account of this development (Simon et al., 2012a).

The most frequent cause of death in 2011 continued to be diseases of the cardiovascular system, which accounted for 40.2 percent. The overwhelming majority of those affected were older people over the age of 65 with ischaemic heart disease (127,101 fatalities). A total of 221,591 deaths were caused by cancer, the second most common cause of mortality, with most of the victims being middle-aged (Federal Statistical Office, 2012a).

We can expect to see an increase in the number of people requiring nursing care in the years ahead. The Statistical Offices of the Federation and the federal states predict that this figure will probably rise from 2.25 million in 2007 to 2.65 million in 2015. The number of those dependent on nursing care is predicted to be 2.9 million in 2020 and 3.37 million in 2030

respectively. Their share of the population is expected to climb from 2.7 percent (2010) to 3.6 percent in 2020 and 4.4 percent in 2030. Whilst some 35 percent of care-dependent people were 85 or older in 2007, we assume that this proportion will increase to about 41 percent by 2020 and to about 48 percent by 2030 (Federal Statistical Office, 2012a).

As is also the case in other countries, in Germany today it is mainly cancer patients who receive palliative care (Ostgathe et al., 2011). But if the demographic trend is likely to contribute to an increase in cases of oncological disease, the increasing age of the population will also mean a rise in the frequency of other severe diseases, whether neurological (Parkinson's disease, dementia and MS), cardiovascular, or pulmonary in origin (heart failure and chronic bronchial and lung diseases) (Kruse, 2007; Gesundheitsberichterstattung des Bundes (Federal Health Report), 2006). The average nursing required during the final stage of life is much the same for cancer patients as for those suffering from other diseases (Small et al., 2009).

Recognizing the increased infirmity of people of an advanced age, the WHO has called for suitable provision to be made for people whose age predisposes them to frailty and multimorbidity (Davies & Higginson, 2004). In Germany, the Advisory Council on the Assessment of Developments in the Healthcare System recommends the restructuring of the healthcare system to take account of the demographic ageing process (Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen, 2009).

A large proportion of the infirm aged will require general palliative care, while a considerably smaller proportion will need specialist palliative care.

The proportion of the total population represented by children and adolescents will decline even further in the years ahead because of the persistently low birth rate. However, a rise in the incidence of severe illnesses is being observed in this sector of the population.⁷ Medical advances in recent years have enabled these children and adolescents to live longer. One consequence of demographic change may be that the subjects of illness, death and dying tend to be associated increasingly with older people, whilst the care structures give less attention to children and adolescents.

3.1.2 Social framework

The subject of death and dying has played a much more significant role in public discussion and in the media in recent years, as demonstrated, for instance, by the week in 2012 devoted to many aspects of the subject by the ARD broadcasting station. Removing the taboos from such discussions in society as a whole does not automatically mean that people give more thought to their own deaths. However, a representative survey by the Deutscher Hospiz- und Palliativverbandes (DHPV) (German Hospice and Palliative Care Association) in the summer of 2012 indicated that 39 percent of respondents claimed that the topic of life and death was an important or very important concern for people in their near proximity (DHPV, 2012). Eighty-three percent had already experienced the death of someone close to them. More than half of those surveyed (54 percent) reported having contemplated their own mortality either frequently or at least occasionally.

⁷ In the 16–19 age group, there has been a 45 percent rise in the frequency of life-threatening illnesses over the last 10 years; the figure was 38 percent for 11 to 15-year-olds and 32 percent for 6 to 10-year-olds (Fraser et al., 2012).

The majority wished that the subject were discussed more openly in public.

According to this survey, more than 60 percent of Germans would prefer to be able to die in their home environment (DHPV, 2012). So far, this has been possible for only about 30 percent of the dying; the majority die in hospitals and care homes. The chances of being able to die at home are lower in rural than in urban areas. It is assumed that there is a greater possibility of enabling someone to die at home if they live in a town than if they live in the country because of the better palliative care structures available there, especially in the field of outpatient services.

3.1.3 The individual in society

Because more emphasis is placed on the importance of the individual now than in the past, there is a growing demand for self-determination over one's own life during the entire course of life, the other side of which is an increasing fear of loss of control in the case of severe disease and of the possibility of being kept alive by machines at the end of life as one 'vegetates away', being controlled by others. Public discussions on ethical and legal issues at the end of life have proliferated against this background (Schneider, 2005). As in other countries, this has also led in Germany to statutory regulation regarding advance directives and related issues.⁸

Based on the patient's right to autonomy even if he is no longer able to express his own free will, enduring powers of attorney as well as proxies and patient advance directives are now of major importance in the field of palliative care.⁹ Determining and acting in accordance

⁸ Third Act amending the Guardianship Law dated 29 July 2009 (Federal Gazette I 2009/48) (http://www.gesmat.bundesgerichtshof.de/gesetzesmaterialien/16_wp/betraendg3/bgbl120092286.pdf; Status: 12 September 2014).

⁹ According to a survey, however, only 26 percent of respondents have actually drawn up an advance directive, although 43 percent have given the matter serious thought at some time (DHPV, 2012).

with the presumed will of patients with a congenital or acquired mental disability or those suffering from dementia or who are incapable of giving consent are decisive elements of palliative care. Ethical and legal issues also play an important role in relation to changes to therapeutic goals, e.g. withdrawing life-prolonging measures (Institute for Public Opinion Research, Allensbach 2010).

3.1.4 Charter for the care of the critically ill and the dying in Germany

At the end of a two-year working process which benefited from the input of more than two hundred experts, the *Charter for the care of the critically ill and dying in Germany* was presented to the public in 2010 (DGP et al., 2010). More than fifty organisations and institutions adopted the charter. In its five guiding principles, this document highlights the challenges facing social policy, lists the requirements to be met by care structures and at all levels of training, enumerates the development perspectives for research, and compares the standard of palliative care in Germany with that found in other European countries. More than 620 institutions have since signed the charter. Meanwhile, the document is being used as a basis for preliminary work on the development of a national palliative care strategy.

3.2 Regulatory sphere

3.2.1 Provision of care in Germany

Depending on where the patient lives, palliative care in Germany can be provided at various locations: in domestic surroundings, which might include ‘one’s own four walls’ or likewise a care home or residential unit,¹⁰ in hospital, or in an inpatient hospice. The palliative care provided at these locations is governed by a number of different statutory regulations.

In hospital, palliative care for inpatients can be provided on general or intensive care wards or in high-dependency or palliative care units.¹¹ According to the German Association for Palliative Medicine (DGP), in August 2012 there were around 240 palliative care units in Germany (DGP, 2012). These institutions are not all funded in the same way. Some have applied for recognition as ‘defined special services’ [besondere Einrichtungen] by the statutory health insurers and have negotiated per diem rates with these (DKG, 2011), whilst others are remunerated according to set case rates (DRGs) plus additional allowances (InEK, 2013). The services provided in the currently 195 inpatient hospices (DHPV, 2013), which include nine children’s hospices, are governed by Art. 39a of the German Social Code, Book V (SGB V).¹²

As far as outpatient services are concerned, Art. 39a SGB V describes the services of outpatient hospice facilities (which currently number around 1,500 [DHPV, 2013]). In addition, since 2007 the Statutory Health Insurance Competition Strengthening Act has regulated specialist outpatient palliative care (SAPV) in domestic surroundings together with Arts. 37b and 132d SGB V. The act provides the financial basis for the services to be rendered (Cremer-Schaeffer & Radbruch, 2012).¹³

3.2.2 Updating of legislation

Just as conditions surrounding the care of palliative patients have changed over recent years, so there has also been an updating of laws and regulations in order to fulfil the needs of recipients of such services. The regulations governing narcotics in particular have been adapted in the course of a multi-stage process, which culminated provisionally in the amendment

¹¹ High-dependency units are sometimes also referred to as intermediate-care units.

¹² Cf. Art. 39a SGB V (cf. Annex).

¹³ Cf. Arts. 37b and 132d SGB V (cf. Annex).

¹⁰ Cf. Art. 37b (1) SGB V (cf. Annex).

to Art. 13 of the Narcotics Act (BTMG) on the supply of narcotics in emergency situations (DGP & BOPST, 2012).

3.2.3 Legal and ethical principles

Treatment at the end of life is basically subject to the same regulations as treatment at any other stage of illness. Decisions on end-of-life treatment and the limitation of treatment are made within the context of palliative care. The limitation of treatment covers situations in which life-sustaining treatment is lawfully withdrawn or not given in the first place. This may occur if life-sustaining measures are not indicated or if the patient refuses his consent, as within the framework of an advance directive or by making a verbal statement to this effect. In such cases, the National Ethics Council suggests that the preferred terminology should be 'allowing to die' rather than 'passive euthanasia' (National Ethics Council, 2006, p. 51).

According to this terminology, the treatment provided at the end of life comprises all medical measures, including palliative care, which are taken during the last phase of life with the intention of alleviating suffering. It also includes measures which might possibly shorten the natural process of dying, such as the administration of a high dose of pain medication or deep sedation, without which it might not be possible to control distressing symptoms. The alternative term of 'indirect euthanasia'¹⁴, which is also in use, should be avoided, as the death of the patient is not the end objective of the action taken.

Killing on request (active euthanasia), on the other hand, is not a measure to be taken within the scope of medical treatment, but should be regarded as outside and independent of it.¹⁵ It is always prohibited pursuant to Art. 216 of the German

Criminal Code (StGB), even if it is committed by a physician and at the request of the patient (Lipp & Strasser, 2012).

Providing someone with medical assistance to commit suicide (physician-assisted suicide) is controversial from both a scientific and a legal standpoint. The philosophical and ethical argument is that as the patient has a right to self-determination, his autonomous will to end his life should be respected. The normative justification for doctors assisting their patients to commit suicide draws in addition on the ethical principle of seeking to do good (beneficence). According to this argument, assisting a patient to end his life when his suffering is extreme and untreatable might potentially be considered as one of the duties of a physician. Opponents of physician-assisted suicide point to the practical difficulties when it comes to verifying the patient's ability to make autonomous decisions and the authenticity of his choice. They further believe that tolerating physician-assisted suicide would, in practice, lead inevitably to killing with or even without a request to this effect being made by the patient (Schildmann & Vollmann, 2006). The legal opinion whereby a physician cannot be prosecuted either for failing to take action or for assisting a rational suicide is widely accepted in jurisprudence, although in practice it has not yet been recognised without reservation. Uncertainty also exists as to where to draw the line between 'voluntary' and 'involuntary' suicide; in the case of 'involuntary' suicide the physician must attempt to save the patient's life and can be prosecuted if he fails to do so (Lipp, 2009). There is currently a dispute on the issue of whether helping someone to commit suicide for commercial ends or in an organised way should be classified as a criminal offence¹⁶, and whether physicians should be prohibited by their professional code of conduct from assisting

¹⁴ Federal Court of Justice in Criminal Matters, judgment dated 15/11/1996, BGHSt 42, 301.

¹⁵ Federal Court of Justice in Criminal Matters, judgment dated 25/6/2010, BGHSt 55, 191.

¹⁶ Official document 17/1112 of the German Parliament dated 22/10/2012.

a suicide (Lipp & Simon, 2011). The German Medical Association (BÄK) states in its basic principles on the end-of-life care provided by doctors that it is not one of the professional duties of a physician to assist a suicide (BÄK, 2011). Both the European Association for Palliative Care (EAPC) and the DGP are of the opinion that killing on request and physician-assisted suicide cannot be part of the mission of palliative care (Materstvedt et al., 2003).

There is, however, no doubt that one of the responsibilities of a physician is to treat with respect a patient's desire for death – including, more specifically, his desire for suicide. First and foremost, this means discussing the palliative care options regarding relief of suffering with the affected patient, his family, and the other members of the care team, and attempting to find a joint solution (Nauck et al., 2014).

3.2.4 Recognising palliative care as a human right

Against the backdrop of the Universal Declaration of Human Rights, some groups argue that the right to physical and mental integrity includes the right to receive the appropriate palliative care (Open Society Institute, Equitas, 2009).

The Prague Charter urges governments worldwide to ensure that patients and their families can exercise their entitlement to access palliative care by integrating such care into healthcare policies, as well as by ensuring that access to essential medicines, including opioid analgesics, is assured (EAPC, 2013).

3.3 Technological sphere

Like all other patients, those receiving palliative care benefit directly from the development of new drugs such as pain relief medication (analgesics), as well as from the introduction and improvement

of therapeutic products and medical aids. Technological innovations can have a positive impact on palliative care, for instance by helping to fulfil the patient's desire to spend the last phase of life in his home environment. New technologies can prevent patients from being hospitalised, which contributes to cost savings. Such innovations can be particularly beneficial in the palliative care of children and adolescents who have very specific care needs. Since different service providers generally cooperate in the provision of palliative care, there is a need for them to be able to communicate smoothly within the respective care networks and to be supported by appropriate, needs-based technology with proper data protection safeguards.

3.3.1 E-health

A potentially considerable body of personal information relevant to patient health can be mined from data held by e-health structures¹⁷, in particular telemonitoring. This is all the more beneficial when, within the context of so-called personalised medicine, various digital patient data (including images, demographic data and test results) are gained from a wide range of electronic files. In terms of palliative care, an evaluation of such data can open up new, previously unexploited possibilities, e.g. the ability to gain an overview of the resources used during the last phase of life or to evaluate laboratory data (plasma protein) and computer tomograms (to assess muscle mass) to study how cachexia develops in the course of an illness.

3.3.2 Ambient Assisted Living

People whose lives are restricted because of mobility issues, sensory deprivation or poor motor skills can be helped to live independently with the aid of ambient

¹⁷ The term 'e-health' describes the use of information and communication technology to design, support, link and – ultimately – integrate all processes and participants in the health service. The term 'personal health' characterises a further stage of development which allows new types of person-centred, individualised forms of prevention, diagnosis, therapy and care to be used by incorporating domestic and mobile systems.

assisted living (AAL) systems. These enable palliative patients to live in their own homes for as long as possible, if they so desire. In recent years, a large number of AAL research projects have developed prototype solutions. Yet so far, there is no fully-operational market for AAL applications except in isolated domains such as emergency call systems for the home and audio/video communication. One important reason for this is that palliative patients usually suffer from more than one illness or impairment requiring treatment; indeed, they can be afflicted by numerous symptoms and health problems or restrictions which develop dynamically in the course of the illness and frequently interact with one another. Consequently, a suitably wide-ranging and expandable system is required to meet their particular set of needs.

3.4 Economic sphere

Average per capita health expenditure exhibits a particularly sharp increase during the final year of life, mainly due to hospitalisation (Brockmann, 2002; Federal Health Report, 1998; Nöthen, 2011). Studies and surveys show that palliative care measures have a reducing effect on costs, because the dying are not subjected to unnecessary therapeutic interventions, hospital stays can be avoided, and the patient's situation can be kept stable for longer by providing a comprehensive package of care, including non-medical care (Fassbender, 2005; Smith et al., 2012). In a Canadian analysis of existing information from administrative databases used by the health service, the costs for the final year of life amounted to \$ 10,421 for patients receiving palliative care and \$ 19,729 for those in receipt of conventional care (Hollander, 2009). Israel reported costs of \$ 4,761 for those receiving inpatient hospice care as opposed to \$ 12,434 for those in receipt of conventional care, which generated higher costs

mainly because of the higher number of hospital admissions (Shnoor et al., 2007). Following the introduction in Catalonia of the nationwide provision of palliative care, the cost of treating each cancer patient was reduced by EUR 2,250 (Paz-Ruiz et al., 2009).

Health economic analyses at a European level have come to the conclusion that palliative care can reduce costs in the health service (Moreno et al., 2008). This is particularly the case when the recipients of the palliative care are children and adolescents (Gans et al., 2012; Fassbender et al., 2005).

Because of the high level of resources required by patients, funding for inpatient palliative care cannot adequately be met by charging flat rates per case. Institutions such as palliative care units, which as a rule treat critically ill patients, are at a disadvantage in a system where calculation is based on average costs. That is why in Australia, for instance, a system of budgeting based on level of complexity was developed, which took the progression of an illness into account when allocating funds. In Germany, palliative care units still have the option today of applying for recognition as 'defined special service' and charging per diem rates. This makes it possible for treatment to be more needs-based than otherwise, rather than determining how long treatment should last so as to optimise the flat-rate-per-case payments. However, the political will is for all palliative care units to charge flat rates per case. Moreover, where outpatient care is provided by GPs, there is no system for paying fees for psychosocial support services, nor for funding bereavement services, which is an important preventive measure in terms of subsequent potential health effects on the bereaved.

It is generally the case that many areas of palliative care are unable to cover their costs. Such a care system is often only

able to operate by virtue of civic involvement through volunteering, or through donations and the work of foundations.

3.5 International context

3.5.1 Palliative medicine internationally

From its origins in Great Britain, the hospice idea spread rapidly through the English-speaking world; in 2010 in the USA, for instance, there were 4,700 hospice programmes treating 1.4 million patients and 1,300 palliative care programmes in hospitals (Foley, 2010).

The rate of expansion in Europe has proceeded at a speed comparable to that seen in the USA. Thus, the last few years have witnessed the establishment of professional associations and of palliative and hospice services in many European states.¹⁸ The European Parliament is examining how guidelines and recommended actions for the healthcare policies of its member states can be formed from the model projects completed in the area of palliative care (Moreno et al., 2009; Moreno et al., 2008). However, there are significant differences within the European Union (EU) when it comes to standards of care (cf. Fig. 1). Only a few countries have statutory regulations and an entitlement to specialist outpatient palliative care (SAPV) equal to that offered in Germany. In eastern European countries, the dynamic with which some palliative care strategies and structures are being developed is impressive. One such example is Romania, which is working on a national strategy for palliative care and has established a training centre for palliative care in Braşov, a reference centre for eastern and southern Europe (National Strategy for Palliative Care Romania, 2012).

3.5.2 Germany's position in comparison with other countries

A wide-ranging study in 2010 examined the quality of death in forty countries around the world (Economist Intelligence Unit, 2010). The criteria by which quality of death was evaluated were the existence of basic healthcare at the end of life, access to specialist end-of-life care, and the costs and quality of such care.¹⁹

While Great Britain was the clear leader, many highly developed countries found themselves ranked relatively low. Germany was in eighth position overall, behind Austria and the Netherlands but ahead of Canada and the USA. It scored well on the provision of basic healthcare at the end of life, but did less well when it came to the opportunities for accessing specialist end-of-life care. The costs of specialist care in Germany were comparatively low, while in terms of the quality of care, it occupied eighth place behind Great Britain, Hungary, the USA, Austria, Poland and the Czech Republic. As far as the two criteria on which Germany did less well were concerned – access to and the quality of specialist end-of-life care – the experts have come to the conclusion that good palliative care requires initiative and support from the highest echelons of government, and that basic and advanced training will have to be intensified with the focus on outpatient care.

An inner-European comparison by the European Parliament in 2007 came to a similar conclusion; the study awarded Great Britain the top ranking in Europe and also assigned Germany to eighth place (Moreno et al., 2008).

This situation is also reflected in the fact that at international level, it is predominantly Great Britain, or occasionally

¹⁹ These criteria were given different weightings in the study: quality accounted for 40 percent of the total score, access for 25 percent, basic healthcare for 20 percent and costs for 15 percent.

¹⁸ <http://www.eapcnet.eu> (Status: 12 September 2014).

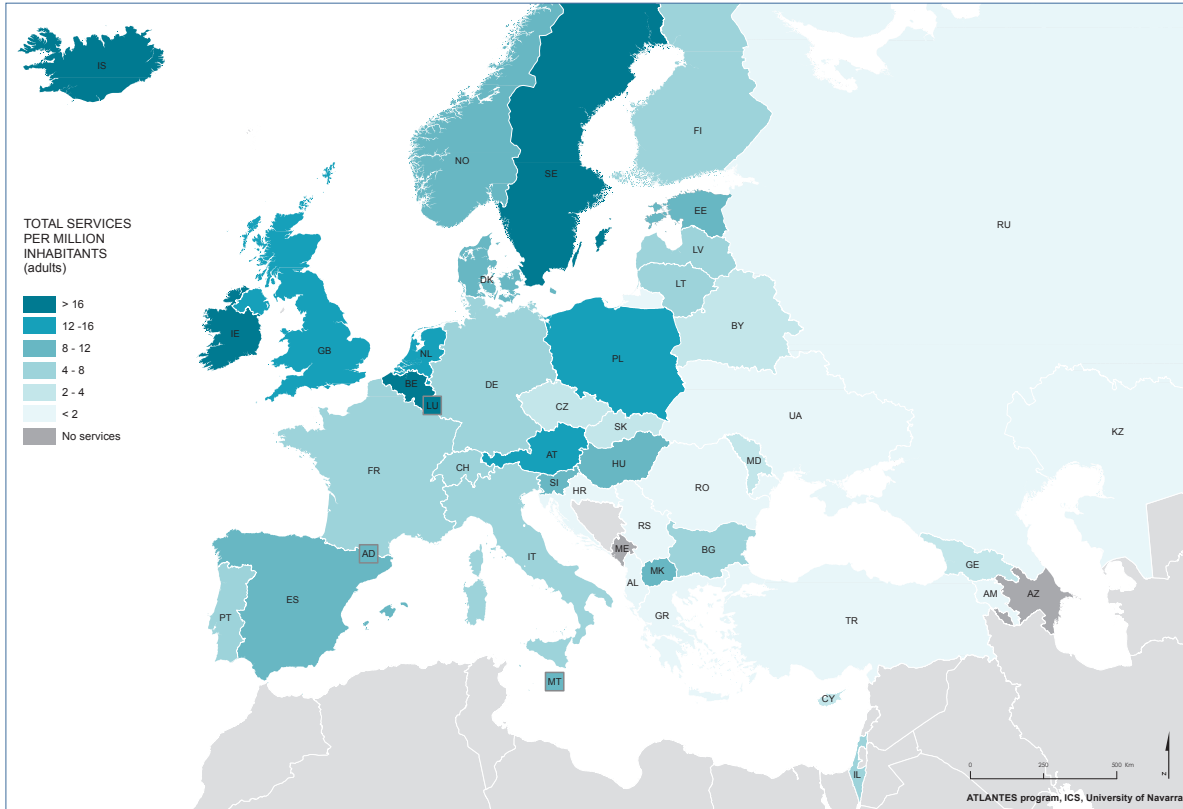


Fig. 1: Palliative and hospice services per million inhabitants in the European Region of the WHO (Centeno et al., 2013)

Ireland, Norway or Romania, which sets the standards and provides examples of best practice, but not Germany.

At European level, German palliative care physicians demonstrate their international commitment and professional expertise by participating, for instance, in a large number of research projects and consortia. Nonetheless, developments in Germany have remained almost unnoticed in other countries. That is true of our clinical care, our teaching, and also our research. One of our goals for the years ahead should be to raise our country's international profile in the field of palliative medicine and care, just as we have already succeeded in doing in areas such as pain management.

3.6 Conclusion

Demographic changes mean we can anticipate a sharp rise in the number of patients requiring palliative care in the years

ahead. Statutory and regulatory requirements in the recent past have been shaped in such a way as to make such care possible. Yet compared with other countries, Germany is only in the middle field when it comes to palliative care.

The targeted expansion of care is necessary; we should also take advantage of modern technology such as telemonitoring and ambient assisted living. Such a further development of the palliative care system can be expected to result in cost savings by providing us with an opportunity to avoid end-of-life treatments which are no longer indicated.

4 Structures

4.1 Service providers

Palliative care in Germany is provided at different levels: by GPs and physicians specialising in this field in the home or in residential care facilities, for example. Care is also provided by outpatient palliative and hospice services and teams in the home environment as part of a package of specialist outpatient palliative care (SAPV), although not in all federal states. Care may also be provided elsewhere, such as in inpatient hospices or in hospital (in palliative care units or other departments). Palliative care should be made available at different levels. Only a small number of patients with life-threatening medical conditions require specialist palliative care and the involvement of a specialist palliative care team. The majority of patients are in need of general palliative care, which is provided by those primary care suppliers (GPs and nursing care services) and specialists (oncologists, geriatricians, etc.) who treat patients with life-threatening diseases and have good fundamental knowledge and good basic skills in palliative care (Radbruch & Payne, 2011).

4.1.1 Outpatient palliative care

General outpatient palliative care (AAPV): AAPV can be provided within the contractual healthcare system by any accredited doctor in accordance with current regulations. However, they should have acquired a basic qualification in AAPV. AAPV can also be provided by outpatient nurses with a basic qualification in palliative care. For most of the patients in need of palliative care, AAPV provides perfectly adequate support.

Hospice services: The support provided by volunteer staff to people with incurable and life-threatening conditions and their families is an important feature of outpatient hospice work. Hospice services are provided primarily in the home environment (either as AAPV or as SAPV), but they can also be supplied in hospitals, care homes or inpatient hospices. The volunteers take on a wide range of practical support services which are intended to make it easier for those affected to cope with day-to-day concerns as they experience the existential crisis associated with the end of life and approaching death. Paid staff coordinators support and assist the volunteers in their work and may also take responsibility for coordinating other palliative care services, depending on the organisational level and the supply structure of the hospice service.

Specialist outpatient palliative care (SAPV): In accordance with statutory health insurance agreements, patients with incurable and life-threatening diseases have a legal entitlement to SAPV if AAPV is no longer able to meet their needs, regardless of whether they live in a home environment or in a residential care facility (G-BA, 2010). The main services offered under SAPV are specialist advice on palliative medicine and care and/or the care itself, up to and including the comprehensive management of support based on the patient's individual needs. The teams work closely together with other service providers (such as community-based doctors, nursing services, hospitals, residential care facilities, hospice services and pharmacies). The involvement of other professional groups such as

social workers, psychologists, religious/spiritual counsellors and physiotherapists by the SAPV teams is not generally covered by health insurance funds. Special features of the care offered to children and adolescents were outlined by the National Association of Statutory Health Insurance Funds in 2013 (GKV-Spitzenverband et al., 2013).

SAPV is implemented differently from one federal state to another (Jansky et al., 2011). Cross-sectoral care models are currently the exception rather than the rule. Nationwide availability of care by SAPV teams is not yet ensured (G-BA, 2011).

4.1.2 Inpatient palliative care

Inpatient hospices: Inpatient hospices are independent facilities which ensure that people with incurable, life-threatening diseases receive palliative care where such care cannot be provided in the home environment.²⁰ Inpatient hospices are institutions with a family-like atmosphere, which are generally part of a networked care structure within the regional health and social welfare system. Children's hospices have an extensive trans-regional catchment area, which means that planning has to be managed at national level. Medical care is provided within the contractual healthcare system by an accredited GP or by a physician specialising in this area of healthcare (with a sub-specialisation in palliative medicine).

Palliative care units: Palliative care units are independent specialist institutions integrated within a hospital to care for people with incurable and life-threatening conditions. The objectives of treatment are to improve or stabilise the condition of individual patients, to improve their quality of life, and to discharge them eventually, if possible to their

own homes. Palliative units are wards or areas of wards which are designed to be as homely as possible.

Hospital palliative care support teams: The multi-professional and sometimes also inter-institutional services, which have been established in the field of palliative medicine, are becoming an increasingly important aspect of hospital care. These services consist of teams of doctors, nurses and other professional groups and provide appropriate palliative care in other hospital wards, too (EC, 2004). They frequently assume responsibility not only for pain therapy and symptom control, but also for managing the patient's discharge from hospital.

4.1.3 Palliative care networks

The network of service providers in the field of palliative care is constantly expanding, but has not yet reached all parts of Germany, and its density varies from one region to another. There are considerable gaps in provision in rural areas. This is particularly true in the case of outpatient palliative care. The catchment area for outpatient service providers in rural areas can be enormous. In terms of SAPV for children and adolescents, patients may often live more than 100 km away from the team providing treatment (GKV-Spitzenverband, Verbände der Krankenkassen auf Bundesebene, DGP & DHPV, 2013). In addition to this deficiency in coverage, there is an absence of criteria by which to evaluate the quality of the networks.

4.2 Funding agencies

The services are funded by – and their performance is in many cases evaluated by – statutory and private health insurance funds, the civil servants' welfare scheme, statutory and private nursing care insurance funds, employers' liability insurance associations and statutory ac-

²⁰ Hospices catering specifically for children and adolescents also provide additional services such as respite care for parents and day care facilities for siblings.

cident insurance funds, personal liability insurance schemes as well as local authorities (social services departments). They are not proactive; an application must first be submitted.

While there is no question that medical and nursing-care measures are among the palliative care services paid for by the funding agencies, there are no blanket regulations governing the important area of psychosocial care, with the exception of outpatient services covered by Art. 39a SBG V. Payment for many such services is currently inadequate or even non-existent. This leaves service providers facing the dilemma of being unable to reconcile the discrepancy between the ethical entitlement of the patient to comprehensive care and the financial feasibilities.

4.3 Recipients of the services

Palliative care measures are targeted at people with an incurable, life-threatening condition and their families.²¹

While cancer patients currently make up by far the majority of those receiving palliative care, it is becoming ever more important – in a society where chronic illness is increasingly prevalent – to open up access to palliative care to other patient groups too. Examples of disease entities requiring palliative care include severe chronic pulmonary diseases, chronic renal and cardiac diseases, and serious neurological conditions, such as ALS, MS, Parkinson's disease and dementia. There are also complex geriatric conditions. Particular attention should be paid to patient groups which are less prominent in the public perception, such as AIDS sufferers (Cremer-Schaeffer & Radbruch, 2012).

4.3.1 Children, adolescents and young adults

Paediatric palliative patients suffer from a large number of sometimes very rare conditions. Their age-span ranges from premature babies to infants, children of primary school age, adolescents and young adults. Many patients are unable to communicate verbally. The broad spectrum of underlying illnesses and stages of development concerned explains the very wide range of syndromes, complicated treatment plans and individual care structures (MAGS, 2009).

4.3.2 People from a migrant background

In Germany in 2011, 19.5 percent of the population came from a migrant background (Federal Statistical Office, 2012b). As a result, there is a corresponding rise in the number of people from a migrant background in need of palliative care. The first generation of so-called 'guest workers' has now reached the age where serious illnesses occur more frequently than earlier in life. When it comes to the care of children and adolescents too, the number of those who come from or have close ties with a different cultural background is increasing. Cultural differences and the specific attitudes to issues of life and death or to patient information and autonomy, which are associated with these, present challenges to service providers in the field of palliative care. This applies particularly when it comes to supporting families; patients and their family members might have very different views of family life, depending on their gender and because of generational differences. In such cases, service providers must exhibit a particularly high level of cultural sensitivity and good communication skills (Grammatico, 2008).

4.3.3 People with mental disabilities and with dementia

It is only relatively recently that international scientific publications have addressed the subject of palliative care for people with mental disabilities (Friedman

²¹ There is of course a degree of overlap between the following groups to which no further reference is made here.

et al., 2012; Morton-Nance & Schafer, 2012; Tuffrey-Wijne, 2012). There has been a marked increase in the number of projects and publications in the field of dementia diseases. Apart from numerous studies on the measurement and treatment of pain, the palliative medicine approaches adopted in the case of patients with dementia who exhibit pronounced behavioural changes or psychological symptoms have barely attracted the interest of researchers, despite the fact that these often coexist with severe cases of dementia (Passmore et al., 2012; Byrne et al., 2006).

4.3.4 The aged and patients with multimorbidity

In order to ensure that the rising number of old and oldest patients receive suitable palliative care provision, it is essential for it to be made available in nursing homes.²² In North Rhine-Westphalia, a state-wide palliative care strategy was drawn up for nursing homes (MGEPA, 2014). The occupants of nursing homes should have access to the same satisfactory level of palliative care as people living in their home environment or in hospitals. While a number of homes already offer palliative care as part of their care package or at least consider doing so, other funding agencies and institutions have done little or nothing about the matter. Who bears responsibility for the aged and patients with multimorbidity is a matter that still requires clarification in some respects. Geriatrics, gerontopsychiatry and palliative care can make reasonable contributions to improving the quality of life of such people where indicated. If this area is to function effectively, unambiguous clarification is required about the respective areas of responsibility.

²² The DGP and DHPV professional associations have published a policy paper on the development of hospice culture and palliative care in geriatric nursing homes (DHPV & DGP, 2012).

Service providers who care for very old persons or those with multimorbidity require specialist skills, for instance in the area of communication and in dealing with ethical issues such as nutrition (e.g. the provision or withdrawal of artificial feeding).²³

4.4 Interest groups

Various interest groups and specialist associations as well as self-help organisations have played a significant role in public discussions, research activities and endeavours to advance the field of palliative care in Germany. Other important stakeholders include the German Medical Association and the State Chambers of Physicians, Associations of Statutory Health Insurance Physicians, and the umbrella organisations of welfare associations. Self-help organisations represent the interests of individual patient groups or families (patients with ALS, family caregivers, bereaved parents, etc.). On a political level, it is the federal and state ministries, regional and local authorities, town councils and municipalities that are providing the stimulus for the further development of palliative care.

Some of these interest groups set important standards. Yet the systematic involvement of all the relevant interest groups in development and decision-making processes has proved the exception rather than the rule across the board in the field of palliative care.

4.5 Conclusion

Whilst there is now greater palliative care provision than before for cancer patients in Germany, there has not yet been any successful expansion of such care to oth-

²³ The German National Academy of Sciences Leopoldina has prepared a joint statement on this area of concern with other parties.

er patient groups (e.g. those with chronic kidney, heart or lung conditions).

It is particularly important to develop suitable care strategies for patients with dementia, the aged and those with multimorbidity that can also be implemented in nursing homes.

Likewise, strategies should be developed which provide palliative care suited to the needs of people from a migrant background.

Gaps in the provision of palliative care, which exist primarily in rural areas and in services for children and adolescents, should be addressed by making needs-based care more widely available.

5 Quality and qualifications

Qualifications for those working in palliative care are an established feature of basic and advanced training schemes. The necessary specialist skills and palliative approach with its goals and value orientation are taught and promoted at all levels of training for professional service providers and in skills courses for voluntary helpers. The scope of training options for professional helpers ranges from palliative medicine as a cross-disciplinary subject for medical students and trainee nurses to instruction for counsellors on advance directives and for helping assess the probable wishes of the patient.

5.1 Training

The first systematic recommendations on training in palliative medicine to appear in Germany were published in 1996 with the *Curriculum Palliativmedizin. Für Medizinstudenten und Ärzte in Palliativmedizin (Palliative medicine curriculum. For medical students and doctors practising palliative medicine)* (Hecker, 1996; Cremer-Schaeffer & Radbruch, 2012). When the Medical Licensure Act was amended in 2009, a qualification in the cross-disciplinary subject of palliative medicine became compulsory. Since 2013, students are only admitted to their practical year if they have such a qualification, and since 2014, every medical student who wishes to be licensed must have a knowledge of palliative medicine. Classes on the subject are presently an integral part of student training curricula at universities. However, there are no nationwide regulations on the minimum number of hours or on the standard of content for training courses in

palliative medicine.²⁴ The first initiatives towards achieving a broadly coordinated development of teaching content are appearing at both national and European level, such as in the Munich Declaration on the new cross-disciplinary area of palliative medicine (Dietz et al., 2011) and in the Athens Resolution of the European Medical Students' Association (EMSA, 2008).

Art. 3 of the Nursing Act (KrPflG) has referred to palliative measures as being part of the training curriculum since 2003.²⁵ Palliative care is also covered by the examination regulations for nursing. In Art. 3 No. 6 AltPflG (Geriatric Nursing Act), providing wide-ranging support for the dying is one of the specified targets of training. Although this objective may encompass palliative care measures, there is not yet any standardised training for palliative caregivers.

5.2 Additional qualifications

The sub-specialisation in palliative medicine was incorporated in the (Model) Specialty Training Regulations of the German Medical Association (BÄK, 2013)²⁶ in 2003, and this was initially adopted virtually in its entirety by the State Cham-

²⁴ Something in the region of forty teaching hours might be conceivable, for instance (Dietz et al., 2011).

²⁵ Act on Nursing Professions and amendment to other acts dated 16 July 2003. Article 1 contains the Act on Nursing Professions (KrPflG). Reference is made here to Art. 3 Para. 2 Federal Law Gazette I 2003/36.

²⁶ This additional training entitles specialist doctors who have already qualified to obtain a sub-specialisation in palliative medicine by completing a 40-hour training course in palliative medicine followed by 120 hours of case study seminars including supervision.

bers of Physicians.²⁷ The German Medical Association and the DGP published a curriculum for physicians signing up for this additional training (BÄK & DGP, 2011, based on BÄK & DGP, 2004). Some six thousand physicians have since obtained the qualification (Nauck, 2011). Similar qualifications have to date been introduced in roughly twenty countries around the world. Only in a few countries, such as England and Ireland, does palliative medicine have a specialty status.

The first basic palliative care curriculum in the area of nursing was published back in 1996, and remains a basis for training today (Kern et al., 1996). Courses accredited by the professional associations require 160 hours of training and must comply with the requirements of Art. 39a SGB. These courses provide quality-assured training which is largely standardised and could become the basis for a state-recognised training qualification in nursing care. Some 16,500 individuals have completed advanced palliative care training so far.²⁸ Curricula have also been published for professional groups working in the fields of psychosocial care and physiotherapy (Gisbertz et al., 1999; Uebach, 2004).²⁹ A separate curriculum has been drawn up specifically for paediatricians (Kaldirim-Celik et al., 2013).

5.3 Quality assurance

As equal partners in the healthcare system, hospice and palliative care services must set themselves the same challenges vis-à-vis quality management. It goes without saying that the quality requirements which are standard in other fields

in terms of structure, processes and outcomes cannot be applied automatically to hospice and palliative care; allowance must be made for the distinctive features of such services.

The creation of a well-founded database is an important prerequisite for ensuring that quality standards are met in palliative care. Models are currently being developed to collect reliable data from the healthcare sector with due consideration for palliative care.

Hospice and Palliative Care Evaluation (HOPE) is a documentation and quality assurance instrument which has been undergoing a continuous process of development and validation since 1999, and which conducts an annual benchmarking³⁰ study of participating institutions (Stiel et al., 2012).³¹ Data on the provision of palliative care for more than 20,000 patients has since been documented. Many palliative care facilities, such as palliative care units, inpatient hospices and outpatient hospice services, use this system as an external quality assurance instrument and for benchmarking.

The National Hospice and Palliative Care Register collates patient-related data from the day-to-day provision of hospice and palliative care across regions, professions and sectors at least once a year for a minimum random sampling period of 3 months and a sample size of 30 patients.³²

²⁷ In Hamburg, the sub-specialisation palliative medicine also requires a practical element of the training to be completed at a teaching institution. The qualification can also be obtained by working for 12 months with a qualified instructor in palliative medicine.

²⁸ Database of the Palliative Care Centre in Bonn; report by Martina Kern, April 2013.

²⁹ Cf. also: <http://www.dgpalliativmedizin.de/sektionen/sektion-psychologie.html> (Status: 12 September 2014).

³⁰ The term 'benchmarking' is used here to describe a continuous process which compares the quality of care supplied in one's own institution with that available in other facilities on the basis of a preselected checklist of quality indicators. Its findings are based on the documentation of care service providers.

³¹ Cf. <https://www.hope-clara.de> (Status: 12 September 2014). This is a project which is being conducted jointly by the DHPV, the German Cancer Society and the DGP.

³² Cf. <http://www.hospiz-palliativ-register.de> (Status: 12 September 2014).

5.4 Conclusion

National specifications have now been formulated which apply to basic and advanced training courses for physicians, although their implementation varies considerably between universities and federal states. It is essential that an agreement be reached on common standards of quality applicable to the practical implementation of these medical teachings.

In the meantime, quality assurance structures such as the National Hospice and Palliative Care Register have now been created which make it possible to ensure that high standards of quality are met throughout Germany. However, participation in these optional quality assurance measures remains low. Consequently, incentives should be introduced to encourage participation; service providers could, for instance, include relevant clauses in palliative care contracts.

Improving quality assurance will at the same time supply an important body of information for health service research in palliative care.

6 Research structures

Palliative medicine research structures have been permanently established at only nine of the 36 university medical institutions in Germany.³³ They have limited resources at their disposal in terms of both personnel and funding, with the result that only slow progress is being made at these centres towards the advancement of research into palliative medicine.

No permanent resources are available at the majority of medical faculties (27) for research into palliative medicine. Individual research projects into palliative medicine have, however, been initiated by other departments and disciplines, such as general medicine, anaesthesiology and psychosomatic studies.

Funding programmes designed specifically to promote research into palliative medicine are not well developed in Germany. Since the early days of palliative medicine, German Cancer Aid has funded pilot projects on clinical care (and provided start-up financing for the majority of chairs in palliative medicine) as well as sponsoring research projects on issues related to palliative medicine. However, research funding from German Cancer Aid is meant for clinical applications, and is approved only for studies on cancer patients.

German Cancer Aid now funds twelve top oncological centres. Although the clinical care provided by these centres

has to include palliative medicine skills, the funding programme does not specifically support research into palliative medicine.

The Robert Bosch Foundation has funded a number of pilot projects in recent years aimed at improving clinical palliative care, as well as providing financial support for continued professional development. However, it has funded only a small number of research projects.

In September 2012, the Federal Ministry of Education and Research (BMBF) initiated a round of funding for its 'healthcare research' action plan as part of the Federal Government's framework programme on health research. Its invitation to tender emphasised issues of patient safety and quality of life, and the funding guidelines outlined the particular need for research aimed at improving the quality of patients' lives in the fields of palliative medicine and pain management.

To date, there are no specific funding programmes in Germany for research in the field of palliative medicine. In the EU's Seventh Framework Programme for Research, a call was published in 2012 on the subject of health innovation in the 'Cooperation' activity area to promote investigator initiated studies [IIT] and observational studies on supportive and palliative care (EC, 2012). Although a few individual German centres are represented in EU-funded projects and in other international networks,³⁴ there is not a single independent German research association.

³³ There are currently eight professorships in palliative medicine at medical faculties in German universities: in Aachen, Bonn, Cologne, Erlangen, Freiburg, Göttingen, Mainz and Munich. There are also two professorships in paediatric palliative medicine at Witten-Herdecke and Munich as well as two other professorships in palliative medicine – specialising in spiritual care and social work respectively – in Munich.

³⁴ <http://www.eapcnet.eu/Themes/Research/ResearchProjects.aspx> (Status: 12 September 2014).

7 Research agenda

7.1 Needs and priorities

Even if it is no longer possible to cure a patient of his highly advanced, life-limiting disease, he is still entitled to receive the best possible treatment. Consequently, palliative medical treatment needs research in order to identify the best possible therapeutic options and to improve upon them, as well as to create a better understanding of the situation in which the dying find themselves.

Research into palliative medicine is necessary in order to identify new approaches (e.g. in the treatment of fatigue or weakness), to compare existing therapeutic options (e.g. in opioid therapy), and to gain a better understanding of the problems which arise, so that new solutions can be developed on the basis of these insights (such as how to respond to a patient's wish to die).

An important distinction is that contrary to non-terminal illnesses, where efficiency targets are largely defined on the basis of objective parameters, in palliative care it is the individual subjective perspective of the patient which is most important. This must be suitably reflected in the research.

Because of the comprehensive nature of palliative care, a very broad-based interdisciplinary research approach must be conceptualised and a range of different research paradigms utilised. As a consequence of this, appropriate use must be made of research methods from the social sciences and humanities in addition to biomedical research methods. A professionally

sound spectrum of biomedical and social science research designs as well as qualitative and quantitative methods are required if different issues are to be adequately responded to. Mixed method studies³⁵ are also essential, because different dimensions are relevant at the same time as far as the object of the research is concerned, especially in the case of complex interventions.

This broad approach requires a research agenda in which the questions to be answered and the methods to be used are placed in a framework oriented on the patients and their needs and requirements.³⁶ An initial set of research priorities from the perspective of experts in the field of palliative care was compiled in a European survey, which described the treatment of pain, fatigue and cachexia (emaciation), assessment tools, and the final days of life as research priorities (Sigurdardottir et al., 2012).

The aim of palliative care is to maintain or restore the best possible quality of life for patients. As a result, the subjective perspective of the patient is of paramount importance when conducting research into palliative medicine. As well as examining his existing needs, it is particularly meaningful to study what a patient and his family regard as important to them. Ultimately, patients, their families and relatives should be involved at every stage of research so that the focus continues to be on the patient's perspective. The British Cancer Ex-

³⁵ Mixed methods describes the combination of different epistemological positions (http://obssr.od.nih.gov/scientific_areas/methodology/mixed_methods_research/index.aspx, Status: 12 September 2014).

³⁶ This was highlighted in the *Venice Declaration* and elsewhere (IAHPC & EAPC, 2006).

periences Collaborative (CECo) has made such involvement possible in recent years; this enabled patients to act in an advisory capacity when studies were planned and conducted, later to contribute their own research proposals (e.g. on friendship in cancer) and eventually even to plan their own studies (NCRI, 2011).

7.2 Basic biomedical research

Basic biomedical research is of considerable importance if we are to make further advances in controlling the symptoms which affect the critically and terminally ill.

The most prevalent symptoms – anxiety, dyspnoea (shortness of breath), nausea and pain – are associated with a high level of suffering for the patient (Lindqvist et al., 2013). In many cases, those providing treatment do not recognise fatigue as being particularly distressing, or take it seriously (Radbruch et al., 2008). However, insufficient research has been carried out into the precise pathophysiological basis for these symptoms. If we are to be able to alleviate them more effectively, basic biomedical research will have to be targeted on this specific area.

7.2.1 Current state of research

Molecular mechanistic pain research is on the threshold of rapid development. Firstly, the molecular structures of the target molecule with atomic resolution are being described increasingly on the basis of X-ray structure analyses. For instance, in 2012 it became possible to model and analyse thermodynamically a key molecule of the hereditary pain syndrome erythromelalgia, and to gain an understanding of why certain pharmaceuticals were more effective than others.³⁷ Similar results are anticipated from the structural analysis of the four opiate receptors (Filizola & Devi,

2012). Secondly, these high-resolution structural analyses of the key molecules which receive, transmit and process pain signals should be seen in the context of the latest gene sequencing method, namely ‘next generation sequencing’ (NGS). This represents an advance towards achieving personalised medicine, which might make it possible, for instance, to select the opioid best suited to treating an individual patient’s pain on the basis of his genome.

As far as research into the principles of pain medicine is concerned, the greatest progress has been made in the development of antibody treatments. These target the nerve growth factor and/or its receptor TrkA. However, these procedures are not without side-effects (such as joint problems), and therefore require further refinement.

In comparison with the basic research being conducted into pain, research into other symptoms is still at a rudimentary stage. The number of publications in PubMed³⁸ on ‘palliative’ in association with one of these other symptoms highlights the level of imbalance that exists: ‘palliative and pain’ (11,516 citations) appears much more frequently than ‘palliative and anxiety’ (1,099), ‘palliative and dyspnoea’ (1,338), ‘palliative and nausea’ (1,203) or ‘palliative and fatigue’ (887). There has been detailed literature available on the origin of the symptom of pain for more than fifty years; current examples include works by McMahon et al. (2013) and Baron et al. (2013). Much the same is true of the symptom of anxiety. This is not the case for other symptoms relevant to palliative medicine such as nausea and dyspnoea (shortness of breath) (Simon et al., 2012b; Benze et al., 2012a; Benze et al., 2012b). Thus, there

³⁷ The condition is associated with an ion channel mutation (Na(V)1.7) (Yang et al., 2012).

³⁸ PubMed is an English-language text-based meta-database of all the life sciences and biomedical articles contained in the United States National Library of Medicine (NLM) (<http://www.ncbi.nlm.nih.gov/pubmed>, Status: 12 September 2014).

are rational grounds for giving fresh impetus to the pursuit of basic research on these symptoms without, however, reducing the level of support for basic research into pain and anxiety, as these symptoms can also develop into distinct disease entities of considerable clinical relevance.

7.2.2 The state of research in Germany: an international comparison

Germany has a well-respected tradition in the field of medical and pharmacological pain research, and is ranked highly at international level. Based on the number of publications in the leading journal *PAIN*, German pain research is in second place after the USA and ahead of Canada and Great Britain. Certain technologies (X-ray structural analysis and NGS, as well as basic neurobiological research) are available at an advanced level in Germany. The country also has a high international reputation for its research into the physiology of respiratory regulation (Richter & Spyer, 2001).

There is no noteworthy expertise either in Germany or in any other country in terms of basic research into other symptoms. There is an absence of cooperative ventures between clinical palliative medicine working groups and existing oncological researchers on the study of nausea or cachexia.

7.2.3 Themes and subject-matter requiring further development

Nausea and dyspnoea are particularly promising areas for basic research. There

are many pharmacologically-based approaches for the treatment of nausea, but the clinical evidence for anti-emetics (anti-nausea drugs) is weak (Davis et al., 2010; Benze et al., 2012a; Benze et al., 2012b). Several signal transduction pathways can contribute to the development and treatment of nausea (cannabinoids, opioids, dopamine, serotonin, transient receptor potential (TRP) channels, etc.). There is a shortage of good animal models required to enable us to make the transition from basic to clinical research. Dyspnoea can be treated symptomatically with opioids and anxiolytics (drugs that inhibit anxiety). A solid basic research has already been conducted into both classes of drugs, and this will enable future research to branch out into the specific field of palliative medicine for the treatment of dyspnoea.

In terms of human experimentation, research into the processing of pain signals (Klein et al., 2005) should be accompanied by research to identify human surrogate models of dyspnoea or nausea, e.g. through the use of functional imaging.

Other possible areas for basic research in the field of palliative medicine are cachexia (emaciation) and fatigue. The development of animal models and human surrogate models is essential if research into the causes and, more especially, the progressive course of such symptoms is to be carried out in a more differentiated manner. In this area too, a robust set of basic research results is

Catalogue of topics for basic research

- Expand research programmes on the neurobiology of pain to incorporate aspects of palliative medicine
- Expand research programmes on the neurobiology of anxiety to incorporate aspects of palliative medicine
- Basic research on other relevant symptoms (dyspnoea, nausea, cachexia, etc.)
- Research on drug therapy for rare indications and in fields where only small numbers of cases are anticipated (orphan drug programmes)

available – for instance, on the influence which the various cytokines have on the development and maintenance of cachexia (Fearon et al., 2012; Laviano et al., 2012) – on which it would be possible to build up basic research focusing specifically on palliative medicine.

7.3 Clinical research, methodology, translational research

7.3.1 Current state of research

The level of clinical research in palliative medicine is negligible in comparison with other fields of medicine (Kaasa & Radbruch, 2008). Barriers are often found among the care staff: the predominant guiding principle in palliative care is characterised by benevolence and compassion, and this emphasis on empathy often results in rational questions such as ‘Why’ or ‘What is better?’ appearing subordinate or negative. As a result, research projects are viewed with mistrust, because they do not appear to be in conformity with their guiding principles. Some of the professional groups involved in palliative care are less ‘research-oriented’ than physicians as a result of their training background (e.g. nursing staff, social workers and physiotherapists).

There are constant complaints about a lack of evidence (Nauck & Radbruch, 2012). Even international research associations rarely conduct clinical studies (Klepstad et al., 2011). It is difficult from a methodological viewpoint to conduct intervention studies with recipients of palliative care, as only a small number of patients are treated at each individual centre, and the attrition rate is high for those with advanced disease progression (Jordhoy et al., 1999).

There is even a lack of clinical studies in the area of cancer pain relief. The breakthroughs in basic research on pain as described in Chapter 7.2 are not being transformed into new forms of treatment.

In 2011 and 2012, sixteen new analgesics were licensed by the US Food and Drug Administration (FDA),³⁹ not one of which had a new drug target or a new mechanism of action. Without exception, they were reformulations of existing drugs.

As a supplement to and an ongoing extension of rigidly symptom-oriented palliative medicine treatment, an attempt is being made in the field of oncological research to make a scientific analysis of a causal oncological palliative therapy, the aim of which is not to obtain a cure but to prolong life or alleviate symptoms. Recent findings about how little benefit is derived from oncological palliative therapy by patients with a low life expectancy reinforce the call for an early integration of palliative medicine. However, there is an overlap here between the issues addressed by clinical research in the field of palliative medicine and the research into oncological supportive therapy. Independent studies conducted on issues relating to palliative medicine are rare.

To date, only very little independent clinical research on palliative patients with diseases other than cancer has been performed. In regions with a higher proportion of HIV/AIDS or TB patients, an increasing number of intervention studies are being published, e.g. on the use of androgens for fatigue (Thiem et al., 2012). Only isolated intervention studies have been published on issues relating to palliative medicine for patients with advanced lung, heart or kidney diseases, or for patients with life-threatening neurological diseases.

7.3.2 The state of research in Germany: an international comparison

While Germany’s oncological research occupies a respected position in international research networks, the country’s research into clinical palliative medicine is still in its infancy.

³⁹ <http://www.painresearchforum.org> (Status: 12 September 2014).

In Germany, but also internationally, published efficacy data on the control of many symptoms with or without drugs in accordance with the rules of good clinical practice (GCP)⁴⁰ are the exception rather than the rule. There are a number of methodological, but also ethical reasons for this (reservations about conducting research on critically and terminally ill people, divergent therapeutic goals, problems relating to informed consent at the end of life or with retrospective research methods, inclusion and exclusion criteria in drug trials, etc.) (Bennett et al., 2010; Pautex et al., 2005).

7.3.3 Themes and subject-matter requiring further development

The results obtained from intervention studies on patients receiving palliative care are essential, as they provide a body of evidence as a basis for decision-making regarding the use of medication and treatment structures. Such studies should be expedited. In view of the methodological difficulties concerned (recruitment problems and high attrition rates in palliative medicine studies), innovative approaches to research methodology must be developed in the first instance. This is particularly relevant to clinical research, although there are also similar problems in other fields of palliative medicine research.

Qualitative studies can be used to generate clinically relevant hypotheses and for the formulation of relevant quality criteria. The combination of qualitative and quantitative methods can allow for triangulation⁴¹ of the research data,

thus validating an otherwise methodologically weak study. Innovative methods such as N=1 studies or enriched enrolment (selective recruitment) can also produce meaningful research findings. However, studies with enriched enrolment or multiple cross-over have also been criticised, as the significance of such studies is restricted to a relatively small target group, and can be generalised only to a limited extent.⁴²

Against the background of such changes in methodology, clinical study programmes are required in which comparable results can be obtained by comparable methods and it is also possible eventually to pool results from several intervention studies, so that an evidence-based recommendation can be made of essential medication to treat different symptoms. This should also include intervention studies on less common symptoms such as itching or sweating, and studies on procedures from complementary medicine. The ideas and approaches generated through basic research should be developed as rapidly as possible into applicable therapeutic procedures by research associations and validated in clinical studies (translational research).

In the area of epidemiological studies, longitudinal studies must be conducted as the illness progresses to supplement the findings obtained from cross-sectional studies.

⁴⁰ 2003/94/EC European Commission Directive on GCP and German GCP Ordinance dated 5/8/2004 on clinical trials with drugs. The German Drug Law (AMG) also makes reference to this [Act governing the use of drugs (1976), last amended by Art. 2a Act dated 27/3/2014 (Federal Law Gazette I p. 261)]. http://www.gesetze-im-internet.de/bundesrecht/amg_1976/gesamt.pdf (Status: 10 September 2014).

⁴¹ In social research, triangulation describes a research strategy which uses various perspectives or methods to study the same phenomenon, so that the strengths of one approach balance out the weaknesses of another.

⁴² Enriched enrolment: only subjects who experienced a therapeutic effect from the trial medication during a preliminary phase are included in the study. N=1 study: each patient serves as his own control, generally with multiple cross-over between the trial medication and a comparative therapy, and is evaluated individually. The individual outcomes of several patients can then be summarised in the overall evaluation.

Catalogue of topics for clinical research

- Development and verification of innovative research methods
 - Qualitative studies and mixed-method studies
 - N=1 studies, enriched enrolment
- Clinical study programmes for the control of symptoms with drugs
- Intervention studies on common symptoms such as pain, anxiety, dyspnoea, etc.
- Intervention studies on less common symptoms such as itching, etc.
- Complementary medicine in palliative care
- Longitudinal studies as the illness progresses
- Interventions in the terminal phase
- Studies on the effect of antineoplastic therapies in controlling symptoms (chemotherapy, radiotherapy, etc.) and studies on the side-effects and negative aspects of these antineoplastic therapies
- Interventions in the case of non-cancer patients:
 - Advanced cardiac disease
 - Chronic obstructive pulmonary disease (COPD)
 - Neurological disease
 - Geriatric patients
 - Patients with dementia
 - Children, adolescents and young adults
- Translational research:
 - New types of administration route
 - New types of intervention for the treatment of frequent symptoms with or without drugs

7.4 Research on psychosocial and spiritual issues

In the scientific debate on psychosocial and spiritual issues, several disciplinary schools of thought can be distinguished in the field of palliative care, which in some cases exhibit a marked degree of overlap in terms of both their theoretical basis and their practical impact: In addition to a psychological and sociological perspective which extends as far as sociocultural and socio-existential matters, it is also important to consider palliative care in terms of cultural studies and the humanities, in particular theology, philosophy and ethics. The level of research carried out from these perspectives and with different focal points differs in scale, and the individual aspects have been weighted differently as palliative research as a whole has evolved. For instance, particular attention is cur-

rently being paid internationally to the spiritual issues concerned. In addition, in the area of research into the psychosocial aspects of palliative care, there are overlapping focal points, which touch upon several of the aforementioned perspectives (e.g. the research strands on care for family members and the stress experienced by palliative care teams).

7.4.1 Current state of research

In the English-speaking world in particular, the increasing number of publications in these areas in recent years testifies to the level of interest among researchers in the field of palliative medicine. In PubMed, 320 of the 941 publications featuring the key phrases 'palliative and spiritual' have been published since 2011 alone, and of 1,061 publications on 'palliative and psychosocial', 338 have appeared since 2011.

The **psychological perspective** in palliative care considers emotional characteristics and (intra/interpersonal) psychological dynamics in the context of critical illness and dying. Important research strands in this area include studies on coping and resilience. Extensive research exists on the psychology of dying (thanatopsychology) (Neimeyer et al., 2004; Stroebe et al., 2008; Wittkowski, 2012a; Wittkowski & Streng, 2011). Thanatopsychology deals with such themes as coping with one's own death and dying and with the death and dying of others, the different stages of dying and grieving, and how children develop an understanding of death. The prevalence and differential diagnosis of certain psychological symptoms, such as anxiety and depression as well as traumatic stress, have also been investigated (Brenne et al., 2013; Mystakidou et al., 2012; Oechsle et al., 2013; Potash & Breitbart, 2002; Wittkowski, 2012b). In addition, studies and review papers have appraised psychological interventions at the end of life for patients as well as for couples (Breitbart, 2002; McLean & Jones, 2007).

The central issue from a **sociological perspective** concerns how arrangements around dying differ between one palliative care setting and another. Essentially, this examines the relationship between various interpretations (e.g. of a good/bad death) and the institutional and organisational practices around treatment, care and support for the patient and his family. Research in this field has considered such issues as the organisational development of palliative care in the context of the health-care system and in relation to certain other specialist areas of medicine (Clark, 2007). Another important aspect is the question of who defines what a good death is, and what role this plays in any potential claims to omnipotence in palliative care (Stiefel & Guex, 1996). Differences between traditional, medically established and individual expectations of death have been described and an ideological representation of the peaceful

death portrayed in a critical light (Göckenjan & Dresske, 2005). There has also been a series of (representative) population surveys on the themes of hospice work, death and dying, advance directives and attitudes to the end of life (cf. Chapter 3.1.2).

In addition to the institutional and organisational arrangements around dying, another crucially important question concerns the typical differences in the needs, requirements and wishes of patients and their families, and how the processes of dying are dealt with, up to and including the socio-existential perspective that takes into account the social and existential challenges facing patients and their families. In this context, the social isolation of patients and family caregivers was investigated, and possible counter-measures described, for instance through the provision of day care clinics (Payne, 2006; Bradley et al., 2011). Financial needs and problems in association with severe, life-limiting medical conditions have also been highlighted as one aspect of socio-existential research into palliative care, and models have been proposed to prevent such issues arising (Cross & Emanuel, 2008; Hanratty et al., 2007).

Other areas of concern from a sociological and **cultural studies perspective** include the need to be mindful of the specific cultural backgrounds of patients and family members, as well as the (inter-) cultural skills of those providing their palliative care. These aspects, as well as the accessibility to people with diverse cultural backgrounds of the various hospice and palliative care services on offer, are central issues which also highlight the issue of social inequality at the end of life (cf. also Chapter 7.11). In terms of palliative care, the cultural studies perspective also concerns itself with comparing cultures when it comes to the way in which serious illness, death and dying are perceived in different cultural contexts, attitudes towards them, and how they are managed. Research in this area often fo-

cuses on the spiritual or religious characteristics of different cultural contexts.

Questions about the meaning of life, religious bonds, identity, rituals and the balance between fear of disintegration and hope of integration are aspects of the **spiritual perspective**. Research in the area of spirituality is currently attracting considerable international attention.⁴³ Review papers have been written about the spiritual needs of patients and their families (Kissane, 2000; Ettema et al., 2010; Kalish, 2012) and about the measurement of spirituality (Selman et al., 2011). An important review article on the stress factors faced by care teams was written by Mary Vachon (this was admittedly published in 1995, but it still remains relevant today) (Vachon, 1995). Considerable international research has been carried out on stress and risk factors for carers, not only across the professions but also for specific professional groups or disease entities (Papadatou, 2009). In Germany, the work by Müller and Pfister entitled *Wie viel Tod verträgt das Team? (How much death can the team endure?)* (2013) and the study on supporting those who provide advanced levels of nursing care (Schröder et al., 2003) are worthy of mention. Important research publications on family carers in the area of palliative care include a systematic review paper on assessment tools for studies on the experiences of family carers, a systematic review paper on psychosocial interventions for family carers, and an EAPC white paper on providing support for this group (Hudson et al., 2010; Payne et al., 2010a; Payne et al., 2010b).

7.4.2 The state of research in Germany: an international comparison

In Germany, no wide-ranging empirical research has yet been conducted on the social organisation or cultural framing of processes of dying, or on the psychosocial and spiritual needs of the individuals involved (Heller et al., 2012). The few findings which have been reported indicate essentially that, especially if the patient is receiving outpatient care, it is crucially important to provide his social circle with psychosocial support and to give due priority to the spiritual aspects of the patient's palliative care (Schneider, 2013).

All things considered, research into the social and cultural factors surrounding death and dying in particular is much more pronounced in the English-speaking world and is, more importantly, institutionalised accordingly (through research centres, international journals, etc.), whilst in contrast the entire research field of death and dying still appears to be marginalised in Germany (Wittkowski, 2013). Research into social-science practice in particular, which explicitly attempts to remodel the various perspectives of those involved in the dying process – patients, family members and carers (doctors, nurses, social workers, religious/spiritual counsellors and volunteer staff) – can only be described as inadequate.

Even the field of academic research into providing spiritual support for the dying, and the question of what form such support should take, appear to have been much neglected. The professorship in spiritual care established in June 2010 at the interdisciplinary centre for palliative medicine (IZP) at the university hospital in Munich-Grosshadern represents a determined, albeit to date isolated first step towards making an academic study of the theme of spirituality in the context of hospice and palliative care in Germany.

⁴³ However, this increasing attention is leading to a widening of its definition. Thus the EAPC Taskforce on Spiritual Care in Palliative Care provides the following definition: "Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred." (<http://www.eapcnet.eu/Themes/Clinicalcare/Spiritualcareinpalliativecare.aspx>, Status: 13 September 2014). By widening the definition in this way there is, certainly, a risk that 'spirituality' might be used as an umbrella term for psychological, sociological and anthropological issues.

7.4.3 Themes and subject-matter requiring further development

Because of the lack of systematic psychosocial basic research and in the absence of broad-ranging qualitative and quantitative studies, it has not yet been possible to make evidence-based statements about the precise psychosocial and spiritual needs and requirements of patients and their families in Germany (Feldmann, 2010).

A central theme exists when examining the question of the heterogeneous nature of dying as experienced by patients and their families, as well as when considering the corresponding options made available by service providers with their different profiles and organisational forms (Schneider, 2012). In concrete terms, research topics should focus on such factors as the different ways in which psychosocial and/or spiritual needs are expressed by patients and their family members and on how these findings can be applied in practice. Against the background of the confrontation with the heterogeneous nature of dying, the options for dealing with severe diseases, death and dying on the part of carers should be remodelled, so that such factors can be reflected in practice. This includes making a critical examination of the implicit assumptions prevalent in the hospice movement and in palliative care, for instance that facing up to one's own death and dying is meaningful and life-enhancing.

Theories about how to deal with death and dying, which have been under development more recently in the field of social sciences, point also to the relevance of material factors when it comes to arranging the processes of dying – for instance, in terms of the architectural characteristics of the rooms in which people die, the materials with which they are equipped, and the use of technical artefacts such as pain-relief pumps, hospital beds, etc. in one's home environment. Dealing with the increasing mechanisation of medicine and of society as a whole,

which Naisbitt refers to as a megatrend (High Tech High Touch), is another matter of concern (Naisbitt, 1982, 1999).

If the realm of practice is formed on both basic research and applied research and if dying is to be regarded as a “holistic” phenomenon from various perspectives and/or across different disciplines, it is important to clarify what exactly characterises basic research and applied research (and/or research into efficacy) from a theoretical, methodological and methodical viewpoint and from the specialist perspective concerned. Above all, quantitative and qualitative methods must be used equally alongside each other. In the area of basic research, models can be developed and tested for their feasibility and efficacy, for instance on the question of which forms of organisational development are particularly well-suited to initiating learning processes in multiprofessional palliative medicine, and the optimum way of ensuring that the opinions of terminally ill patients are heard at team meetings.

The important areas of responsibility which psychology must fulfil in the field of palliative care⁴⁴ give rise to matters requiring research and further development in the following superordinate thematic areas: psychological support for patients and their family members, issues relating to organisational psychology in the area of palliative care, and basic research on theoretical models of psychology in palliative care.

As part of the psychological support provided to patients and family members, it is crucial in the first instance to develop and evaluate suitable interventions tailored to the different needs and requirements of patients and family members, and to allow for various indications (therapeutic, stabilising, to strengthen resources, etc.). It is especially important also to take the needs

⁴⁴ For the job description of psychologists in palliative care, cf. Fegg et al. (2009).

of patients with non-oncological conditions into consideration. In addition, the further development and evaluation of suitable methods of psychological assessment and diagnosis are essential in the field of palliative care. In this context, it is also important to make an evaluation of any potential cognitive impairment which might affect the patient's ability to make a self-assessment and to make decisions, such as in the case of changes to treatment objectives and in decision-making processes.

From an organisational psychological perspective, a systemic insight into emotional and psychological dynamics in the context of critical illness is of paramount importance for the professions involved in palliative care. There is a need for research here into the perspectives and motivations of different professions, for instance within the framework of treatment planning and ethical decision-making. Moreover, suitable communication models and interventions must be developed to promote self-care within teams in response to the changing structure of the palliative care landscape.

The discussion about death and dying which palliative care has helped to trigger among professionals and in society gives us cause to reconsider theoretical psychological models and strategies and to develop them further. Basic psychological research can help us to address some fundamental questions here. Personality models should be reviewed to ensure that they benefit practitioners in the field of clinical psychology in terms of classifying typical prerequisites in palliative situations, as well as for how they relate to different ways of handling pain or taking medication. It would be useful to re-examine the definitions of psychological 'health' and 'illness', so that symptoms such as anxiety, depression, agitation and dissociation suffered by the critically and terminally ill might be suitably classified. Options should be developed to enhance comprehensibility,

manageability and meaningfulness, and to reinforce human resilience.

In the final analysis, the development of spiritual aspects in palliative care is focused on anthropological categories based on a holistic understanding of the patient. This places man's subjective search for meaning and transcendence (Koenig, McCullough & Larson, 2012; Anderheiden & Eckart, 2012) and his longing for identity, wholeness and fulfilment, deliverance and healing in the spotlight, but also the way in which man understands and leads his life in terms of its meaning (Puchalsky et al., 2006), or as a network of relationships and meaning which give life coherence (Zwingmann, 2005). Existential questions about the meaning of life, 'strategies' for dealing with fundamental conflicts of sense, and recourse to systems of meaning which are important in this respect are the principal themes in this field of research,⁴⁵ working in which would appear to require as open-ended a definition of spirituality as possible. Only thus is it possible to combine a theoretical reflection on the phenomenon with the concrete requirements in terms of the practicalities of supporting the dying, and so to achieve a 'system-internal' rationale in contrast to a 'system-alien' conceptualisation (Roser, 2007).⁴⁶

Virtue ethics rooted in the paradigm of the helping professions can take as its starting point intersubjectivity and the – by definition – asymmetrical forms of communication between the dying and those caring for them, and establish a new ethics of interpersonal relationships on this basis. More extensive research needs to be made into these particular dimen-

⁴⁵ Six characteristic areas of research have been described: a general discussion on spirituality and palliative care, the spiritual needs of the palliative patient, tools and interventions in relation to spirituality, the meaning of hope and of religion in palliative care, and spirituality in relation to palliative care staff (Sinclair et al., 2006; Heller, 2012).

⁴⁶ The views adopted by Emmanuel Lévinas, Paul Ricœur and Martin Buber can be regarded as approaches to a reflection on the meaning of spiritual support based on closer scrutiny of the ethical dimension of inter-human relationships.

sions of acquiring a specific skill set. On studying the phenomenon of intersubjectivity more closely, one finds that an ethical consideration also comes to the fore: the need to differentiate between an individual, existential encounter with death and the organisational standardisation of

end-of-life care. It is crucial to consider the relationship between spirituality and ethics in terms of its substance as well as with respect to the close structural bond that exists between spiritual care and ethics in the various organisational contexts of end-of-life care (Roser, 2007).

Catalogue of topics on psychosocial and spiritual issues

- Broad, open discussion of methods (basic and applied research)
- Psychological perspective
 - Needs and requirements of specific target groups for psychological support
 - Development and study of appropriate psychological diagnostic procedures in palliative care
 - Development and evaluation of appropriate psychological interventions to support patients and family members (therapeutic / stabilising / to strengthen resources)
 - Perspectives and motivations of different professions within the framework of ethical decision-making and against the background of a systemic appreciation of emotional and psychological dynamics within the context of severe illness
 - Development and evaluation of appropriate communication models within the team and of interventions to promote self-care within the team
 - Assessment of personality models and definitions of psychological 'health' and 'illness' to allow for a proper classification of emotions, behaviours and mental symptoms as they relate to critical illness and at the end of life
- Sociological perspective
 - Reconstruction of key terminology which directs actions in relation to critical illness, dying, death, the finite nature of life and feasibility (e.g. a good/bad death)
 - Dying as a social process: characteristics of the institutional and organisational arrangements around dying (including recognising the relevance of the 'death room' and 'death objects')
 - Various needs and requirements of patients and family members, inequality of opportunity to access palliative care, up to and including the social and existential needs of patients and family members
 - Models to support patients and families facing social and existential challenges, including prophylactic approaches
- Cultural studies perspective
 - Special cultural characteristics of patients and family members as they cope with critical illness, death and dying, and (inter-)cultural skills on the part of carers
 - Identification of what different cultures have in common and where the differences lie in their interpretations of illness, death and dying, as well as in their practices
- Spiritual perspective
 - Definition of the profile of spirituality and spiritual care in palliative care
 - Intersubjectivity and ethics of interpersonal relationships
 - Spiritual needs of patients and family members
- Organisational practice and coping with stress factors in palliative care teams
 - Strategies and forms of organisation aimed at reducing stress
 - The significance of the changing hospice and palliative care landscape in terms of the level of stress experienced by carers

7.5 Research on legal and ethical issues

The professed goal of palliative care is to regard and treat each patient as an individual: “*Ideally, the patient will retain the autonomy to make his own decisions about where he receives care, his treatment options, and his access to specialist palliative care.*” (Radbruch & Payne, 2011, p. 220). This specific approach gives rise, *per se*, to the demand for (individual) ethical aspects as well as patient rights to be regarded as an integral part of the care package. Against this background, it is obvious that medico-ethical issues must be interpreted as a subsection of the overall palliative care strategy (Gross & Grande, 2010). Patients’ rights must also be conceptionally and completely integrated into this strategy.

7.5.1 Current state of research

Ethical and legal research within the context of palliative medical care concerns such topics as the right to self-determination and the protection or restoration of patient autonomy so that, for instance, the right to self-determination can be exercised (Almack et al., 2008; Pfeffer, 2005) as well as – as an expression of this self-determination – examining the available tools of wide-ranging advanced care planning (e.g. advance healthcare directive, advance directive, lasting or enduring power of attorney and healthcare proxy) and their applicability and/or scope in the context of palliative medicine (Seymour et al., 2004).

Similarly, research projects have been conducted into the ethical issues associated with actual palliative treatment options. Of particular interest are the question of supplying hydration and nutrition and the restriction of these at the end of life (Rietjens et al., 2004), and the indication and use of terminal and/or palliative sedation (Cassell & Rich, 2010; van Delden, 2007; Materstvedt & Bosshard, 2009; Swart et al., 2012; Ma-

terstvedt & Kaasa, 2000). Questions concerning the indication of a treatment and changes to the objective of treatment (restriction, withdrawal and/or discontinuation of treatment) (Göckenjan & Dresske, 2005; Sykes & Thorns, 2003) have also been studied at the classical interfaces between palliative care and (clinical) ethics.

Research on clinical ethics consultation (*Klinische Ethikberatung* – KEB) belongs within the joint domain of palliative care and clinical ethics, especially since care-related end-of-life decisions play a special role in KEB both qualitatively and quantitatively. The same applies to issues concerning the palliative patient’s wish to die (Stiel et al., 2010) and the contiguous fields of killing on request and physician-assisted suicide (Rady & Verheijde, 2010). The extent to which normative premises are positioned in palliative care is just one interesting aspect of this (Hahnen et al., 2010; Hahnen et al., 2009).

Also of note are a few key topics classically associated with medical ethics. Although these do not relate solely or indeed primarily to the field of palliative care, they are nonetheless of particular significance in this context: this includes, for instance, questions relating to research ethics and ethical questions about the extended use of technology-based services (such as telemedicine or AAL) in the case of palliative patients.

As far as legal matters concerned, the focus is mainly on the legal framework for end-of-life treatment, medical indication and dialogue-based decision-making, especially at the end of life, and the protection of or creating the conditions necessary for patient autonomy.

After an intensive preliminary period of scientific study and having been discussed at length in the political arena, the basis on which decisions are made about limiting medical interventions at the end

of life and the importance of an advance directive are now clearer than in the past and are governed by statutory regulation (cf. Art. 1901a BGB). In the process, dialogue-based decision-making has become legally regulated (Art. 1901b Para. 1 BGB). However, there is still a considerable lack of clarity about its concept and practical application and about the statutory provisions and requirements relating to it. Likewise, comparably little research has been conducted into defining and changing the objective of treatment, or about the legal provisions and requirements governing the medical indication for this.

Also of importance is the concept of (patient) autonomy, which is related to that of dialogue-based decision-making, although the term ‘autonomy’ is not defined uniformly across the various research disciplines (Christman, 1989; Rössler, 2002; Spickhoff, 2003). In medicine, autonomy is often taken to mean little more than informed consent, or a pragmatic definition of autonomy is adopted, for instance by using everyday experiences as a benchmark for autonomous decisions (Beauchamp & Childress, 2012; Beauchamp, 2005). The concept reaches its limits when the people concerned are, by tradition, granted either no or only limited power to make their own decisions. The law reveals a degree of uncertainty about which material or procedural conditions must exist for a decision to be deemed to be autonomous and consequently deserving of respect (Lipp, 2000; Duttge, 2006b). Neither is there clarity about how the relationship between individual autonomy and the patient’s social circle should be conceptualised and used to direct the actions taken. This applies to both the doctor-patient relationship and the significance of the patient’s social circle when medical decisions are made.

7.5.2 The state of research in Germany: an international comparison

In Germany, professional associations such as the Academy for Ethics in Medi-

cine (AEM) and the DGP have only recently turned their attention to the thematic interfaces between medical ethics, medical law and palliative medicine. So far, only a few research contributions have addressed the above-mentioned subject areas. The existing research desiderata apply to every field: moreover, it is conspicuously the case that care concepts in palliative medicine often refer exclusively to institutionalised palliative care, although they are or should be a necessary component in other specialist fields of medicine. Similarly, the studies available focus on underlying oncological diseases, despite the fact that the number of patients with advanced internal, neurological or geriatric conditions is increasing rapidly.

As in the past, there is still a particular lack of interdisciplinary scientific activities and of multicentre studies. Among the areas where research is still needed is the collection of quantitative and qualitative data on medical work practice during the final phase of life (Schildmann et al., 2010). Many national and international research contributions can be found on the subject of the desire for death among palliative patients alone, and/or on the contiguous areas of killing on request and physician-assisted suicide.

However, it is important to remember that normative issues are also invariably an expression of certain social and cultural conditionalities. Unlike in the case of clinical issues, it is much less practicable and meaningful to apply research results obtained abroad to a German context when it comes to ethical matters. The same is true of legal issues to a certain extent. However, such research encompasses not only national law, but also international regulations and the administration of justice in international courts. It also considers the legal systems of other countries and compares the legislation they have adopted with the aim of conducting a critical evaluation and

developing new, improved solutions (the better-law approach). However, to date it has addressed only a few aspects of palliative care in greater depth.

7.5.3 Themes and subject-matter requiring further development

Given the urgent need to prioritise, the ethical and legal issues related to palliative care listed in the table below are those that should be undertaken and studied first of all. There are a number of other themes, however, which would be worth investigating in a second round of research.

Autonomy is undoubtedly a key concept in modern medicine and medical law. One responsibility of palliative medicine might be regarded as being the protection or restoration of patient autonomy. With its central position in medical law once again having been recognised and affirmed in the legal regulations on advance directives [Third Act Amending the Guardianship Law] (2009) and the Patients' Rights Act (2013), it is now important to clarify both the constitutional conditions of autonomy and the circumstances under which a decision may be regarded as not being or no longer being made autonomously. Although the legal concept of being able to give informed consent certainly has a long tradition, there remain many aspects of it today which are still a matter of dispute (Hager, 2009).

Interventions should be designed, implemented and evaluated on the basis of interventions from clinical medicine (Temel et al., 2010) and clinical medical ethics (Schneiderman, 2003), which can provide support for physicians, patients and other interest groups as they make medically and ethically based decisions at the end of life. The appropriate studies will require researchers to have medical, ethical, but also legal expertise, if there is to be a realistic possibility of interdisciplinary research associations implementing

their findings at the earliest available opportunity.

For instance, the legal implications of the relationship between the objective of treatment and medical indications require further study in the field of palliative care. The question of when treatment should be limited because further medical care would be 'futile' is an especially problematic one. This issue is crucial to the physician's support for the dying patient (BÅK, 2011), but remains largely a grey area as far as the law is concerned. Initial studies have shown that this should focus on questions about whether life-saving measures are indicated (Duttge, 2006a) and on the change of treatment goals (Lipp, 2012). These research approaches must be pursued further and in greater depth.

There is also a need for research into the legal implications of the problematic area of physician-assisted suicide. It is essential to clarify what circumstances must exist if the law is to view an expression of the desire for one's own death as having been made 'freely' or otherwise. This will require genuinely law-based research to be conducted that also examines and adopts findings from other disciplines. But even treating somatic illnesses against the patient's will ('coercive treatment'), which is currently under discussion mainly in the context of treating mental illness, can be particularly problematic if the recipient of the palliative medicine treatment is a patient who, in addition to his somatic illness, is also suffering from dementia or some other severe mental disorder.

Neither has much research been conducted into whether and in what circumstances trust must be regarded as being a necessarily complementary element of patient autonomy, and what role is played in this respect by the medical professions, the family, self-help groups, the hospital as an institution and, potentially, certain aspects of faith.

Catalogue of topics on ethical and legal issues

- Ethical and legal issues
 - Self-determination of the patient (patient autonomy)
 - Advance care planning tools (advance healthcare directive, advance directive, lasting or enduring power of attorney and healthcare proxy)
 - Supply of hydration and nutrition and their restriction at the end of life
 - Palliative sedation – indication and performance from an ethical viewpoint
 - Desire for death and for assistance with dying for palliative patients
 - Refusal of treatment and treatment against the wishes of the palliative patient
 - Involvement of palliative patients in scientific studies
 - Importance to be attached to palliative medicine in the future when allocating scarce resources in the healthcare system (allocation debate)
 - Implications of the increased use of technology-based services (e.g. telemedicine and AAL) among palliative patients
- Interventions to support ethics-based decision-making at the end of life
- Integration of palliative medicine in clinical ethics counselling
- Autonomy and trust

7.6 Research in the field of medical technology

In the light of the increasingly problematic situation in terms of costs and resources in the health service, the use of information and communication technology is regarded by many countries around the world as being indispensable if practicable forms of care are to be maintained and/or made possible in the first place through the provision of health-related services. In the majority of industrialised countries, the long-term demographic trend is providing additional motivation for the pursuit of such developments.

7.6.1 Current state of research

A number of different research approaches and research fields are associated with AAL. For the most part, technical systems are used as part of service strategies designed to establish personal contact with family members, friends or carers. The group of potential users of such technology is currently very heterogeneous and comprises mainly healthy and active senior citizens who use lifestyle functions

to improve their quality of life (DGBMT, 2007). The PAALiativ project funded by the BMBF was initiated to enable patients with complex medical conditions who suffer from COPD or lung cancer to be able to live independently at home for longer using AAL technologies.⁴⁷ However, at present the target group of patients requiring palliative care is under-represented in the field of AAL research.

AAL systems could also incorporate existing equipment, which reminds patients to take their medication at regular intervals, as well as automatic dispensing systems for both tablets and liquid medication, including infusions. However, there are deficits regarding the interfaces or how the equipment could be integrated into higher-level (personal health and/or AAL) systems.⁴⁸ A systematic evaluation has not yet been conducted here, nor in the field of palliative care.

⁴⁷ <http://www.paaliativ.de> (Status: 13 September 2014).

⁴⁸ A definition of personal health is to be found in Footnote 17.

In addition to AAL research, technical aids have also been developed with the aim of helping people with disabilities and those undergoing rehabilitation to cope with everyday situations. The technical equipment developed assists with mobility and motor skills (walking, and arm and hand functions) as well as with sensory skills (vision, hearing, smell and taste). These projects, most of which are funded by the BMBF, have been designed to help enable those affected to live independently for as long as possible, take part in activities, and play a role in society.⁴⁹ However, it has so far only been possible to incorporate such equipment into a palliative care setting to a very limited extent.

During recent years, software-based communications and quality assurance systems have been developed and established within the scope of a variety of different projects (for instance, HOPE)⁵⁰, in which personal, disease and treatment related data are recorded at the time of admission and at the end of treatment in the palliative care unit. A pilot project aimed at establishing an electronic palliative care file for high-quality SAPV has been in regular operation at participating hospitals since 2012 (Meyer-Delpho & Schuberth, 2013).⁵¹

Pain represents a major challenge in the area of palliative medicine treatment. A large number of basic studies have been conducted on the origins and perception of different forms of pain. These have culminated in the development of new treatment strategies and, with particular reference to medical technology, in the development of pain-relief pumps for the more effective dosaging of

drugs. However, much remains unknown about individual experiences of pain, especially when it is no longer possible to communicate directly with the patient. Similar challenges are presented when it comes to recognising other distressing symptoms such as thirst, hunger, respiratory distress, etc.

7.6.2 The state of research in Germany: an international comparison

The demand for services in the healthcare sector is expanding exponentially across the globe. Germany is strongly positioned in the expanding world market for such products. The field of medical technology is one of the most research-oriented and innovative sectors of cutting-edge technology in Germany. At eight percent of turnover, investment in research and development in this field is twice as high as the industry average (Bräuninger & Wohlers, 2012). In the three principal growth areas of modern medical technology – computerisation (IT and communication technology), miniaturisation (microsystems technology, nanotechnology and optical technologies) and molecularisation (biotechnology, cell and tissue engineering) – Germany generally occupies a leading position in Europe alongside Great Britain (BMBF, 2005).

As far as the development of innovative AAL technologies is concerned, it is true to say that Germany is – thanks to its generous funding of research – strongly integrated in EU endeavours in this field: some research results have already been implemented in practice in the general marketplace, and in other cases their implementation is imminent. However, there remains a lack of solutions specifically designed for the field of palliative care.

While e-health structures are already taken for granted in many countries, and personal health systems are gaining in prevalence in the USA as well as in some European countries, Germany

49 For an overview of BMBF-funded projects, cf. <http://www.gesundheitsforschung-bmbf.de/de/4349.php> (Status: 13 September 2014).

50 For more information on HOPE, cf. Chapter 5.3.

51 <http://www.telekom-healthcare.com/kliniken/die-elektronische-patientenakte-in-der-palliativversorgung-bei-den-lahn-dill-kliniken/1226604> (Status: 13 September 2014).

is lagging behind its international counterparts in this respect. The definition and installation of the necessary nationwide infrastructure for health telematics is still in its infancy. The limited functionality of the electronic health card, which is currently being introduced, is symptomatic of this.

7.6.3 Themes and subject-matter requiring further development

In recent years, a large number of AAL research projects have developed individual prototype solutions. Yet so far, there has been no fully operational market for AAL applications except in isolated areas such as emergency call systems for the home and audio/video communication. One important reason for this is that people in need of long-term care usually suffer from more than one single disease or impairment requiring treatment; indeed, they can be afflicted by numerous symptoms and health problems or limitations, which frequently interact with one another and require corresponding assistance functions to compensate for them. Consequently, a wide-ranging and expandable system is required to meet the particular set of needs of such people. However, for this to be possible a comprehensive standardised system platform is needed which can incorporate the individual applications and products of a range of manufacturers. So far, there is only a limited availability of such developments, but they are currently being pursued enthusiastically, particularly at European level with the development of the universAAL⁵² platform.

A potentially considerable amount of personal information relevant to patient health can be extracted from data held by e-health structures, in particular telemonitoring, and this will also be valuable for palliative care.

So far, AAL developments have barely addressed the provision of palliative care at home. The first steps in this direction might take the form of developing typical user profiles and studying them to determine the extent to which needs can be met with existing solutions: in this way, new service models can be developed for palliative care in which medical technology plays an important role.

A first step could be taken by making increased use of modern information technology to provide comprehensive care for palliative patients, especially those receiving SAPV. This might include, for instance, developing information systems which ensure that the various individuals involved in the palliative patient's care have access to the same level of information. The use of modern information technology would also make it possible to increase the provision of SAPV, primarily in rural districts.

Research in the field of medical technology is able to give patients with limited communication skills new specifically-designed assistive technologies, which help patients to express their independent wishes (communication) and to act independently (motor functions).

This can be taken one stage further by developing innovative procedures which use medical technology to identify distressing symptoms automatically – in particular pain, thirst, hunger and anxiety – and to initiate strategies (activate alarms) as required.

As far as the control of symptoms, such as wound management, is concerned, digital image transmission can be used during teleconsultations by outpatient nursing services, but also by other carers or family members in order to access specialist nursing or medical expertise for the improvement of wound care. The technical components required for this – as well as the findings of relevant pilot projects – are already available.

⁵² <http://universaal.org/index.php/en/> (Status: 14 September 2014).

Catalogue of topics on research in the field of medical technology

- Telemedicine, e-health
 - Development of personal health systems
 - Development of methods for mining data from e-health
- AAL
 - Development of new service models
- Development of assistive technologies
 - Improving the ability of patients to communicate
 - Improving motor skills
- Developments in the field of medical technology for symptom control
 - Processes for the automatic identification of distressing symptoms
 - Wound care
 - Drug administration

7.7 Health services research

According to a report published by the German Research Foundation (DFG) in 2010, health services research examines “[...] *healthcare and – to give a narrower definition – the medical care of our population, its planning, organisation, regulation, evaluation and optimisation*” (Raspe et al., 2010, p. 6). It is also concerned with collaborative ventures between the different areas of care, the possibilities, limitations and problems associated with coordinating the activities of collective stakeholders, each pursuing its own interests, but also the unintended consequences of care provision, partly due to political steering or economic constraints.

Health services research in the field of palliative care concerns itself with both palliative care as an activity and the institutions of palliative care. Activity-oriented care research is the object of clinical research (cf. Chapter 7.3) and is not dealt with here in any greater depth. Institution-oriented health services research is concerned exclusively with palliative care from a professional point of view.

7.7.1 Current state of research

Based on a review published in 2012 (Brundage et al., 2012), it is possible to obtain an overview of the current status of health services research in the field of palliative medicine, at least as far as research output (the number of publications) in the field of oncological care is concerned. This review summed up the year 2009, according to which 8 percent of all publications in the field of oncological healthcare research in that year were dedicated to the theme of palliation (by comparison, prevention accounted for 4 percent, screening for 16 percent, diagnosis/assessment for 10 percent, treatment for 32 percent, survivorship for 19 percent, and the health system for 10 percent). Although this is not an insignificant percentage, it does demonstrate that palliative care research has some catching up to do as far as oncological research is concerned.

Of the research conducted into palliative care issues in the field of oncological care, sixty-one percent of the studies were concerned with the quality of palliative care. About 23 percent were dedicated to the subject of access to palliative care, only 3 percent to the costs, and 14 percent to health and/or wellbeing. If one assesses the state of palliative care re-

search on the basis of this synopsis of the research conducted into oncological care, then it is clear that palliative care research has a most noticeable backlog in the areas of costs, access and health. The neglect to which the issue of cost has been subjected in the past is particularly striking.

7.7.2 The state of research in Germany: an international comparison

In Germany, health services research is still in its relative infancy and remains under development, although noticeable shortcomings are apparent in the field of palliative medicine/palliative care.

A search in the *Web of Science* (which lists medical and social science journals with an impact factor) for the key phrases 'health services research' and 'palliative' found a total of 51 publications in January 2013. If these are broken down by country, the USA leads with 18 articles, but Germany occupies second place with 12 articles (in third place is Canada with 11, and in fourth Great Britain with 6). Most of the articles were published in international journals, primarily in *Palliative Medicine* and in the *Journal of Clinical Oncology*. Of these 51 articles, 47 were published in English and 4 in German. However, this achievement is based largely on the output of a single location in Germany.

7.7.3 Themes and subject-matter requiring further development

Since the processes of most activity-oriented palliative care are studied by palliative medicine itself, the main object of palliative care research should be the institutions around care, i.e. the care structures and processes involved in outpatient and inpatient care.

Given the potential shortcomings which we have already shown to exist in research into palliative oncological care, research into the quality of this institutional aspect of care should be maintained

at its current level in the future, but at the same time there should be more research into access to and the effects and costs of palliative care. This also applies to the subject of palliative care staff, which has been greatly neglected in the past. Topics such as work stress, the pressure of making decisions, roles of the professions involved and employee health should be studied more closely in the future, in order to create the knowledge base for the sustainable, long-term development of palliative care (key phrase: staff retention).

As far as research into needs and access is concerned, it is important to establish the actual level of need for palliative care. Research should also be carried out into such issues as equality of access and the accessibility of palliative care. In particular, there is an absence of information about the demand in an average year for general or specialist outpatient palliative care by the critically and terminally ill patients in Germany who satisfy the requirements for such care.

In the field of quality research, there is no framework for quality indicators. This primarily involves indicators used to assess the quality of structures and processes. Therefore, there is also no identification of key performance indicators. Such parameters can be used to determine which care structures and processes are successful, and which are less so.

As well as developing performance indicators to assess the quality of structures and processes, impact indicators must also be developed, which can then be used to verify the effectiveness of care measures. It would also be meaningful to study the different dimensions of dying – not only, in the narrower sense, from a medical and nursing viewpoint, but also the social, mental and spiritual aspects of dying – from the perspectives of the different individuals involved and in terms of their interactions with one another.

Once this comprehensive body of information has been collated and a systematic comparative study has been made, it will also be possible to conduct research into the economic aspects of palliative care and into the cost-benefit ratio in particular.

Research into palliative care institutions and their employees should focus on interdisciplinary interactions and collective decision-making processes within the multiprofessional team. Previous research findings (Temel et al., 2010) suggest that the inclusion of palliative care in treatment pathways, primarily with the

objective of integrating palliative care at an early stage, is of great interest.

Other themes associated with research into palliative care include the networking and coordination of care (e.g. interprofessional coordination), the problems encountered at the interfaces of care services, e.g. at sectoral boundaries, and the study of complex interventions up to and including the development of standards for such interventions. As evaluation methods are becoming increasingly sophisticated and more pertinent to everyday life (Davis & Mitchell, 2012), it is be-

Catalogue of topics on issues in health services research

- Research into needs and access
 - Demographic research focusing on the needs of the critically and terminally ill
 - Need for care to be provided in various settings
 - Equality of access to palliative care
- Patient research
 - Recording patient preferences, patient orientation and patient-centredness
 - Use of tools for patient surveys (Patient Reported Outcomes) in order to optimise care
- Quality research
 - Development of a framework for quality indicators
 - Identification of key performance indicators
- Research into efficacy
 - Development of indicators on the quality of outcomes
 - Effect/efficiency of care measures
- Research into costs
 - Cost-effectiveness of different forms of palliative care
 - Cost-benefit ratio of palliative care measures
- Research into organisational and employee-related issues
 - Quality of work, cooperation and social cohesion in palliative care facilities
 - Employee health in palliative care facilities
 - Decision-making processes and the associated stress
 - Early integration of palliative care in clinical treatment pathways
 - Employee health in palliative care facilities
- Innovative approaches to care
 - Studies on the networking and coordination of palliative care
 - Problems at the interfaces of care
 - Evaluation of care-specific team, human resources and organisational development
 - Specific measures for human resources development
 - Specific measures for organisational development
 - The study of complex interventions
- Compilation of mortality statistics and palliative care registers

coming less and less difficult to conduct evaluations in the field of palliative care at the actual point of provision.

Any research on death and dying and on healthcare provision at the end of life in particular must be supported by mortality statistics that are as comprehensive as possible. As in other fields of medicine (such as oncology), the development of patient registers would be a very useful means of compiling such statistics, and would also be helpful in many other issues in the field of research into health services in palliative care.

7.8 Quality assurance in basic and advanced training

7.8.1 Current state of research

Considerable progress has been made in recent years in establishing palliative medicine in pre- and postgraduate medical training (Ilse et al., 2012; Dietz et al., 2011). When developing the curriculum further, it is just as important in the area of palliative medicine as elsewhere to ensure not only that the needs of the student are taken into account, but also that the knowledge, skills and attitudes acknowledged at the time to be vital for palliative care are integrated into the teaching programme. In order to ensure that this is the case, accompanying research on the standard of teaching in basic and advanced training is gaining in importance in palliative medicine, too.

7.8.2 The state of research in Germany: an international comparison

In Germany, however, very little research has been conducted into the subject of basic and advanced training. Following the publication of a few isolated papers in which the evaluation of teaching sessions was conducted, instruments have now been developed which can be used to evaluate the standard of teaching (Pfister et al., 2011) or to assess the content of the curriculum (Schiessl et al., 2013).

There is still no standard of reference. The existing curricula for doctors and nurses have been revised and updated on several occasions. In 2010, Münster University of Applied Sciences conducted an international comparison of curricula for palliative care nurses which is shortly to be published.

7.8.3 Themes and subject-matter requiring further development

Given that attitudes play such an important role in approaches to palliative care, there is a need for studies that address the issue of which didactic constructs are useful in adult education. This might include, for instance, empirical studies on the question of whether and at what point multiprofessional learning is indicated in further education if successful results are to be achieved in the field. The first studies have already been carried out in the area of evaluation.

The patterns of the allocation of duties and responsibilities between the different health professions (such as between medicine and nursing) play an important role in palliative care. It would be interesting to establish, for instance, the extent to which nurses with qualifications in other fields could and should – since contextual conditions have altered – perform important duties in the area of palliative care in order to ensure that there are no gaps in the care provided.

In the light of increasing specialisation and the involvement of increasing numbers of professional groups in palliative care, research should be undertaken into the competences and the key skills common to all of the professional groups in order to establish whether those competences described in the curriculum meet the requirements of the working environment.

Ultimately, the goal of medical education is to improve patient care. That is why the primary focus of research into all

levels of training must be on its effect on improving the situation of both the patient receiving treatment and his family. However, research of this kind is extremely time-consuming; observing the development of professional health carers requires a period of observation extending over several years, and it is difficult to set up control groups for comparative purposes.

At least a longitudinal before-and-after comparison of teaching interventions makes it possible, however, to draw indirect conclusions about the quality of teaching, for instance by asking students to assess their own ability to cope with the demands of palliative medicine and by simply testing their knowledge.

Catalogue of topics on standards of quality at various levels of training

- Description of professional job profiles and their possible extension
- Research into core skills in palliative care
- Review of didactic constructs
- The importance of multiprofessional learning

7.9 Research into the palliative care of children and adolescents

7.9.1 Current state of research

Research into the palliative care provided to children and adolescents is still a very young discipline. A literature search in PubMed in December 2012 for the key phrase ‘palliative care’ produced a total of 11,440 hits, but when combined with ‘pediatric’, ‘paediatric’ or ‘child*’, it identified only 727 publications. A rough overview of these reveals that they are mainly descriptive in character. They are observational studies and reviews which report on the development of, introduction to or first experiences in the field of palliative care for children and adolescents. There was an almost complete absence of controlled studies.

The lack of randomised controlled studies was the subject of much discussion during the drawing up of the *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses* (WHO, 2012). Because of the shortage of such randomised studies from the field of paediatrics, randomised

controlled studies with adults were often referenced when drawing up the guidelines; the findings were then extrapolated to children, instead of basing recommendations on observational studies or case reports from the field of paediatrics. However, this procedure attracted much criticism (Drake et al., 2013), because one of the results was that treatments (such as bisphosphonate therapy for bone pain) were not recommended for children because of the severe side-effects sometimes observed in adults, despite such side-effects never actually having been observed in children.

7.9.2 The state of research in Germany: an international comparison

As far as its research into palliative care for children and adolescents is concerned, Germany lags well behind the USA, Great Britain and Sweden.⁵³ These three countries have just a few working groups with a very strong research record: at Harvard Medical School in Boston, Great Ormond Street Children’s Hospital in London and the Karolinska Institutet in Stockholm.

⁵³ Germany now has two professorships for paediatric palliative medicine: in Witten/Herdecke and in Munich.

In Germany, publications have appeared on the subjects of pain and palliative care in association with children and adolescents. The research has had outstanding results, particularly in the areas of cancer pain and opioids as well as sleep disorders in children with complex neurological conditions, and has also gained international recognition.

7.9.3 Themes and subject-matter requiring further development

Two main factors are characteristic of the palliative care of children and adolescents (Zernikow & Nauck, 2008):

1. the small number of patients, as a consequence of which there is a low density per catchment area;
2. the highly heterogeneous nature of the patient group, arising from the patients' different positions on the psychosocial and cognitive development spectrum, their different care groups and diagnoses, and the complex syndromes from which they suffer and which vary from one individual to another.

Basic research work is therefore required in the first instance on epidemiological aspects of palliative care for children and adolescents. This should include a description of the characteristics of the affected young people and their families: how many children and adolescents are being cared for in Germany, to what age groups do they belong, and from which symptoms are they suffering?

In addition, the circumstances of their care situation will also have to be taken into account. Where are the children and adolescents looked after (in a hospice or hospital, at home, in a palliative care unit?), and who is looking after them (parents, a paediatric nursing service, an outpatient hospice service?). Which professional groups are involved in their care? How is the care structured, and what is the optimal care structure?

Research questions of especial relevance to the field of paediatrics also concern the role and situation of the family, including parents, siblings and grandparents, and the importance of friends, teachers and other attachment figures. Questions concerning the special requirements of families from a migrant background play a particularly important role. How often are children from a migrant background treated, and what is the best culturally sensitive way of arranging care for families from such a background?

In its current guidelines (WHO, 2012), the WHO specifies a number of important research topics relating to the measurement and treatment of pain:

- observational tools used by third parties to assess chronic pain in infants and in patients who are unable to communicate verbally,
- a comparison between alternative opioids and morphine,
- the value of intermediate-potency opioids such as tramadol and tilidine,
- the value of adjuvants such as ketamine and gabapentin for pain relief.

Complex interventions are generally necessary to control symptoms, and proving their effectiveness can be associated with substantial methodical problems. In order to assess the effectiveness of these interventions, the impact of the intervention must be measured against a predetermined outcome quality indicator. When providing children and adolescents with palliative care, this gives rise to three main problems: the lack of any defined outcome quality criteria, the absence of validated assessment tools, and the patient's limited ability to communicate.

Consequently, there is also a need for basic research to be carried out in the area of symptom assessment and to define indicators on the quality of outcomes

for children and adolescents receiving palliative care. There are no validated assessment tools for a large number of the symptoms experienced by the affected children, such as diurnal restlessness and sleep disorders, fatigue, cachexia, spasticity, hypersalivation, dyspnoea and neuropathic pain. Many of these symptoms – and indeed the situation in general – can have a considerable impact on the health of the parents too. Here again, there is a lack of suitable assessment tools which might enable future researchers to study the effectiveness of interventions.

There is a pressing need for work in the fields of pharmacokinetics, pharmacodynamics and pharmacovigilance to improve the treatment of symptoms. Paediatric palliative patients are often given a large number of drugs simultaneously,

with little consideration for the possibility of adverse interactions. It is generally the case that the effects and kinetics of most pharmaceuticals have not been studied in relation to children with complex medical conditions or for their specific indication for palliative medicine treatment, which can lead to considerable uncertainty in respect of the choice and dosage of the drugs. This may in turn endanger the patient, not only because of the ineffectiveness of the medication, but also as a result of unexpected side-effects.

Many affected patients rely on technical support, such as ventilators (e.g. children with muscular disease). Research is required here in the field of medical technology, especially with a focus on the interaction between growing children and machines.

Catalogue of topics on the need for research in paediatric palliative care

- Epidemiological issues: diagnoses, number and age groups, symptoms
- The care situation: where and by whom, which professional groups, optimal care structures and networking
- Assessment and treatment of pain
 - Observational tools for the assessment of chronic pain in infants and in patients who are unable to communicate verbally
 - Comparison between alternative opioids and morphine
 - The value of intermediate-potency opioids such as tramadol and tilidine and adjuvants for pain relief
- Assessment of symptoms, outcome quality indicators
 - Development of validated assessment tools for symptoms experienced by children
 - Instruments to measure the influence of illness on the health of the parents
- Pharmacokinetics, pharmacodynamics and pharmacovigilance; interactions between drugs
- Research in the field of medical technology on the interaction between growing children and machines

7.10 Research into the palliative care of the aged and patients with multimorbidity

7.10.1 Current state of research

An increasing number of older people are living with frailty and disability and

are suffering from several chronic diseases by the time they die. Patients over the age of 65 who are admitted as acute patients to a medical environment such as a geriatric ward often have a limited prognosis, because their advanced age is coupled with a large number of existing

diagnoses. At present, such patients are offered access to suitable palliative care far too infrequently, even if they are in great need of it (Genz et al., 2010; Hagg-Grün et al., 2010; Schneider & Walter, 2009).

Despite there being substantial numbers of very old patients with complex medical conditions, only a negligible number of publications on their palliative care have appeared. Thus, although in February 2013 a literature search in PubMed for ‘palliative’ combined with ‘elderly’ produced 18,330 hits, there were a mere 15 results for ‘palliative’ combined with ‘multimorbidity’. In the past, most of the patients receiving palliative care suffered from oncological diseases. However, research has also been focusing to an increasing extent on patients with dementia-related illnesses. A PubMed search for this subject produced 712 hits. Studies are currently being carried out into such areas as the assessment and treatment of pain, the administration of antibiotics to treat infections, tube feeding and decision-making at the end of life, as well as the situation in care homes. A recent Cochrane Review indicated that the introduction of palliative care and hospice culture to US care homes is having a positive effect (Hall et al., 2011a).

Additional issues arise in the case of older patients with mental problems other than dementia. Improvements in the medical treatment and psychosocial care of people with psychiatric illnesses such as addiction, schizophrenic psychosis and major depression, or with behavioural disorders in conjunction with mental disabilities, mean that they are also living longer. At the same time, however, the existence of such illnesses is known to be associated with a higher mortality rate compared with the rest of the population. The causes for this are little-known (Lawrence et al., 2010). One

hypothesis is that these groups of people take less advantage of the medical care available (Lawrence et al., 2010). Beyond that, there is little data to hand about the utilisation of palliative care structures; it can also vary depending on the psychiatric condition concerned (Chochinov et al., 2012; Woods et al., 2008; Ganzini et al., 2010). It is safe to assume that for these people too, there is a need for palliative care once their illness progresses to a certain stage. For instance, people with schizophrenic psychosis experience an increased incidence of cancer and a higher mortality rate (Bushe & Hodgson, 2010).

Palliative care for people with mental disabilities is only gradually being addressed by international nursing publications (Friedman et al., 2012; Morton-Nance & Schafer, 2012; Tuffrey-Wijne, 2012). The number of projects and publications in the field of dementia-related illnesses has increased considerably. Apart from a substantial number of studies on the assessment and treatment of pain, there has as yet been little focus on the trajectories of patients with distinctive behavioural and psychological symptoms, despite the fact that these often affect patients with advanced dementia (Passmore et al., 2012; Byrne et al., 2006).

7.10.2 The state of research in Germany: an international comparison

The research listed here provides an overview of the prevalence of publications devoted to these patient groups. Most of the studies have been conducted outside Germany. To date, only two German universities have a chair in both geriatrics and palliative medicine (Cologne and Erlangen-Nuremberg). In 2011, the WHO presented a survey entitled *Palliative care for older people: better practices*, in which it emphasised the need for additional research to be carried out into this group in particular (Hall et al., 2011b). In

Germany, geriatric and (geronto-) psychiatric experts are turning their attention increasingly to the field of palliative care (DHPV & DGP, 2012).

7.10.3 Themes and subject-matter requiring further development

To date, very few studies have been carried out on collaboration between the fields of palliative medicine, geriatrics and gerontopsychiatry, despite there being a consensus about the need for it (Genz et al., 2010; DHPV & DGP, 2012). Symptoms such as pain, dyspnoea, fatigue, depression and other distressing problems often fail to be treated appropriately and effectively. This results in a poor quality of life and loss of dignity for older people. In addition, the older people often undergo unnecessary and stressful examinations, treatments, hospital stays and admissions, such as to intensive care units.

Access to high-quality palliative care for the older people and closer cooperation between the fields of geriatrics and palliative medicine could meet the needs of such people more effectively and help avoid unnecessary costs in the healthcare

and social welfare systems (Emmert et al., 2013). However, more studies are required here.

There are epidemiological questions that should be asked *a priori* in respect of very old patients with multimorbidity. Which patients and how many require palliative care, and when should it begin? What are their diagnoses, to which age groups do they belong, and from what symptoms are they suffering? Their waning ability to provide verbal information makes it especially problematic to assess symptoms which are experienced subjectively, such as fatigue, dyspnoea and nausea. There is a need to develop suitable assessment tools. It is also important to portray care models for these groups, also for special settings such as units for dementia patients with pronounced behavioural abnormalities.

An additional research topic in its own right is the care of long-term older residents with complex medical conditions in forensic psychiatric hospitals. Studies should also be conducted into the extent to which gerontopsychiatric, geriatric and palliative care structures can or must be coordinated with one another.

Catalogue of topics on the need for research in the case of the aged and patients with multimorbidity

- Epidemiological questions against a background of wide-ranging geriatric and gerontopsychiatric symptoms
- Assessing the needs and requirements of this group in palliative situations
- The value of early integration of palliative care for geriatric patients and those with dementia
- Development of criteria to assess the objective of treatment in the case of multimorbidity
- Collection and evaluation of economic aspects of healthcare
- Pharmacokinetics, pharmacodynamics and pharmacovigilance as well as drug interactions in the case of the aged and patients with multimorbidity
- Care models: when, where, by whom, which professional groups, use of technical aids
- Development of integrated models with geriatric, gerontopsychiatric and palliative care structures

7.11 Research on society and the end of life

7.11.1 Current state of research

Wide-ranging and significant research has already been internationally conducted on issues relating to how society manages the end of life and, in particular, how health and social care adapts to the changing needs of an increasingly ageing and multimorbid population (Cohen & Deliens, 2012; Ewers, 2005; Singer & Bowman, 2005). The longer we live as a result of medical, technical and also sociocultural advances harbours both risks and opportunities for people with live-threatening diseases and their immediate social circle, but also for the wider society in which they live and the national health and social welfare systems from which they seek support. Sustaining health and preventing illness during the final stage of life are also being researched in equal measure. This includes questions about the availability and stability of family-centred and informal support systems, aspects of epidemiology and health reporting, as well as questions relating to the design of health systems (including an international comparison of these). The health technology assessment (HTA), steering of end-of-life healthcare policy and, finally, the participation of relevant interest groups must also be examined, particularly the groups of individuals most directly affected, all of whom have to be kept informed (Stjernswärd et al., 2007).⁵⁴ The organisation of physical and social conditions in order to provide care in the community and by the community ('compassionate cities') is also significant here.

7.11.2 The state of research in Germany: an international comparison

For many years, the subject of end-of-life care was largely disregarded by stakeholders in Germany's healthcare system and by social discourse in the country. Only

very recently – not least prompted by initiatives in the area of healthcare research – has Germany too been paying closer attention to end-of-life issues from the perspective of the health sciences. Questions relating to comparative health system research and the steering of healthcare policy are often in the foreground, since these research initiatives are expected to provide the momentum for future decision-making and policy-making processes in Germany. It is, however, generally true to say that research activities in this country lag far behind those of other countries, not least as a result of shortcomings in German public health research.⁵⁵

7.11.3 Themes and subject-matter requiring further development

The health science debate on social and health inequality, which has been widely discussed in the international arena, cannot be allowed to overlook the final stage of life. There is already a known and well-documented link between poverty and health (Lampert & Kroll, 2010), although this cannot be attributed to one single cause, but is multifaceted and complex; less is known, on the other hand, about how social and health inequality affect the final phase of life and its course, or about what opportunities exist for society as a whole to face such inequality. Against this background, there remain a large number of challenges to be confronted by researchers, the key question being: what marks the characteristics of sociocultural conditions, social challenges, and the arrangements made for dying in today's society?

Before answering this, researchers will first have to examine questions in the fields of cultural history, social structures, and medical and cultural anthropology, addressing such matters as the cultur-

⁵⁴ The question of shaping physical and social environmental conditions also plays an important role (Kellehear, 2005).

⁵⁵ The German National Academy of Sciences Leopoldina has published a statement on the subject of public health together with acatech (the National Academy of Science and Engineering) and the Union of the German Academies of Sciences and Humanities.

al, social and historical changes in family structures and their significance for palliative medicine, as well as, for instance, changes in our perception of age and ageing (e.g. from the ideal of the wisdom of old age to that of youthful vigour in old age). Here, too, it would be interesting to extend research into a comparison between different cultures; to examine, for instance, how palliative care is practised beyond Europe – in Japan or India, perhaps. On the other hand, against this background of inequality particular attention ought to be paid to contemporary cultural and social conditions. As our culture evolves towards a society preoccupied with good health, ever-greater importance is attached to the individual with his specific health needs and resources. As a result, our current understanding of health and illness is being replaced by a status quo in which our sense of individual wellbeing is increasingly being dominated by apparently infinite options for health enhancement. This perspective means that illness, and in particular severe chronic diseases, death and dying, are gradually disappearing from the social constructs of health and illness. This is accompanied by an increasing plurality of value concepts in regard to death and dying, and greater heterogeneity in the living environments of different sectors of the population: this applies not only to people from a so-called migrant background or of different ethnic origin, but overall to men, women, the young and the old in their generation-specific life courses, biographical patterns, regional life contexts, etc. In general it can be assumed that there is an increasing differentiation between contrasting subcultures of dying, each with its own different form of social organisation for the end of life and correspondingly distinguishable ‘realities of dying’.

Aspects of setting and target-group oriented health promotion and disease prevention are of particular relevance here – primarily with regard to family-centred and informal support systems, which bear

most of the burden of end-of-life care.⁵⁶ Groups at special risk – perhaps those from a migrant background, educationally disadvantaged groups, the homeless, etc. – deserve special attention. This applies especially to providing users with information about the available options and limitations in terms of organising their own end-of-life period independently, or of coping with a life-threatening disease, or about the availability of hospice and palliative care. Further attention must be given to the provision of generally accessible, quality-assured, barrier-free and independent patient information for different target groups and sectors of the population. In this context, there is general unanimity about the desirability of conducting research into how the social organisation of dying should manifest itself in the future, following changes in voluntary services with the resulting consequences – not only for volunteer-staffed hospice work, but also for the relationship between paid and unpaid work throughout the palliative care branch. The question of which sectors of the population volunteer and their motivations for doing so must be clarified by empirical means, as must the consequences associated with this for social selectivity in the area of palliative care provision.

From specialised palliative medicine options to voluntary hospice work, the different ways in which the end of life can be managed in practice depend on how it is perceived in society: from political awareness, which translates into a readiness to allocate resources or pass legislation, to just being present in people’s everyday knowledge. One of the reasons why appropriate empirical research into social discourse – into the struggle for interpretation made public in the media and in politics regarding how the end of life should be managed and the role

⁵⁶ The setting-oriented approach aims to take account of the patient’s social context and living environment.

which should be played in this by palliative medicine/palliative care – seems necessary is that a more satisfactory political position can be adopted accordingly and more effective responses developed to the way in which care is organised in practice.

The social and political evaluation of palliative care must also be discussed against the backdrop of the structural reorganisation of the healthcare system already underway, as its economisation progresses and pressure to reduce costs grows. (Is palliative care just a ‘cheap alternative’, or the optimum model for end-of-life care?)

Also of practical relevance is the question – which again requires empirical clarification – of who makes which decisions at the end of life and under what (knowledge) conditions, and the role played in this by the respective relationship constellations and institutional/organisational contexts involved. Empirical evidence in this area remains scarce. The more dying is perceived ‘holistically’, and the more intensely society discusses assistance or support in dying in terms of dig-

nity, autonomy, trust, etc., the more important it is to obtain meaningful research findings about the way in which the agenda of dying is set by the respective participants acting in their own interests (Bührmann & Schneider, 2008, p. 145), and its relationship to an implicit organisational adherence to conventional approaches to the dying process.

The relationship between the organisational practices of paid employees and volunteers (networking research) and the associated attitudes (the attitude of professionals to hospice and palliative care culture) should be studied from the point of view of professionalism and organisational sociology. Empirical answers are required to questions, which have barely been raised in the past, about power relationships and structures relating to the existence or absence of obligations and the hierarchical relationships between the institutional stakeholders. This is an area with close ties to that of cooperative relationships between the different players and the much-discussed subject of networking structures in the field of palliative care.

Catalogue of topics on social issues

- Discourses on cultural interpretative patterns relating to illness, death and dying
- Social organisation of dying
 - Cultural and social conditions
 - Social inequality at the end of life
- Setting and target-group oriented health promotion and disease prevention
 - Family-centred and informal support systems
 - User information to facilitate the independent shaping of the final stage of life
- Changes in voluntary services
- The perception of palliative care in society and the significance of its role

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9 List of abbreviations

AAL	Ambient Assisted Living
AAPV	General Outpatient Palliative Care (Allgemeine ambulante Palliativversorgung)
AEM	Academy for Ethics in Medicine (Akademie für Ethik in der Medizin)
ALS	Amyotrophic Lateral Sclerosis
AltPflG	Geriatric Nursing Act (Altenpflegegesetz)
BÄK	German Medical Association (Bundesärztekammer)
BGB	German Civil Code (Bürgerliches Gesetzbuch)
BGBI	Federal Gazette (Bundesgesetzblatt)
BGHSt	Judgments of the Federal Court of Justice in Criminal Matters (Entscheidungen des Bundesgerichtshofs in Strafsachen)
BMBF	Federal Ministry of Education and Research (Bundesministerium für Bildung und Forschung)
BTMG	Narcotics Act (Betäubungsmittelgesetz)
BtMVV	Narcotic Drugs Prescription Ordinance (Betäubungsmittel-Verschreibungsverordnung)
CECo	Cancer Experiences Collaborative
COPD	Chronic Obstructive Pulmonary Disease
DFG	German Research Foundation (Deutsche Forschungsgemeinschaft)
DGP	German Association for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin)
DHPV	German Hospice and Palliative Care Association (Deutscher Hospiz- und PalliativVerband)
DMP	Disease Management Programme
DRG	Diagnosis-Related Group / Flat Rate
EAPC	European Association for Palliative Care
EC	European Commission
EU	European Union
FDA	Food and Drug Administration
GCP	Good Clinical Practice
GKV	Statutory Health Insurance (Gesetzliche Krankenversicherung)
HOPE	Hospice and Palliative Care Evaluation
HTA	Health Technology Assessment
IIT	Investigator Initiated Studies
IZP	Interdisciplinary Centre for Palliative Medicine (Interdisziplinäres Zentrum für Palliativmedizin)
KEB	Clinical Ethics Consultation (klinische Ethikberatung)
KrPflG	Nursing Act (Krankenpflegegesetz)
MS	Multiple Sclerosis
NGF	Nerve Growth Factor
NGS	Next Generation Sequencing
NLM	National Library of Medicine
SAPV	Specialist Outpatient Palliative Care (Spezialisierte ambulante Palliativversorgung)
SGB	German Social Code (Sozialgesetzbuch)
StGB	German Criminal Code (Strafgesetzbuch)
WHO	World Health Organisation

10 Methods

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10.2 Reviewers

This report was reviewed by five independent scientists. These were:

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The academies would like to thank the reviewers for their many constructive remarks and suggested improvements. These were taken into account when preparing the final version, as were the comments of the executive committee and the standing committee of the German National Academy of Sciences Leopoldina.

10.3 Approach

The standing committee of National Academy of Sciences Leopoldina set up the working group on 24 June 2011 at the suggestion of Leopoldina. The report is supported by the German National Academy of Sciences Leopoldina and the Union of German Academies of Sciences and Humanities.

The working group then prepared the text of the report in three sessions. An editorial group comprising the spokespersons and active members of the working group scrutinised the text carefully over the course of five sessions. The report was approved by the standing committee of the German National Academy of Sciences Leopoldina on 4 December 2014.

11 Annex⁵⁷

11.1 Art. 37b SGB V Specialist outpatient palliative care (SAPV)

(1) Insured persons with an incurable, progressive and highly advanced disease with limited life expectancy and who require particularly complex care are entitled to receive specialist outpatient palliative care. This service must be prescribed by a statutory health insurance physician or hospital physician. The specialist outpatient palliative care comprises medical and nursing services and the coordination of these, in particular for the purpose of pain therapy and to control symptoms. Its objective is to enable the insured person pursuant to Sentence 1 to be cared for in familiar surroundings at home or in a family environment; this may include, for instance, institutions providing integration assistance to the disabled, and welfare facilities for children and adolescents. Insured persons in inpatient hospices are entitled to the partial performance of the necessary medical care within the framework of specialist outpatient palliative care. This shall apply only if and to the extent to which other service-providers are not obliged to provide this service. The specific needs of children must be taken into consideration.

(2) Insured persons in inpatient care facilities as defined in Art. 72 Para. 1 of Book 11 are entitled to specialist palliative care, with Para. 1 applying *mutatis mutandis*. Contracts pursuant to Art. 132d Para. 1 shall regulate whether the service referred to in Para. 1 is to be provided in the care facility by contractual partners of the health insurance funds or by the staff of the care facility; Art. 132d Para. 2 shall apply *mutatis mutandis*.

(3) The Federal Joint Committee shall regulate the details of the services in the guidelines pursuant to Art. 92, in particular

1. the requirements specific to the illnesses pursuant to Para. 1 Sentence 1 and arising from the individual healthcare needs of the insured person,
2. the content and extent of specialist outpatient palliative care, including its relationship to outpatient care, and the cooperation of service providers with the existing outpatient hospice services and inpatient hospices (integrative approach); due consideration is to be given to long-established care structures, and
3. the content and extent of cooperation between the prescribing doctor and the service provider.

⁵⁷ Publishers' translation.

11.2 Art. 39a SGB V Para. 1 Inpatient and outpatient hospice services

Insured persons who require no hospital treatment are entitled under the contracts pursuant to Sentence 4 to benefits towards inpatient care or day care in a hospice providing palliative medicine treatment if outpatient care cannot be provided in the insured person's home or family environment. The health insurance fund shall offset the benefits pursuant to Book 11 and bear 90 percent of the eligible costs pursuant to Sentence 1 and 95 percent of the costs in the case of a children's hospice.

11.3 Art. 132d SGB V Specialist outpatient palliative care (SAPV)

(1) Where this is necessary in order to ensure that the insured person receives the appropriate care, the health insurance funds shall conclude contracts with suitable facilities or individuals for the provision of specialist outpatient palliative care, which shall also regulate the payment for and invoicing of such services, with due consideration for the guidelines pursuant to Art. 37b. In addition, the contracts must regulate the manner in which the service provider is to provide consultation services.

(2) The Central Federal Association of Health Insurance Funds shall make recommendations jointly and uniformly with the participation of the German Hospital Federation, the Associations of Care Facility Sponsors at National Level, the Central Organisations of Hospice Work and Palliative Care and the National Association of Statutory Health Insurance Physicians on

1. the requirements which must be met by service providers in terms of materials and human resources,
2. measures to ensure quality and provide additional training,
3. benchmarks for the needs-based provision of specialist outpatient palliative care.

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The German National Academy of Sciences Leopoldina, acatech – National Academy of Science and Engineering, and the Union of the German Academies of Sciences and Humanities provide policymakers and society with independent, science-based advice on issues of crucial importance for our future. The Academies' members are outstanding researchers from Germany and abroad. Working in interdisciplinary working groups, they draft statements that are published in the series of papers *Schriftenreihe zur wissenschaftsbasierten Politikberatung* (Monograph Series on Science-based Policy Advice) after being externally reviewed and subsequently approved by the Standing Committee of the German National Academy of Sciences Leopoldina.

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