



Integrated palliative care

Jeroen Hasselaar

Sheila Payne

(editors)



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Acknowledgements

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The editorial team

Jeroen Hasselaar - project coordinator InsupC

Sheila Payne - dissemination lead

Maaïke Dautzenberg - project manager

Design

Puntje op de i, Ede, the Netherlands (Marja van Vliet-van Beek)

Photography

Anthony Greenwood

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List of authors

ALPHABETICAL ORDER

- Gülay **Ateş**, Researcher, Department of Palliative Medicine, University Hospital Bonn, Germany.
- Csilla **Busa**, Researcher, Senior Research Associate, Department of Hospice and Palliative Care, Institution of Primary Health Care, Medical School University of Pécs, Hungary.
- Carlos **Centeno**, Medical Specialist and principal researcher of the Atlantes Research Programme, ICS, IdiSNA, Instituto de Investigación Sanitaria de Navarra, University of Navarra, Spain.
- Agnes **Csikos**, Medical Specialist in Palliative Medicine, University of Pécs, Hungary.
- Maaïke **Dautzenberg**, EU-project manager at Radboud University Medical Center and senior health care researcher and consultant at Dautzenberg Research & Advice (in collaboration with Free University Amsterdam), Netherlands.
- Anne **Ebenau**, supportive researcher at Radboud University Medical Center, Netherlands.
- Eduardo **Garralda Domezain**, Research assistant of the Atlantes Research Programme, ICS, IdiSNA, Instituto de Investigación Sanitaria de Navarra, University of Navarra, Spain.
- Marieke **Groot**, Senior Researcher in Palliative Care at Radboud University Medical Center and Senior Lecturer at HAN University of Applied Sciences, Netherlands.
- Jeroen **Hasselaar** (Project Coordinator InSup-C), Senior Researcher in Palliative Care, Radboud University Medical Center, Netherlands; projectleader Dutch Federation UMCs, Netherlands.
- Michaela **Hesse**, Researcher, Department of Palliative Medicine, University Hospital Bonn, Germany.
- Sean **Hughes**, Lecturer, International Observatory on End of Life Care, Lancaster University, United Kingdom.
- Birgit **Jaspers**, Senior Researcher and Research Coordinator, Department of Palliative Medicine, University Hospital Bonn, Germany.
- Lisa **Linge-Dahl**, Researcher, Department of Palliative Medicine, University Hospital Bonn, Germany
- Johan **Menten**, radiation-oncologist and palliative medicine physician, Radiotherapy-Oncology & Palliative Care, University Hospital Leuven, and associate professor Catholic University Leuven, Belgium.
- Sheila **Payne**, Emeritus Professor, International Observatory on End of Life Care, Lancaster University, United Kingdom.
- Nancy **Preston**, Senior Lecturer, International Observatory on End of Life Care, Lancaster University, United Kingdom.
- Lukas **Radbruch**, Chair of Palliative Medicine, Department of Palliative Medicine, University Hospital Bonn.
- Ildiko **Radvanyi**, Medical Specialist in Palliative Medicine, University of Pécs, Hungary.
- Sven **Schwabe**, Research Associate, Department of Palliative Medicine, University Hospital Bonn, Germany.
- Karen **Van Beek**, radiation-oncologist and palliative care physician, Radiotherapy-Oncology & palliative Care, University Hospital Leuven, Belgium.
- Marlieke **van der Eerden**, PhD Researcher, Radboud University Medical Center, Netherlands.
- Suzy **Van Ende**, Head Nurse palliative care unit University Hospital Leuven, Belgium.
- Sandra **Varey**, Senior Research Associate, International Observatory on End of Life Care, Lancaster University, United Kingdom.
- Jeroen **van Wijngaarden**, Senior researcher, institute of Health Policy and Management, Erasmus University Rotterdam, the Netherlands.

Foreword

Palliative and end-of-life care has come a long way in 20 years. We have seen a number of strategic shifts in thinking about what palliative care is, what it should deliver and to whom. From a service historically designed to address the needs of advanced cancer patients in the last days and weeks of life, the evidence for and practice wisdom of palliative care would dictate that there is an urgent need for early intervention across a spectrum of chronic life-limiting illness and that palliative care has the potential to contribute to the quality experience of living and dying for all citizens.

In the 21st century, with over 40 million people worldwide likely to need palliative or end-of-life care for their life-limiting or chronic illness, the importance of innovative and novel approaches to engaging with communities to meet this need is immutable.

The aspiration for greater integration of palliative care within the wider healthcare system is also implicit in the clear messaging of palliative care as a public health issue. The recent World Health Assembly resolution 67.19 notes:

Realizing the urgent need to include palliation across the continuum of care, especially at the primary care level, recognizing that inadequate integration of palliative care into health and social care systems is a major contributing factor to the lack of equitable access to such care...

(67th World Health Assembly 2014:2).

The InsupC project conducted under the European Union 7th Framework Programme has striven to meet that need. Through its collaborative approach across several countries, this programme of investigation has identified excellent exemplars of where integration of care planning and care delivery has shown innovation, dynamism and better

outcomes for the patients and families. There are salient messages which emanate from this important international study for the evolving paradigm which is palliative care.

The first is that palliative and end-of-life is not about a place of care. Rather, it is about 'care-in-place', targeted care, reflecting visible need, wherever the patient and family choose to be.

The second is that it reminds us of the inherent value that palliative and end-of-life care places on culture and responding to the mores of individual difference so that each experience of care is uniquely designed and coherently executed. Hence, the voices of the patient and family experience are embedded in this work.

Third, it reminds us of the importance of multidisciplinary working and realising that integration is about partnership and a willingness to work in flexible and novel ways to improve the patient and families experience. For those living with debilitating illness in the face of changing goals of care, this flexibility is the essence of true integration of care.

Most importantly, integration of palliative and end-of-life care speaks to the very foundation of our discipline and the vision of Cicely Saunders in realising that her model of care could speak to the wider healthcare system and has the ability to transform. The InsupC project is a powerful example of the potential for transformation and speaks to a new world view of what palliative and end-of-life care should be.

Challenges remain, not least the need to provide stronger and more responsive communication systems to streamline integration structures. This takes resources but more, reorientation of health

services – and that feeds back to the global public health messages of the World Health Organisation and the need to engage at a political level to effect change.

This book provides the impetus for what can be done and what can be changed. The next 20 years for palliative and end-of-life care will be very different to what has gone before. Understanding the value of what integration of care can bring to patients and families is the new horizon for our discipline.

As President of the European Association for Palliative Care, I welcome the visionary approach expressed in this book and the learning we can achieve from the examples shared therein. My hope is that the work of InsupC is distilled and disseminated so that the potential of palliative and end-of-life care is fully realised for all those we care for.

A handwritten signature in black ink that reads "Phillip Larkin". The signature is written in a cursive, flowing style with a prominent flourish at the end.

Professor Phillip Larkin
President, European Association for Palliative Care

Chapter 1

Introduction

JEROEN HASSELAAR AND SHEILA PAYNE

What is palliative care?

Palliative care concerns the care for patients with a life limiting disease such as cancer and chronic heart failure. The World Health Organization (Sepulveda et al 2002) defined palliative care as follows: "Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Integrated palliative care

The integration of palliative care seems self-evident. The definition of the World Health Organization mentions the importance of integral person based care with attention to somatic, psychosocial, and spiritual aspects of care. Moreover, not only patients but also relatives are mentioned pointing to the social system of the patient. Thirdly, a team based approach is proposed to connect the expertise of all relevant professional caregivers. Finally, early assessment is mentioned, referring to the wish to integrate palliative care more with disease based 'curative' strategies. Altogether, one might wonder whether palliative care integration needs more attention. The answer is yes. It is not clear if and how the idealistic picture as painted in the WHO definition is implemented in daily practice. Moreover, whether this definition has enough potential to guide practice development is also not clear. Investigations show that many patients experience transfers from home to hospital in the last phase of life, and people frequently spend their last phase of life in places that are often not their preferred place of care. Furthermore, it seems that there are considerable differences in the practical organization of palliative care within health systems across Europe. How patients and family caregivers

experience the integration of the palliative care they receive is not yet clear, nor is it clear to what extent palliative care practices are integrated in the (local or national) health system.

Project InSup-C: Integrated palliative care in Europe

These concerns inspired a consortium of European parties to design a project, named InSup-C, to explore the integration of palliative care. The consortium consists of 11 partners; more details can be found in the annex of this book. The main aim of the project was to investigate promising practices for the integration of palliative care across Europe and to formulate requirements for best or better practices for palliative care integration in Europe.

In the project, data from an inventory of 23 promising initiatives for integrated palliative care were selected by the following criteria (van der Eerden et al 2014):

- the initiative is an established local palliative care collaboration;
- the collaboration must contain at least two different organizations;
- a hospital can be part of that collaboration;
- collaborating healthcare professionals must provide direct patient care (not only an advisory function);
- the collaboration has a multidisciplinary background (professionals of different professions must be involved, e.g. physician (specialist, GP), nurse (specialist), social worker, Allied Health Professional, spiritual worker, complementary therapist, others);
- the collaboration aims to provide palliative care for one or more target diagnostic groups in the study (Advanced COPD/CHF/cancer).

Within the InSup-C project, the following working definition for integrated palliative care has been

used: Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to realize continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid.

Inspiring examples of integrated palliative care across Europe

Integrated care can be briefly described as: the right care, at the right time, in the right place, by the right person. The book starts with a chapter on opportunities and barriers for palliative care integration in Europe. The following chapters illustrate five examples of promising palliative care practices across Europe that work towards greater integration of palliative care. These five examples are a selection from about twenty case descriptions that have been collected during the project. The editors have selected a group of initiatives that demonstrate several perspectives on palliative care integration, achieved using different models and in

different countries namely: Germany, Belgium, the Netherlands, Hungary, and the UK. Each chapter starts with a short patient (or family caregiver) story to show a user perspective of palliative care integration. We have obtained informed consent from all patients and their families, and their names are anonymized to protect their identity. After this, we present a description of the health system of the country and the background of the palliative care initiative. Finally, we describe the strengths and opportunities for improvement that the initiatives have identified themselves. The final chapter offers general recommendations and suggestions for the further development of integrated palliative care in practice.

We hope that this book will inspire clinical workers and policymakers across Europe. Furthermore, this book gives guidance on how to look at palliative care from an integrated care perspective. Finally, we wish that readers take up the challenges that lay ahead to provide the necessary care to a growing group of patients living and dying with cancer and chronic disease.

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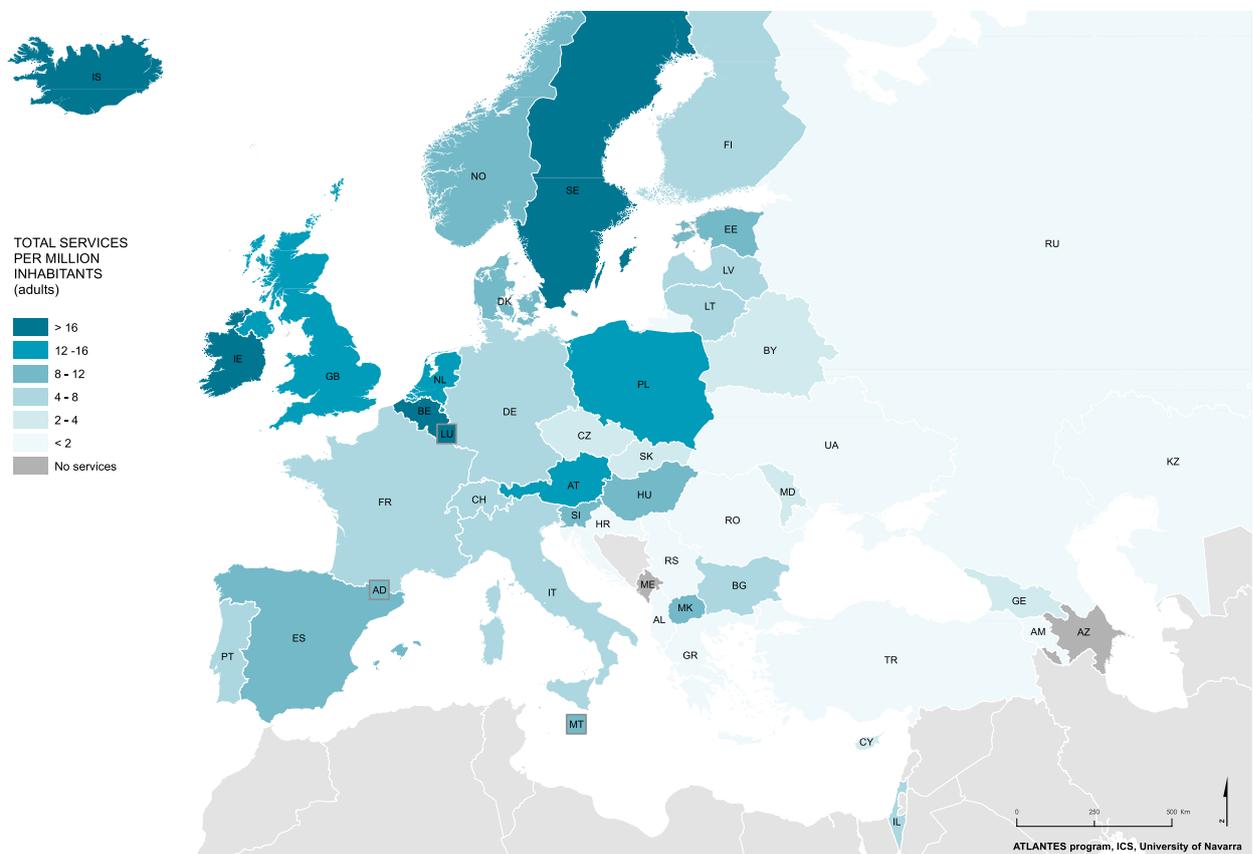
Chapter 2

Public health opportunities to improve palliative care integration across Europe

CARLOS CENTENO AND EDUARDO GARRALDA

The ageing of the European population results in a higher risk of suffering from cancer, neurodegenerative and chronic diseases. Currently, palliative care service provision is unevenly distributed across Europe (see figure below). As a direct consequence, the integration of palliative care in to the national healthcare systems, and in to those disciplines dealing with chronic and advanced diseases, is of the utmost importance to guarantee equal access to appropriate palliative care for citizens in Europe.

This chapter draws upon a previous European study addressing the development of palliative care development in 53 European countries (Centeno et al 2013). It aimed specifically to suggest how to overcome barriers and where to find the best opportunities for the integration of palliative care into healthcare systems. It employs a public health approach and uses a global framework for improving access to palliative care from a political, educational, implementation, and drug availability perspective as recommended by the World Health Organization as a strategy for further development of palliative care (Stjernswärd et al 2007).



Map of palliative care services per million inhabitants across Europe

STRENGTHEN PALLIATIVE CARE POLICIES

Integrating palliative care into policies means revising national health policies, regulations, and allocating funding and adopting specific service delivery models. The WHO in its sixty-seventh World Health Assembly in May 2014, “Urges member states” to develop, strengthen and implement palliative care policies to integrate palliative care services in the continuum of care, across all levels (World Health Assembly 2014).

In the European region, which comprises of 53 countries, national palliative care plans are identified in 18 countries (34%), and over 50% of countries possess palliative care national laws. Still there exist other possible policies to strengthen palliative care provision such as inclusion in general health care, public health or social care laws (Woitha et al 2016). In a study conducted in 2013, national palliative care leaders reported the main barriers to developing palliative care were: the lack of a national plan, the lack of an adequate regulatory framework and insufficient funding. For example, health insurance companies in Europe appear reluctant to reimburse palliative care consultations. Despite the importance of a legislative framework, the greatest issue is the lack of funding allocated specifically for palliative care as reported by 19 countries. The WHO in its declaration reminded governments of the need to ensure adequate funding for palliative care initiatives in policies, education, and quality improvement initiatives. They also support the availability of essential medicines for symptom management.

IMPROVE EDUCATION

Palliative care inclusion into curricula and courses at undergraduate and postgraduate levels, and continuing education for practicing professionals, are key elements for palliative care integration. Besides education, other elements are the engagement of media and public awareness, the development of specialised programmes to train and accredit palliative care experts, and training for family caregivers.

European universities are increasingly including palliative care in pre-qualification courses for future doctors and nurses. In 2015, a study reported that six countries provide mandatory palliative care courses for all medical students. It also indicated that good examples of education are to be found in the United

Kingdom, Belgium, France, Israel, Norway, Austria, Germany, and Ireland (Carrasco et al 2015). In these countries, an educational workforce is developing palliative care education at the undergraduate level. Official certification in palliative care might benefit younger generations in building their careers. Currently 18 countries have a specialty/sub-specialty or a specific competence area in palliative care and ten of these have established it within the past five years (Centeno et al 2015).

INCREASE PUBLIC AWARENESS

Public awareness represents another issue demanding educational efforts. New styles of naming palliative care services, explaining, or working jointly with social care agencies, can promote a better understanding and acceptance in society towards palliative care. Initiatives like caring communities, laws providing access to palliative care, international declarations and other social activities from foundations and civil societies play an important role in raising public awareness.

PALLIATIVE CARE FOR ALL

Implementing palliative care requires developing strategic and business plans that incorporate adequate resources and infrastructures to support palliative care programmes.

A new approach, which has recently been argued for in congresses and public discussions, is that if we aim to provide palliative care for all, we cannot focus only on specialised palliative care. The WHO itself highlights the need of palliative care to be embedded in the continuum of care, with a stress on primary, community and home-based care to achieve universal coverage. But how to find good, valid, feasible and measurable indicators to compare generalist palliative care provision remains an issue. Also, to find and compare promising or even best practices remains difficult to achieve.

MEDICATION AVAILABILITY

Based on the WHO public health model for palliative care, medication availability involves reviewing and improving drug availability policies and practices.

Across most European countries, morphine and other opioids are available and affordable. According to the European Association for Palliative Care Atlas studies, few countries identified problems in opioid availability (Centeno et al 2013). But this does not

mean that morphine, opioids and essential medicines are easily accessible. Availability, as a matter of fact, encounters several accessibility barriers such as “duplicate or triplicate prescription, special forms, accessibility of forms, pay-per-prescription, pay for prescription forms, maximum number of days supplied on one prescription, availability only in concrete designated pharmacies, and only special professionals authorised” to prescribe (Cherny et al 2010).

THE CHALLENGE OF PALLIATIVE CARE DEVELOPMENT

In conclusion, these are times of great opportunities for the development of palliative care (see box). More development and integration is possible if professionals and students are trained in palliative care, and if they have access to well-established palliative care certification programmes as recommended by palliative care national leaders. The expansion of business plans, resources and infrastructures; and widening the regulatory framework would improve the integration into the health care system and must be perceived as a true opportunity by policy makers.

KEY OPPORTUNITIES FOR PALLIATIVE CARE DEVELOPMENT IN EUROPE

- Incorporate palliative care into National Health Plans, regulations, health and social care budgets and service delivery models
- Teach palliative care core competencies at the undergraduate level for all health professionals
- Explain to the public and media what palliative care is and what the benefits are
- Train health professionals as palliative care specialists and provide them with official certification
- Take care of family caregivers by teaching them how to support the patient and take care of themselves
- Introduce a palliative care approach in health programmes for chronic and life threatening diseases
- Develop strategic and business plans that incorporate adequate resources and an infrastructure to support programmes
- Collaborate with palliative care national associations and institutions to find the appropriate path for each country
- Use the WHO public health framework as a guide for develop a National Strategy for palliative care
- Incorporate palliative care into National Health Plans, regulations, health and social care budgets and service delivery models
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- Train health professionals as palliative care specialists and provide them with official certification
- Take care of family caregivers by teaching them how to support the patient and take care of themselves
- Introduce a palliative care approach in health programmes for chronic diseases
- Develop strategic and business plans that incorporate adequate resources and an infrastructure to support programmes
- Collaborate with palliative care national associations and institutions to find the appropriate path for each country
- Use the WHO public health framework as a guide to develop a National Strategy for palliative care

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Karen Van Beek
Suzy Van Ende
Maaïke Dautzenberg
Johan Menten



chapter 3

Enabling patients to stay at home until death: *White Yellow Cross in Belgium*

THE STORY OF PETER AND YVONNE

Peter is 72 years old and lives with his wife Yvonne, who used to be a nurse. He has very severe Chronic Obstructive Pulmonary Disease (COPD) and is oxygen and wheelchair dependent. Talking is difficult. Although he used to be very socially active in the past, he rarely goes out anymore.

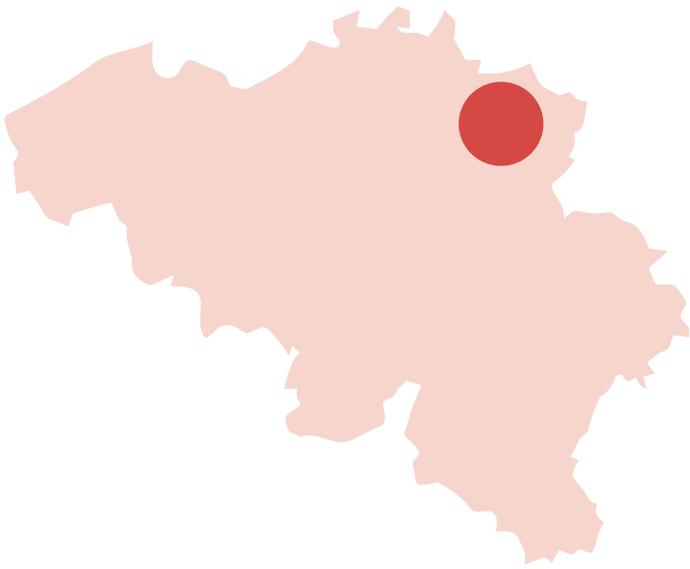
For over a year now, home care nurses of the White Yellow Cross help him to wash and dress in the mornings and put on his nightclothes in the evenings. His nurses evaluate his care needs or problems weekly, such as his back pain or constipation, and coordinate his care. After his last admission in the hospital, the home care nurses have put him on their palliative care trajectory care plan. This means that the nurses and general practitioner are free of charge, and Peter and Yvonne receive some financial support from the government. Despite these measures, it remains tough for them as medication and equipment for his lung disease are quite expensive.

The physiotherapist comes several days a week to teach him to walk with a walking aid. During the week, Peter can always contact his general practitioner for urgent problems. Records are kept on a paper medical file at his home, where home care nurses can write down relevant things that occurred that day and they will record pain and symptom assessments in an electronic nursing file available for the GP to access.

In the beginning Peter reported that he saw too many different nurses. His wife Yvonne contacted the White Yellow Cross and since then only five home care nurses alternately come to their house. Recently his wife cancelled the night visit, as the nurse always came round too early making it impossible to receive visitors at night. His wife now does his care herself, but knows she can always involve the nurses again.

Peter and Yvonne are very satisfied with the care of the White Yellow Cross. They think that the nurses are very professional and have had training in palliative care for COPD patients like Peter, which feels reassuring for Peter and Yvonne. Quite often Peter gets admitted to the hospital. When he is discharged, the hospital notifies the home care nurses and they start their usual caring routine from the moment he is back home. The care is really impeccable, even the general practitioner is enthusiastic and says a bit sarcastically: 'it is the only government funded organisation that works well'. Peter and Yvonne couldn't agree more.





HEALTH CARE IN BELGIUM

Belgium, with over 11 million inhabitants, has a so called compulsory health insurance: everyone has to join a health insurance fund. Health care is primarily funded through social security: working people pay contributions according to their salary. The health care insurance covers 99% of the Belgian population and thus guarantees care for almost anyone who is ill and/or claims medical care. Patients have a free choice of their physician. Payments are usually done by fee-for-service.

PALLIATIVE CARE IN BELGIUM

The gradual development of palliative care in Belgium started in the early eighties. Since the mid-1990s, many initiatives have been undertaken at federal and community levels to enable palliative care. Palliative care is fully reimbursed by health insurance companies and is therefore free of charge for palliative care patients.

Total care provision

Since the introduction of the Palliative Care Law in 2002, patients are entitled by law to receive palliative care. This is defined as the total care provision for patients whose life threatening disease is no longer responding to curative therapies. Patients are entitled to receive information about their illness and to receive palliative care to guide him/her through his/her last episode of life. The major aim of palliative care is to offer the patient and the next of kin as much quality of life as possible and maximum autonomy. This implies multidisciplinary care with physical, and psychological, social and moral support. The Belgian palliative care model aims at enabling patients to stay at home in their last stage of life and to integrate palliative care into usual care. Every hospital has a specialist palliative care team. At home, patients receive care by nurses trained in basic palliative care, supported by a specialist palliative care team that mainly gives advice. This team only provides the direct care when asked to do so by other health professionals.

Financial support

From 1999 onwards, patients who receive palliative care at home are entitled to receive financial support when they meet the criteria of having an incurable disease and a life expectancy of less than 3 months. This is a monthly bonus of € 647 (for a maximum of 2 months). The general practitioner applies for this bonus from the patient's health insurance fund. After approval, patients do not have to pay for the primary care provided by their general practitioner, or for home care, or for physiotherapy. Recently, a national study concluded that this type of palliative care should be not just for terminally ill patients, but for every palliative patient depending on the level of their care needs.

The Palliative Care Indicator Tool (PICT) is used to define palliative care needs

The Flemish Federation of Palliative care (VFPZ) has recently developed a tool that is called the Palliative

Care Indicator Tool. This tool helps to assign patients to three different palliative care categories: (1) Simple palliative care needs, (2) increased palliative care needs and (3) full palliative care needs. It helps patients to benefit from specialist palliative care and the financial support they are entitled to.

Dying at home: seamless care by the White Yellow Cross in Limburg

The home care nursing team White Yellow Cross Limburg, located in the province of Limburg in Belgium, has developed a special palliative care pathway for their patients.

Limburg is Dutch speaking, has both urban and rural areas and a population of over 850.000 (2014). Coal mining was an important industry in the 19th century but in the 21st century heavy and chemical industries have become predominant in some areas. Limburg also produces 50% of Belgium's fruit production.

Home care supported by specialist palliative care

The home care nurses of the White Yellow Cross include nurses with a palliative care role. The home care nurses act as case managers and arrange for additional support if needed, such as materials, specialist care, household helps or night sitters.

Storage room of the White Yellow Cross with medical supplies



The White Yellow Cross has a 24/7 alarm system and availability. These nurses are supported by a second organization called Pallion (the specialist palliative care team in Limburg), and work in close collaboration with others such as the general practitioner or assistants of health insurers. The White Yellow Cross nurses and Pallion have regular meetings with these services to keep patients as independent and self-reliant as is possible in their homes. The general practitioner and home care nurses exchange information through an electronic system so that the general practitioner can monitor the patients' pain and symptoms, including blood pressure or blood sugar levels. After the patient has died, palliative nurses from White Yellow Cross arrange for a meeting with the general practitioner to evaluate the care process.

Comprehensive and well organized

The White Yellow Cross is a comprehensive and well organized service that offers not only nursing care at home, but also family care and medical supplies. They are involved early in the disease trajectory of all cancer patients, but also of chronic disease patients to.

STRENGTHS OF THE WHITE YELLOW CROSS

Specialized palliative care nurses

The White Yellow Cross is unique in the sense that it is the only home nursing service in Belgium that has nurses specifically trained in palliative care. In 2016, in total 27 specialist palliative care nurses work for White Yellow Cross. Each nursing department has one home care nurse specialising in palliative care.

Palliative pathways

The home care nurses of the White Yellow Cross follow a palliative care pathway when the patient is diagnosed with an incurable disease.

When it is clear that a patient meets the palliative care criteria, the nurses discuss the situation with the general practitioner, who contacts the patient and his family, hands over a brochure about palliative care and raises the issue of the supportive palliative care financial bonus. From that moment onwards, symptoms and pain of the patient are monitored daily and the nurses provide holistic care. This specialist palliative care nurse provides advice to other community nurses and the palliative home care team Pallion can be involved.

Bereavement support

Part of the pathway is the aftercare for relatives and other survivors after the patient has died. Nurses send their condolences personally to the family and write a condolence card. One of the nurses attends the funeral. Each year, the White Yellow Cross organise a memorial ceremony to remember deceased patients which can be attended by their relatives.

Continuity of care

Continuity of care is assured by dedicating one nurse who visits patients when he or she is admitted to the hospital. Because this nurse already knows the patient, it is easier to introduce palliative care at home. This facilitates early integration in the trajectory.

The nurses know the patient, family and general practitioner well because they participate all throughout the whole care process.

Regular meetings of the general practitioner with other health care professionals involved in the patient's care, contribute to the continuity of the care process, as well as the good communication between home care nurses and the hospital. Nurses that act as case managers make sure that the patient and family have good care coordination.

Finally, nurses are accessible 24/7 and available 7/7 days a week.

IMPROVEMENT OPPORTUNITIES

Which patients need palliative care?

Despite the existence of a palliative pathway, it remains difficult to know when a patient needs palliative care. Palliative care is still frequently seen as terminal care. General practitioners as well as the home care nurses tend to overestimate the life expectancy of their patients. Consultation between the general practitioner and medical specialists early in the disease trajectory is helpful, also for patients to clarify treatment decisions.

Too few specialist nurses

One nurse per department, who is dedicated as the palliative care nurse, is not sufficient, especially because this nurse has less expertise than the Pallion nurses. Not all nurses are competent to provide holistic care. The quality of this approach depends partially on the personality of the nurse. The patient's openness to holistic care affects this relationship as well, as some patients think that nurses should only perform nursing tasks and 'are not there for existential talks'.



Now we have the same small group of five nurses during the week. It only changes a little in the weekends. We got used to them all. And they told us that they are trained for this. That gives me a feeling of trust
(patient)

KEY RECOMMENDATIONS

More clarity is needed about what is supportive care, palliative and terminal care

The WhiteYellowCross homecare nurses are involved early in any disease trajectory and in this regard they have the potential to provide early integrated palliative care. However, a better understanding and more education about when a patient becomes a palliative care patient is needed, regardless of the underlying disease. Further development of the Supportive and Palliative Care Indicators Tool, adapted to the Belgian situation, could be helpful so that it becomes easier to determine which patient needs palliative care and what level of care they require.

Electronic system for information exchange with the hospital

The White Yellow Cross uses an electronic system to assess and record clinical assessments such as pain levels and blood pressure measurements of the patient, and shares this information with general practitioners. However, information exchange between home care organisations and hospitals is still limited. Electronic information exchange is non-existent.

It is good to have some variation in nurses, because you can talk about something from outside and make a joke, otherwise I just lie here [in bed]. It is not because I am ill, that I have to put on a sad face all day long.
(patient)

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Gülay Ateş
Lisa Linge-Dahl
Michaela Hesse
Birgit Jaspers
Sven Schwabe
Lukas Radbruch

chapter 4

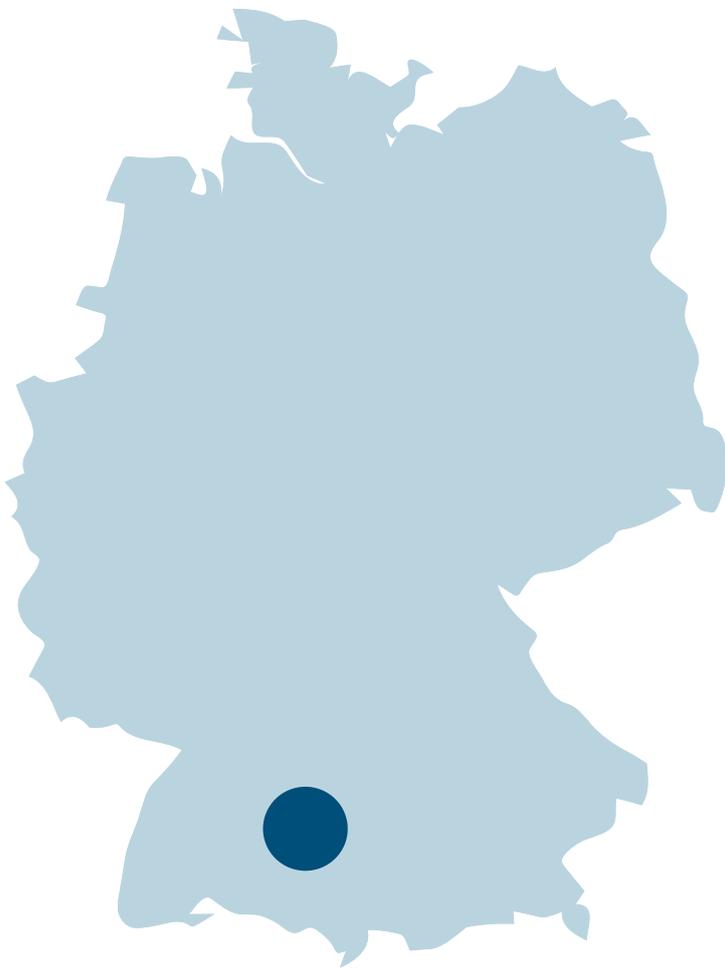
All inclusive:

A One-stop integrated palliative care facility in Germany

THE STORY OF MICHAEL AND CLAUDIA

Michael has cancer and lives with his spouse Claudia. Previously, he was self-employed and used to have a very active life. Besides his work, he played the violin in an orchestra, rode a motorbike and built airplanes as a hobby. It was very difficult for him to give up these activities and be far less socially active than before. It affects the daily life of his family members who are his main caregivers. He spends more and more time in bed and told the palliative care team that he felt that his psychological condition was a burden for his wife. It seems that he is more worried about his caregivers than about himself. He says: "I am able to encourage myself (...) but my family has to deal with all my ups and downs". The regular visits of the palliative care team and their 24/7 availability appears a great help to him. They give him a feeling of being safe and secure which is very reassuring for him and his family members. The team assists the caregivers in organising appointments with the specialised physicians without going through the official channels. "In case of emergency or in case of pain or something like that, they have become my main contact persons. And they are so supportive to us with advice and assistance".





HEALTH CARE IN GERMANY

Health policy in Western Germany after 1945 was shaped by medical practices run by individual physicians and by self-governed organisations and corporations (Diederichs et al 2008). Even today, the health care system in Germany is characterised by self-government. Health care is funded by a system that ensures free healthcare for all via health insurance funds. Insurance payments are based on a certain percentage of the income. The contributions are shared between employee and employer. About 90% of the population is covered by statutory health insurance companies, 5% by a private insurance scheme and another 5% by a mixture of both. A statutory health insurance is compulsory for all people earning less than a certain income (German Medical Association 2016).

PALLIATIVE CARE IN GERMANY

The German health care system offers options for hospice and palliative care including specialist care in palliative care units and inpatient hospices or by specialised teams providing palliative care at home or in nursing homes. Basic palliative care is delivered by home-care nursing services or by the general practitioners (Cremer-Schaeffer and Radbruch, 2012).

Hospice and palliative care not the same

In Germany, the terms hospice and palliative care are not synonymous. Hospice services are either related to hospices (inpatient and/or outpatient) or are independent service providers. A palliative care unit, or a hospital support team, would not be considered as a 'hospice service'. Most often, volunteers accompany patients in their home care setting, but also during hospital stays.

Hospice home care services run by volunteers

Hospice home care services ("Ambulante Hospizdienste") are volunteer services with professional coordinators and trained volunteers providing psychosocial support for the patients and their families. Volunteer services most often also offer bereavement services, mostly with low-level interventions such as bereavement cafés, but also with individual counselling and support (van Beek et al 2013).

Inpatient hospices run by health professionals

Inpatient hospices are independent facilities and staffed by nurses who have specialised in palliative care. Medical care is provided by general practitioners or specialised physicians who work in close cooperation with the hospice and come to see patients on demand.

Inpatient hospices work closely together with volunteer services. Hospices provide care free of cost for terminally ill patients and about 98% patients will die there. According to the law 95% (children's hospices 100%) of the inpatient costs are covered by the health insurers and 5% through donations (§39a Section 1 Social Code Book V).

Palliative care units

The first modern hospice was founded in 1986, whereas the first palliative care unit in Germany was opened in 1983. Compared to other countries, there are fundamental differences in the scope of work

of palliative care units and inpatient hospices in Germany. Admission to a palliative care unit is only possible if inpatient hospital treatment is indicated. Palliative care units are organized as hospital units and are reimbursed through health insurance. They are equipped with beds dedicated for palliative care patients. Patients are admitted to treat symptoms or distress. They are discharged home or to a hospice as soon as possible. Palliative care units are staffed by multidisciplinary teams. Mean in-patient stay is less than two weeks. About 60% of patients will die there, 40% are discharged to their homes or other places of residence (German Association for Palliative Medicine 2014).

Specialised palliative home care

Since 2007, patients with complex palliative care needs (complex pain symptoms, respiratory symptoms, neurological or psychiatric symptoms, other complex symptoms) have the right to receive specialised palliative home care. This specialised care is called 'spezialisierte ambulante Palliativversorgung', abbreviated to SAPV, and is free of charge for the patient and the family. The organisational requirements, and the content and extent of service of specialised palliative home care are regulated by federal state policies and vary considerably from state to state. In most regions, SAPV is provided by multidisciplinary teams,

Patient receiving palliative care from a home care nurse



consisting of nurses and physicians, sometimes also case managers with palliative care training with the option to consult additional expertise. It can include: psycho-oncology, physiotherapy, social workers or spiritual caregivers. Specialised palliative home care can be prescribed by a general practitioner for up to 30 days and can be repeated as long as needed. Specialised palliative home care teams are contracted by the regional statutory health insurers and can also seek contracts with private insurers for remuneration.

A one stop integrated palliative care facility: the example of "Tübinger Project"

As part of a joint project with the University Hospital of Tübingen, a single physician, Dr. Schlunk, launched a palliative home care service at the Paul Lechler-Hospital in 1991, with funding from the Robert Bosch Foundation and the Cancer Association Baden-Wuerttemberg (Krebsverband Baden-Wuerttemberg e.V.). In 1994, the "Tübinger Project" and a fundraising group of the same name were established. The project offers different palliative care options for inpatients, outpatients and home care settings. In 2007, a specialist palliative unit with six beds was established and by 2014 had increased to ten beds. There is a multidisciplinary team. Art and music therapy are also provided. The team also offers psychological and social support to the patients and family caregivers in a way that allows referring the patients to another care setting.

Specialised palliative home care (SAPV) is provided by an interdisciplinary team. Core members of the team are six physicians, a coordinator, a head nurse, ten nurses and administrative officers. All professionals are trained in palliative medicine and/or palliative care. Upon request, further specialist physicians and other professionals (e.g., a psychologist from the University Hospital Tübingen) can be consulted. Additionally, the specialised palliative home care team collaborates closely with the wards of the collaborating two hospitals (Paul Lechler-Hospital and University Hospital Tübingen), the "Brueckenpflege" team, with the patients' general practitioners, other specialists and professions, hospice services, home care services, other specialised palliative home care teams in the region, and the pharmacies with 24/7 services for the emergency provision of drugs and equipment that cannot be provided by pharmacies closer to the patients' homes.

The admission of patients can be initiated by various agents. In 2015, 35% of requests came from wards of the University Hospital or the Paul Lechler-Hospital itself. However, the majority was referred by general practitioners or family caregivers or the patients themselves. After registration and a first visit of the team (physician or nurse), and if the team's criteria for inclusion are met, a care plan will be developed. In the early years, a lot of work was done by professionals on a voluntary basis, without financial resources and in their own free time. At this stage in the 1990s, palliative home care services such as the one founded by the Tübingen initiative, were very rare in Germany.

Fund raising

Meanwhile, reimbursement of specialist palliative home care is available. However, only 80% of the total expenditure accrued in 2015 was covered by health insurance with the remaining 20% paid by the fundraising group "Tübinger Project". Charitable funding fortunately remains high (above 100,000€ per year) making sure that the necessary equipment – such as a portable sonographic equipment, medical bag or a new car for the home care team – can also be financed. Specialised palliative home care teams in the federal state of Baden-Wuerttemberg can, in principle, admit patients at an earlier stage of their life-limiting disease. However, this early integration often results in remuneration problems, because a wide range of their expenditures for treatment or support options will not be fully compensated by the health insurers.

Single reference approach for continuity in palliative care

The "Tübinger Project" provides a single point of reference for the continuity of palliative care. It is an autonomous service located at the clinic for tropical disease – Paul Lechler-Hospital – and it integrates a comprehensive-care approach into their daily work with patients. Some of the hospitals' healthcare professionals (e.g. physicians) are simultaneously employed in the specialised palliative home care team for some percentage of their working time. Following discharge, the physicians from the specialised palliative home care team continue to consult with the severely or terminally ill patients at home. Sometimes it occurs that the responsible physician in the hospital remains the main contact person for a patient and his caregivers no matter what the patient's care setting (inpatient or home

care). Then the monitoring of, and adjustment in the palliative care plan, the professional support and the sharing of information, as well as the counselling of patient and caregivers remain in one hand.

Managing the patient's palliative care plan

The specialised palliative home care team acts as a case manager of the patient's palliative care plan. They help to organise transitions between care settings and to reduce or even prevent hospital admissions. A particular focus of work is to support the patient in staying at home for as long as possible. They try to get in touch with patients early on in the trajectory of a progressive disease, so that an adequate level of trust is established in case of emergencies and in the final phase of the patient's life.



The physician has a dog, and when he goes out for a walk with his dog he just stops by my home.
(patient)

Confidence of patients in primary contact person

This model of professional care-giving was acknowledged by numerous patients and caregivers when they were interviewed. They described the Tübinger Project initiative as their first and single contact point. All respondents had confidence in their primary contact person that goes beyond medical treatment. Firstly, the patients' confidence is built up proactively via regular contact by phone and owing to their extraordinary flexibility for spontaneous visits.

Electronic documentation system for information exchange

Additionally, palliative home care service staff are well organised and well informed, which does not seem to be the case for other physicians involved

in the care of the patients. Using a “cloud” based documentation system, the initiative can quickly share information in real time within the team, while other professionals are informed via phone calls, fax or email. A lot of time can be spent on communication with patients and their relatives for counselling and for obtaining all necessary information. This enables a comprehensive assessment of the patients’ and their caregivers’ needs. The fact that the initiative has been very well known in the community for about 25 years and is well connected to all partners of the “care network” facilitates a good information flow. Last but not least, there is a comprehensive approach that inter-relates biological, psychological and social factors. One family caregiver expressed her positive surprise about the organisations’ support in a situation of family conflict that was a serious concern for the patient.

According to the 2015 annual report, the specialised palliative home care physicians spent most of their time (63%) on home visits and on-call duty and almost one fifth (19%) on counselling by phone. With the help of the specialised palliative home care team, 76% of those who expressed a preference to die at home or at their current care setting were actually able to do so, whereas 24% died in a hospital (Tübinger Project 2016).

STRENGTHS OF THE TÜBINGER PALLIATIVE CARE APPROACH

Factors that support the initiative in its delivery of integrated palliative care are:

- Provides a one-stop palliative care support service
- Appreciates patients’ individual preferences
- Strong team spirit is fostered by a flat hierarchy between care network members
- 24/7 availability of nurses and palliative care physicians
- Prevents hospital admissions
- Significant charity funding
- Plays a coordinating role in the local care network and close collaboration with general practitioners, social care wards, nursing services, hospice outpatient care, hospitals and inpatient hospices
- Good internal information flow (cloud solution), communication and information sharing with the patients’ and local care network

I experience it as a positive togetherness. Since the Tübinger Project started, the patients die at home in absolute peace and with perfect organisation.
(general practitioner)

IMPROVEMENT OPPORTUNITIES

Factors that hinder the initiative in its delivery of integrated palliative care are:

- Predominance of patients with a non-curable cancer disease and far too few patients with other incurable (chronic) diseases such as chronic heart failure
- Re-imburement from sickness funds only for restricted periods of time. Too early integration of patients (with extended duration of specialised palliative home care) is not reimbursed.
- Transition from inpatient hospital care and other palliative care settings, or vice versa, affects the continuity of medical treatment
- Reimbursement of specific medicines or medical equipment is difficult
- Providing continuity of medication and medical devices during the transitions from inpatient to other care settings, and vice versa
- Implementation of a “palliative care ID” showing that a person is being treated by a palliative care team

KEY RECOMMENDATIONS

- A one stop palliative care service with a single contact point gives confidence to patients, can organize transfers between settings and probably reduces hospital admissions
- The presence of palliative care SAPV team in the community helps to build a care network including home visits and telephone consultation
- Integrated palliative care requires a considerable investment of local health care institutions because it is not fully reimbursed
- A cloud based information system appeared to be helpful for information sharing within the palliative care team but may need to be expanded to other involved caregivers
- More and better access for noncancer patients is still needed
- Implementation of a palliative care ID for patients treated by a SAPV team is recommended

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Agnes Csikos
Ildiko Radvanyi
Csilla Busa



chapter 5

Good care and innovation: *an integrated palliative care initiative in Hungary*

THE STORY OF A FAMILY CAREGIVER CALLED YBOLYA

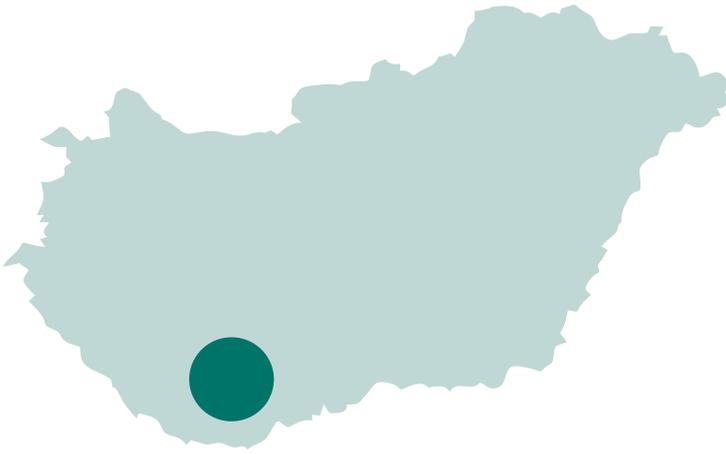
After a delayed diagnostic procedure my father was diagnosed with multiple metastatic lung cancer. Even though my father has been on pain medication for half a year, his pain was not managed well and he was suffering a lot. Doctors did not give us adequate and detailed information about his prognosis, but we felt that his condition was deteriorating. We were in despair. Once when my father was on the Pulmonary Ward treated with intravenous antibiotics for his pneumonia, his doctor referred him to the palliative consult service to seek expert opinion to relieve my father's unbearable pain. Advice was given by the palliative care consultant who suggested changes in his pain management. After his discharge from the hospital, additional support and follow up was provided by the palliative outpatient clinic.

On our first visit to the palliative outpatient clinic, the palliative care doctor was talking with us for an hour. Her personality and full attention helped my father to talk about his problems openly. She gave her time and was really listening to my father and gave a detailed explanation regarding options and plans for his pain and symptom management. The significant reduction in my father's pain was very reassuring and our former hopelessness was replaced by an understanding of palliative care. We visited the palliative outpatient clinic fortnightly, which provided the feeling of being safe and supported. Even humour could take place during these visits.

Although my father's general condition did not improve, our perspectives changed, and this made it easier for us to cope with the situation. Instead of abandonment and rejection, we started to receive support not just for my father but for the whole family. As the disease progressed, my father became weaker and was not able to go to the outpatient clinic. Therefore his palliative care doctor arranged hospice care at home. From that time professionals were coming to our house from the hospice team and my father always received care according to his needs.

We got a lot of help caring for my father, we were taught how to bath and feed him, and we were supplied with home care equipment. The hospice doctor and the nurse were always available when we needed them, their presence and their answers were always reassuring. Our relationship with the hospice care team was very personal - we never felt that our case is only one among many. Their dedicated and professional work was a great help for us during this difficult period. My father could stay at home and die at home as he always wished with the expert support received from the hospice team. My mother and my brother were also grateful that he was comfortable and could spend his last months at home.





HEALTH CARE IN HUNGARY

In Hungary, health care is provided free of charge through the National Health Insurance Fund (NHIF). Services are funded through national taxation. Everyone is entitled to register with a general practitioner who provides primary care supported by district nurses and who can refer to specialist outpatient clinics for advice and specialised care. Prescribed medicines are subsidised and opioid medications are heavily subsidised. Nursing homes and care homes are mainly government funded but can be commercial or charitable organisations as well, still receiving reimbursement from the NHIF. Hungarian patients need to pay out of pocket for some aspects of their care which is therefore not freely available to all people. However, long waiting lists exist to get in to nursing homes or care homes due to the lack of sufficient numbers of beds and units in the country.

PALLIATIVE CARE IN HUNGARY

The Hungarian government regulates four different types of specialist palliative care:

1. Home hospices
2. Inpatient hospice care (freestanding hospice or unit in hospital)
3. Consultation services within hospitals
4. Outpatient clinics

Both home hospice (1) and inpatient palliative care (2) are funded by the National Health Insurance Fund (NHIF) since 2004. However, hospice organisations depend on additional sources of funding (such as charitable donations). The remaining forms of specialist palliative care include consultation services (3) and outpatient clinics (4) which are regulated at a central level, but not reimbursed by the NHIF. Hospitals may directly fund these palliative care services or offer the use of their facilities to specialist palliative care staff. All hospice care services are free of charge for patients and families in Hungary.

Mostly cancer patients

Both home hospice and inpatient palliative care services are legally required to provide a minimum of 80% of their services to cancer patients, and a maximum of 20% to non-cancer patients. This has caused under provision of specialist palliative care services to the non-cancer group. Although non-cancer patients have less access to specialist palliative care services, they may have access to home care or specialist pain clinic services.

Hospice foundations since 1991

The development of hospice-palliative care in Hungary started more than 25 years ago. The hospice movement was launched by Alaine Polcz during the late 80s when the hospice philosophy was completely unknown in Hungary. She was a devoted psychologist who worked with dying children and their families. Alaine Polcz also published several important books on attitudes towards death and dying and challenges during end of life care. The first hospice organization, the Hungarian Hospice Foundation (HHF) was established in 1991. The primary aim of HHF was to attract attention to the problems of the thousands of people dying from cancer, and their services were based on the needs of patients and on open communication between patients and physicians which was not a common practice in those days.

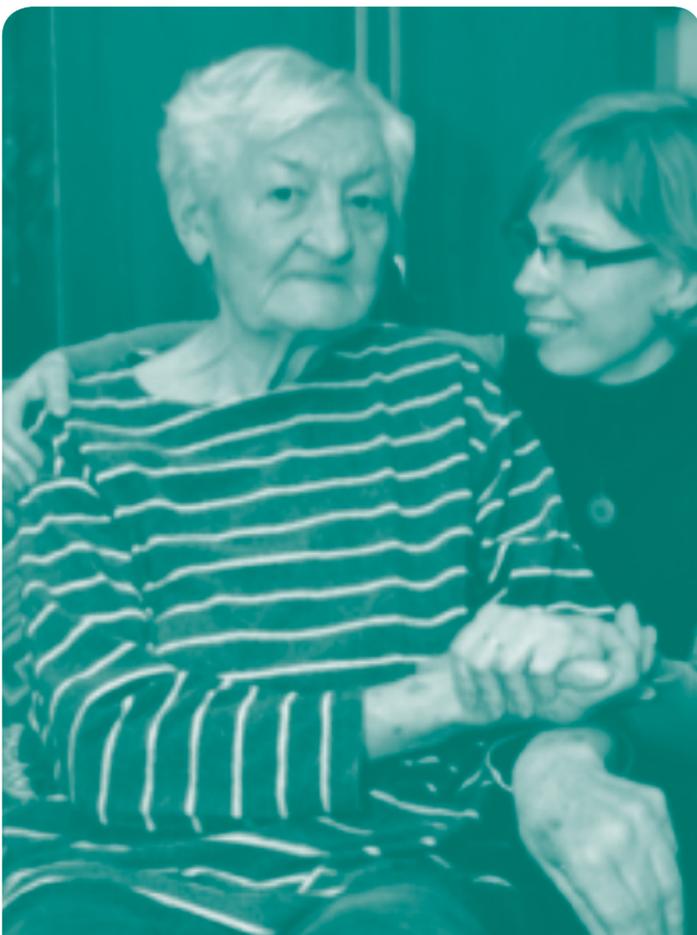
In 1995 the Hungarian Hospice-Palliative Association

(HHPA) was established with the collaboration of 19 hospice service providers. The following achievements and developments in those years are mostly due to the activity of the Hungarian Hospice-Palliative Association in collaboration with civic and professional organizations. In 1997 there was a legal mandate and support for hospice care. Hospice care was described in the Hungarian Health Care Act as the preferred care for terminally ill patients. In 2002 National Palliative Guidelines were developed, reviewed and updated in 2010 and 2015.

New rules and regulations

Following a review by the Hungarian Parliament in 2003 radical changes began at a regulatory level. One of the most important results was a Ministerial Decree of Minimum Standards for Hospice-Palliative Care including defining what this care is with minimum educational and professional requirements for staff. The Hungarian National Health Insurance Fund started financing/reimbursing hospice care from 2004. Hospice care recommendations were integrated in the National Cancer Control Program in 2006. In 2010 the National Health Committee proposed to integrate palliative medicine in graduate and postgraduate medical education, to promote a hospice approach and to develop hospice-palliative care.

Palliative care physician and patient



Home care and inpatient hospice care

Since 2004 two forms of services have become integrated in the health system: home hospice care and inpatient hospice-palliative care. Home hospice services have been continuously expanded and to date hospice home care is widely available across the country. The multidisciplinary team offers hands-on care and also provides advice to GPs and community nurses. They can provide not only end-of-life care but still the majority of patients are referred for terminal care.

Uneven distribution across urban and rural areas

At present, 72 services provide hospice home care with multidisciplinary teams covering almost all locations in the country. Inpatient hospice-palliative services have also developed since 2004, with currently 215 hospice beds available in 15 locations. Unfortunately they are not evenly distributed across the country but mainly concentrated in a few urban areas.

Uneven distribution and limited accessibility

Patients' access to hospice-palliative care is still limited in Hungary mainly due to the uneven distribution of inpatient hospice services. Patients with a cancer diagnosis are eligible for hospice services but the availability of hospice-palliative services for non-cancer patients is limited. Hence 90% of hospice recipients are cancer patients.¹

Another barrier to access care is that despite the professional educational programmes and public campaigns, patients and doctors may still lack adequate information and knowledge about the availability and the benefits of hospice-palliative care. Further extensive training and educational programmes are needed to reduce this barrier.

Most long acting strong and weak opioids are readily available in Hungary. Fentanyl is the most frequently used opioid in the country, making up about 90% of all strong opioids used. There is limited availability of short acting strong opioids, only injectable morphine and tablets can be prescribed. The ultrashort acting strong opioids are not available in Hungary.

¹ Health insurance covers the care for the care provider only in case of patients suffering from cancer, AIDS, autoimmune and chronic neurological disease (ALS, MS).

Access to strong analgesics in hospitals, as well as in inpatient and home hospice care is assured. All doctors can prescribe opioids in an emergency/acute case but the prescribers for long term opioids are GPs in Hungary. However, some GPs do not have sufficient knowledge regarding the use and prescribing of opioid medications.

The Integrated Palliative Care Network in Pécs

Integrated palliative care in Pécs is based on the Clinical Center of Pécs and a wide care network around it. The Clinical Center of Pécs, one of the largest healthcare providers within Hungary, is part of the University of Pécs. The University of Pécs was the first university in Hungary founded by King Louis the Great in 1367. At present, it pursues three types of activity: patient care, education and scientific research. The institution includes 28 departments, institutes and a number of specialist surgeries (outpatient clinics), and the care is backed by an integrated management system.

The University of Pécs has been playing a leading role for more than a decade in the development of hospice-palliative care. The development of an integrated palliative care initiative began with the start of home hospice care in 2004, and by 2016, due to the introduction of innovative forms of care, the initiative provides a unique example of integrated care at a regional level. The University of Pécs formed the first and so far the only hospice palliative care department in the country. The department offers undergraduate and postgraduate education for medical and nursing students as well training for doctors and the multidisciplinary team, and it is also involved in national and international research.

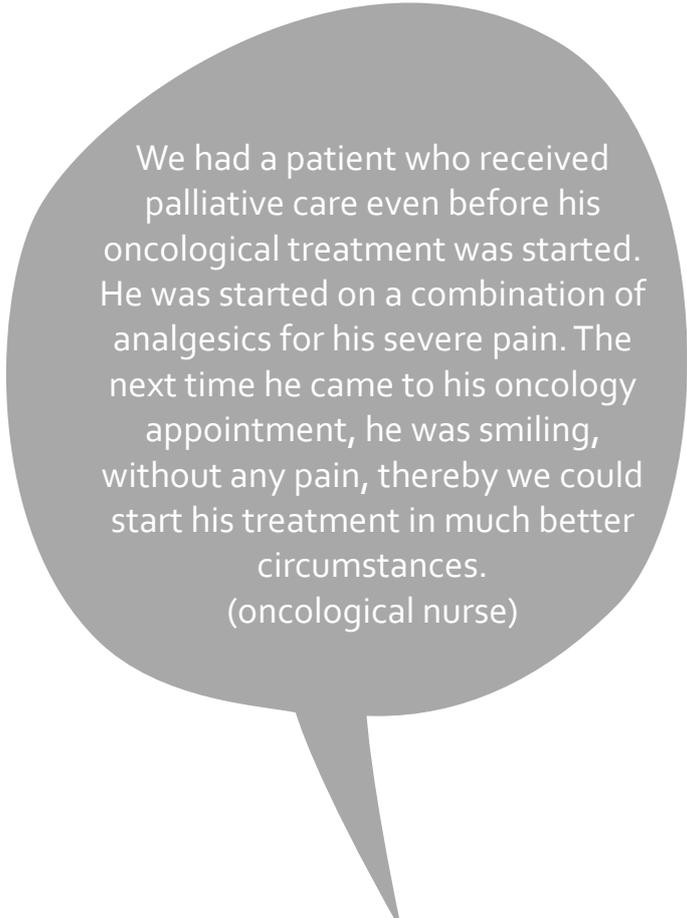
Integrated Palliative Care Network in Baranya County

Baranya is the most southerly county in Hungary. Its land area covers 1710 square miles (4430 square kilometres). Baranya County is bordered by the Danube to the East and the River Drava to the South. The region has one of the most diverse landscapes in the country: the Northern part is a mountain area with large forests, the Eastern and Southern parts are flat. Baranya County has a favourable Mediterranean climate, with a high number of sunshine hours (Local Government of Baranya County, 2009).

According to the Hungarian Central Statistical Office, the population of Baranya County is 371,110,

there are 301 towns and villages. The county seat Pécs is the fifth largest cities of Hungary, but almost 70 percent of the settlements are small villages with a population under 500. Many of the small villages experience socio-economic disadvantage.

The deterioration of the position of the county is related to its economic structure. Industrial production plays a significantly smaller role in the economic performance of the region than is the national average. Unemployment is high, particularly in south Baranya (Local Government of Baranya County, 2009).



We had a patient who received palliative care even before his oncological treatment was started. He was started on a combination of analgesics for his severe pain. The next time he came to his oncology appointment, he was smiling, without any pain, thereby we could start his treatment in much better circumstances.
(oncological nurse)

Services offered by the Integrated Palliative Care Network in Pécs

The following services are available within the integrated palliative care network:

- Consultation service
- Outpatient clinic
- Home hospice care
- Inpatient hospice care

Of these services, hospice home and inpatient care has been available since 2004. The specialist palliative care outpatient service was launched in 2012 and it is one of only five such services in the country.

Although the clinic can receive patients from all over the county, the vast majority of patients are referred from the city of Pécs. Patients can receive care at the palliative outpatient clinic during the early stages of their illness.

Palliative inpatient consultation service is another service that is a novelty in Hungary. It was launched in 2013 and currently, this form of care operates as a pilot programme. Only three examples of this type of service are available in the country.

The main barrier to the widespread uptake of these kinds of services is the lack of regular reimbursement for the services by NHIF.

Multidisciplinary and integrated care

Multidisciplinary care is provided to patients and families in all of the above mentioned services.

Within the Network the following professional care providers are involved in integrated palliative care: palliative care consultant, GPs with a special interest in palliative care, outpatient clinic nurse, hospice nurse, hospice physician, physiotherapist, dietician, social worker, and psychologist. Psychological support and bereavement services are also available within the network.

In addition to professional care providers a number of volunteers work in home and inpatient hospice care. Volunteers support patient care as well the organisation (fundraising, raising awareness, community programmes).

STRENGTHS OF THE INITIATIVE

Diversity of services

The network in Pécs is at an advanced stage of integration of providing palliative care across the continuum of care. An outstanding strength of the initiative is the diversity of forms of care, which enables integrated palliative care to be delivered in the region.

Integration of training and practice

The university education and research background is also very supportive which helps complex and high-quality care in terms of training and practice (care providing).

IMPROVEMENT OPPORTUNITIES

Not enough qualified staff

Compared to the population needs, there are few psychologists, doctors and nurses qualified in palliative care. Many of the care providers are working part-time or in addition to other roles. As in the Hungarian health care system in general, there are concerns about workload of the care providers in the integrated palliative care initiative of Pécs, too.

Lack of funding and late referrals

Funding is a national issue, and every form of health care is affected.

The low and late referral to hospice care is an existing problem as professionals and patients do not have a good understanding regarding the benefit of hospice care.

Lack of information sharing

Continuity of information is another problematic issue in relation to the integration. At present, the IT systems for patient documentation are fragmented across organizations.

My hospice doctor organizes everything within a very short time, everything that I need ... I always get help immediately even calls the pharmacist to make sure I will receive the medication prescribed.
(patient)

KEY RECOMMENDATIONS

Integrated palliative care can be improved rapidly in the short term by:

- Training more palliative care physicians and skilled palliative nurses in the region
- Training for GPs regarding the use of opioid analgesics
- Development of 24-hour on-call services for hospice home care
- Ensuring reimbursement for the inpatient consultation service and palliative outpatient clinic by the National Health Insurance Fund would be an important step to integrate this type of service into the Hungarian healthcare system
- The health system should include access for patients with COPD/heart failure, because the service is currently mostly directed towards cancer patients
- Development of a modern IT system for patient documentation is essential to improve quality and continuity of care in general

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Marlieke van der Eerden
Jeroen Hasselaar
Anne Ebenau
Marieke Groot

chapter 6

Continuity of cancer care between a regional network and a multidisciplinary oncology unit: *An example in the Netherlands*

MARGARET'S STORY

Margaret is 49 years old and diagnosed with incurable lung cancer. She's still receiving palliative chemotherapy. She lies in bed almost all day, is fairly immobile and dependent on others. She is having difficulties with eating and for that she has a stomach feeding-tube. Sometimes she finds it hard that she is not the person that she used to be anymore. Her husband is Karel aged 49 years old. He is her family caregiver. He has experienced burn-out before and consulted the general practitioner about the possibility of his wife receiving terminal homecare and to talk about (future) circumstances. He also adapted his working hours to take care of his wife. As a family caregiver, he is the main person responsible for daily chores and he organizes care (supplies).

Once a day Margaret is visited by a home care nurse called Anja who has specialized in palliative care. Margaret reports that this was arranged after her oncology nurse brought it up during a multidisciplinary meeting. Margaret is not quite sure who is joining these meetings, but does feel that when something is brought up, professionals respond and take action.

Together with Anja, she talks about how she feels and about ways to cope with test results. Margaret remembered that Anja mentioned the possibility of a psychologist, just in case.

Margaret considers her oncologist as her main professional caregiver, because he controls and checks upon her health. He knows what possibilities are left. He is in touch with several nurses and the general practitioner. During the past years, he had sent a report to the general practitioner twice a year, but she thinks it could be more often. She says: "then the general practitioner is more informed. In response maybe, he would come or contact us more often".

Also, she states that the oncologist is a very nice person and tells Margaret that they are in the process together and she is allowed and enabled to decide things along with the oncologist. Margaret states "well, I think that's exceptional, when a physician tells you that. That gives me a good feeling...". Although there's no direct contact with the oncologist, Margaret reported that she can always call and that the oncologist responds as soon as possible, often with clear explanations to Margaret's questions.

She really appreciates these things.





HEALTH CARE IN THE NETHERLANDS

All Dutch inhabitants are legally obliged to have basic health insurance. This insurance covers the costs of, for example, consulting a general practitioner, hospital treatment and medication. In addition to this basic insurance, anyone can volunteer for supplementary insurance to covers costs not included in the standard package. The health insurance system in the Netherlands is based on the principle of social solidarity. Together, we all pay the overall cost of health care. Everyone contributes, for example, to the cost of maternity care and geriatric care. From 1st January 2015 the government has introduced major changes in the way long term care and support are organised. The policy is that people should live at home for as long as possible and that people with a disability live as independently as they can. In the 'new system' municipalities are required to ensure the care and support for people living at home. Medical and other forms of care in the home, such as nursing and personal care, are still covered by healthcare insurance. This is known as 'district nursing'. People who require constant care or supervision are entitled to a place in a residential facility that provides intensive care for vulnerable seniors and people with a disability or psychological condition. The criteria for admission into nursing homes however, are stricter nowadays than a couple of years ago. For this kind of care an 'out of pocket' financial contribution from the person who is taken care of, is necessary.

PALLIATIVE CARE IN THE NETHERLANDS

The term palliative care was first used in Dutch medical literature in 1973. At that time care of the dying was mainly provided by general practitioners, nursing home physicians or medical specialists. Following other countries, the first hospice, called an almost-at-home-house, was founded in 1988. Growing criticism on the content as well as the organisation of the care at the end of life, also led to the establishment of 6 centres for the development of palliative care, appointed by the Ministry of Health, Welfare and Sports during the period 1998-2004. During these years and in close cooperation between universities, academic hospitals, nursing homes, comprehensive cancer centres, hospices and volunteer organisations, knowledge concerning palliative care increased and dispersed.

Regional networks for palliative care cooperation

Regional networks for palliative care cooperation were designed, established and implemented. In this period the first specialist palliative care teams were established in hospitals, although the Netherlands does not have a medical specialty of palliative medicine. Consultation teams in primary care were also established providing 24/7 telephone advice and support about aspects of palliative care to professional caregivers. After the establishment of dedicated centres based on government support, palliative care continued to develop in local services. The national government however took the view that another stimulus was needed for further improvement and therefore launched, in 2014, the National Programme for Palliative Care. In this programme "PALLIANTIE, more than care", funded with 51 million euro, projects stimulating research, education, and implementation could be funded. Part of this programme is the establishment of 8 centres of expertise connected to the 8 university medical centres. These centres of expertise closely collaborate with the regional networks to drive innovation, education, and improvement of palliative care.

At home: generalist health professionals supported by palliative care

It is a shared value in the Netherlands that people should be able to die in their preferred place. The government supports the idea that palliative care must be provided primarily by generalist health

professionals, supported by palliative care experts in case they need advice. This means that general palliative care is provided in primary care as well as in hospitals and nursing homes.

Specialised palliative care in hospitals

In hospitals we see a tendency towards organizing specific palliative care functions such as specialist palliative care consultation teams, dedicated beds for palliative care patients or a dedicated outpatient clinic or day-care. In 2012 a specific financial structure for palliative care in hospitals was introduced (called 'DBC palliative care'). With certain preconditions, six organisational palliative care services are funded now. This system for example requires hospital professionals from several disciplines to work together in multidisciplinary meetings. As such, you can say that it demands integration of palliative care activities.

From the year 2000 onwards, small dedicated palliative care institutions were established; almost-at-home-houses, units for palliative care units in care homes, nursing homes and hospices. In 2016, the Netherlands has around 200 institutions for specialised palliative care.

Entrance of the home care organisation, which is one of the main partners of the initiative



MULTIDISCIPLINARY CANCER CARE CONNECTING PRIMARY AND SECONDARY CARE IN SCHIEDAM

In 2000, a multidisciplinary oncology unit was established in a regional hospital in Schiedam. This oncology unit aimed to provide continuity of care for patients with cancer focused on the patients' needs and regardless of where they are. As patients continuously move between home, hospital and other regional care organisations, an initiative was needed that connected these care settings and optimized collaboration between all professionals involved. A so called 'transmural care' initiative was needed. Transmural care is defined as 'healthcare tailored to the patient's needs, provided on the basis of cooperation and coordination between general and specialised caregivers, with shared responsibility and specification of delegated responsibilities'. The multidisciplinary oncology unit therefore created weekly transmural multidisciplinary meetings in which the unit itself as well as other organisations within the regional palliative care network would be represented. The weekly transmural meetings are held at the oncology unit of the regional hospital in Schiedam. The initiative is part of the regional palliative care network 'Nieuwe Waterweg Noord', covering four medium-sized towns. This regional palliative care network is supported by the Comprehensive cancer centre of the large city of Rotterdam. The unit in itself is not what's so special in the Netherlands, neither is the existence of a network of organisations which try to collaborate in order to organize palliative care smoothly. What makes this initiative special is that the organisations and persons involved have found a way to realize what all individuals and individual organisations strived for but found very hard to put into practice: a seamless web of care around a single patient in need of palliative care and his/her loved ones.

Location of the initiative

The hospital in Schiedam is located in a medium-sized town which is part of the so called health region of Rotterdam. The population of this region is 1.278.525 and the total mortality in 2012 was 1237 per 10,000 citizens (392 caused by cancer; 322 by cardiovascular diseases and 105 by pulmonary disease).

Services offered by the initiative

Transmural multidisciplinary meetings are the unique core of palliative care at the hospital and are

held weekly. They are attended by:

- the hospital's clinical staff (medical oncologist, transfer nurse, specialized oncology nurse, secretary, spiritual worker, dietician, social worker, psychologist)
- a nursing home physician (also palliative care consultant)
- a network coordinator (representing home care and palliative care units)
- invited general practitioners

Both inpatients and outpatients from the oncology unit who are in need of palliative care are eligible to be discussed in the Transmural team. Each participant can refer patients to the meeting. During this transmural team meeting decisions about inpatient and outpatient care are coordinated around patient's needs. After each meeting a work plan is written and sent to all participants including the general practitioners involved. Participants of the Transmural team are paid by their normal employer (hospital, nursing home, network funds). All these aspects give meaning to integrated care by expressing that 'it's time to quit talking and start doing something'.

Network of care provision

The multidisciplinary oncology unit with its transmural multidisciplinary meetings is part of a regional palliative care network which aims to connect all organisations covering the network to provide and coordinate care around patient's palliative care needs. Apart from the hospital, members of the network include:

- Various home care organisations
- Nursing homes
- A Hospice

The regional palliative care network also closely collaborates with a range of other (non-member) care providers:

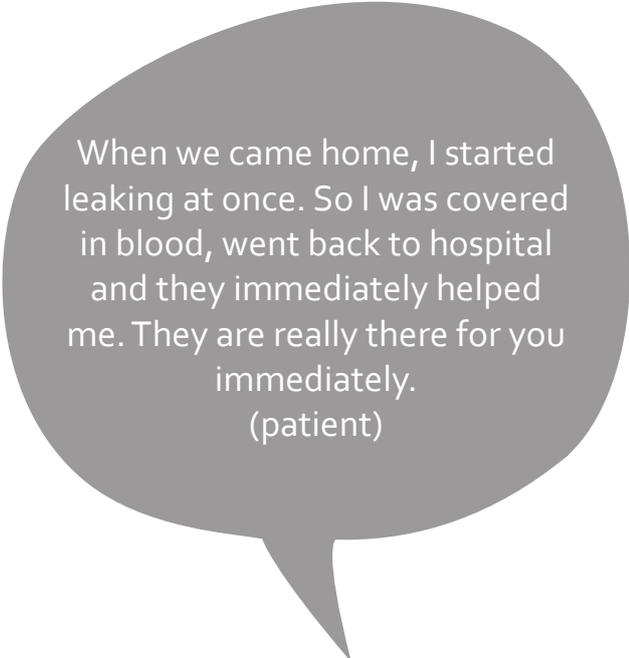
- General practitioners
- Mental health care organisations
- Family caregivers support organisation
- Volunteer organisation for patients with cancer and their relatives
- Home care organisation

Furthermore the regional palliative care network involves a range of working groups and teams responsible for education, quality, coordination of palliative care units, volunteer work, multidisciplinary collaboration (TMM), regional palliative care consultation, out-of-hours general practitioner care.

STRENGTHS OF THE INITIATIVE

Integration of primary and secondary care

As the initiative includes both primary and secondary care levels it seems to effectively realize integrated palliative care for many patients with cancer in the region. The strong link to the regional palliative care network, through participation of the network coordinator in the transmural meetings, enables regional collaboration. Furthermore, the network coordinator is able to take his observations gained through his work in daily care practice with him to his policy part of the job and in this way he can work on solutions of structural problems on a policy level.



When we came home, I started leaking at once. So I was covered in blood, went back to hospital and they immediately helped me. They are really there for you immediately.
(patient)

Network coordinator

Pragmatism is a key word for this initiative. It is effective as it has started from the bottom-up, it involves a small region and is based on longstanding relationships that have resulted in a culture of trust. Some of the participating professionals have many years of experience in oncology and palliative care, so with their vast knowledge and expertise, they are important leaders in regional palliative care. The network coordinator is a key figure in the palliative care network as well as in the transmural meetings. The advantage of this linchpin function is that it facilitates consultation and coordination of care; many people in the region know him, know where to find him in case they need support in their patient care and have already found out what he can do for them.

IMPROVEMENT OPPORTUNITIES

More involvement of general practitioners

Currently it is difficult for general practitioners to attend the weekly transmural meetings, as these are held during general practitioner practice hours. This can be problematic as they are the key professionals in the community. Furthermore they receive a work plan after the meeting, which prevents them from deciding in advance whether it is useful to attend a meeting or not. However, as patients are often only referred during the meeting, it is difficult to invite general practitioners in advance.

Electronic information exchange

The initiative would benefit from an electronic system which would enable general practitioners (and other potential external stakeholders) to attend the meetings within their own practice, such as videoconferencing or transmural electronic patient's records, and to invite them at the time patients are discussed.

Dependence on a few dedicated persons

The initiative depends on the efforts, experience and expertise of a few people. If they drop out, an important part of the experience and expertise of the initiative seems to be lost. Moreover, the model works if the right people are contacted, which seems to work on this scale, but if they aim to broaden it, this might be a challenge.

And the nice thing is, this suddenly occurs to me, [oncologist says]: "I don't do it on my own, we do it together". "Well, I think that's exceptional, when a physician tells you that. That gives me a good feeling...".
(family caregiver)

Mainly cancer patients

At the moment only patients with cancer are discussed in the transmural multidisciplinary meetings and the intention is to expand this to non-cancer patients. However, apart from the challenge of providing education and creating a culture of trust within other departments, lack of funding for staff particularly hinders the initiative to realise its plans.

KEY RECOMMENDATIONS

Non-cancer patients should benefit

The initiative benefits from an external network structure and strong (in)formal links between care professionals within and outside the entire regional palliative care network held together by strong network leadership. The rich experience, informal working routines, strong culture of trust combined with support, structure and documents from the covering palliative care network is important in the way the initiative functions nowadays. It will be beneficial when expanding this model to non-cancer patients.

Strengthen sustainability

As the initiative has already operated for several years its sustainability is obvious. However it will be a challenge to find successors when the core professionals retire or find other jobs.

Sandra Varey
Nancy Preston
Sean Hughes
Sheila Payne



chapter 7

Specialist palliative care in a rural area: *An example in the United Kingdom*

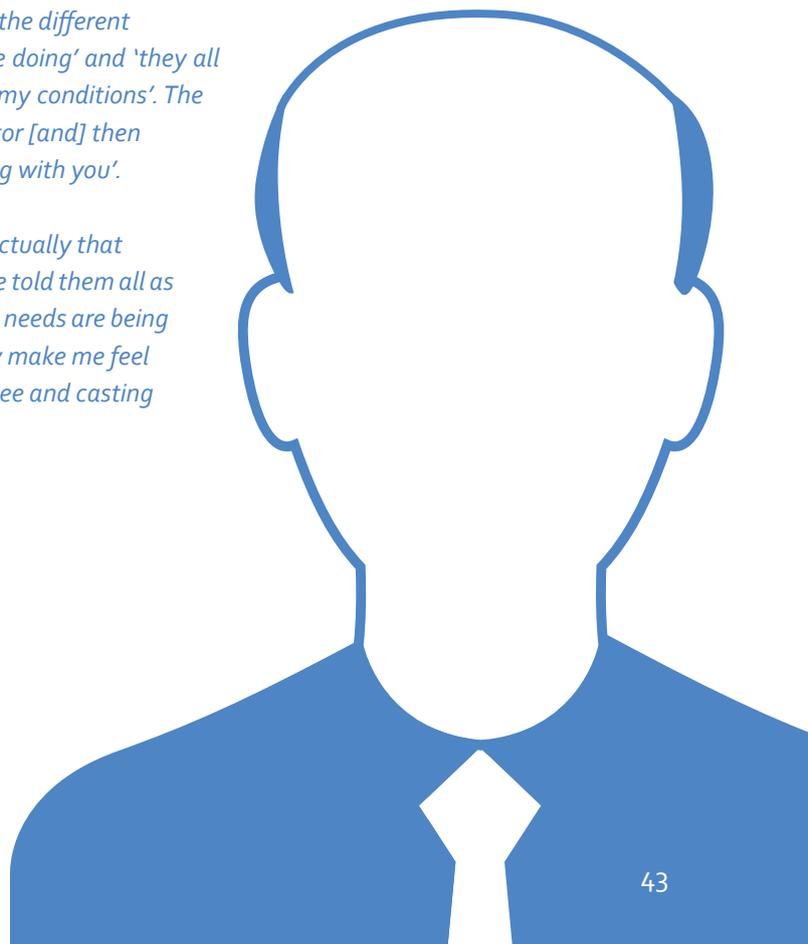
DAVID'S STORY

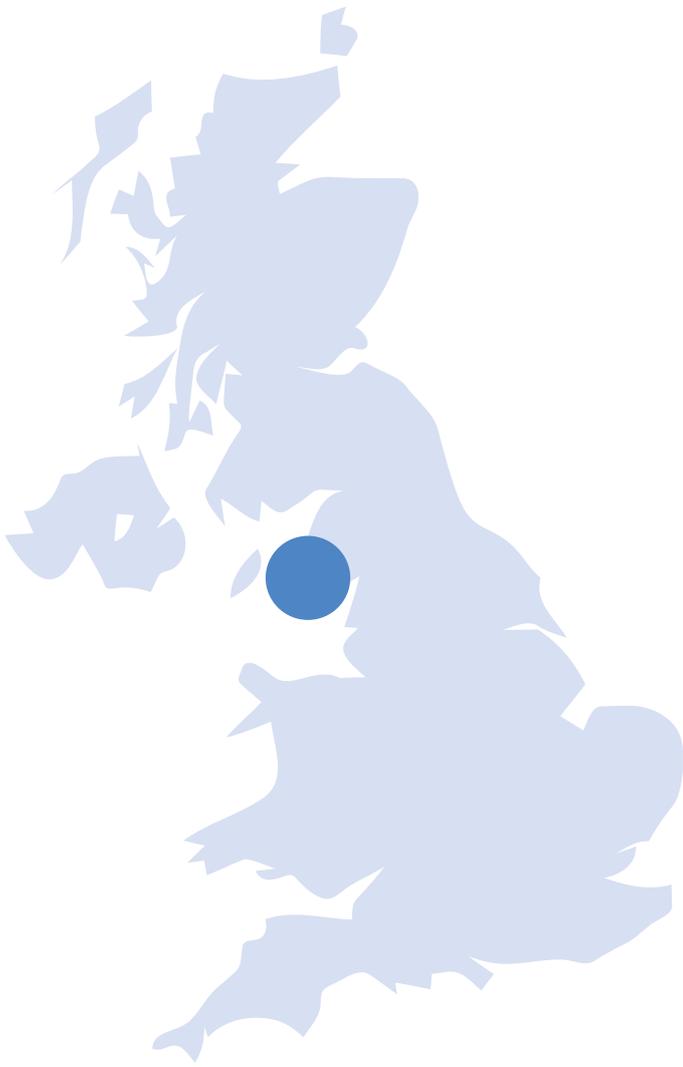
David is 78 years old and has Chronic Obstructive Pulmonary Disease (COPD). David lives with Diane, his wife, who is his family carer. Diane is responsible for every aspect of David's personal care including helping him to wash and dress. David is reliant upon oxygen even if he is 'going to the greenhouse [in his garden] or anywhere'. Due to his breathlessness and a recent fall, David is no longer able to drive and his brother visits regularly and takes him out.

David receives care from a number of healthcare professionals. A Specialist Respiratory Nurse visits him once a month, who is the main healthcare professional who co-ordinates the care David receives from other professionals and services. David sees his own GP every six weeks, usually when he is suffering from chest infections, and David phones his GP whenever he feels unwell. A District Nurse visits David once a month and a Community Matron visits every two months to take blood samples. For a period of time, nurses from a homecare service called Hospice at Home (H@H) West Cumbria visited David two nights each week while he was particularly unwell. A nurse now visits David one afternoon each week for three hours to enable Diane to 'go and do her shopping'.

David is very happy with the services he receives and says that he 'couldn't wish for better' care. Although lots of different people are involved in his care, David says: 'I get the sense that they're all as one'. David says that information sharing across the different professionals works well and that 'They all know what they're doing' and 'they all seem to know each other' and 'what's going on with me and my conditions'. The only problems that David experiences are 'if there's a new doctor [and] then you've got to go through the whole story again of what's wrong with you'.

Of the care and support he receives, David says: 'I'm pleased actually that there's so many [people who] care about me, you know, and I've told them all as well that I'm pleased that they're there'. David feels that all his needs are being met by the different people involved in his care and says: 'They make me feel as if I'm important, not something that they're coming out to see and casting aside as soon as they leave'.





HEALTH CARE IN THE UK

In the UK, health care is provided free of direct charge through the National Health Service (NHS). Services are funded through national taxation. Everyone is entitled to register with a general (medical) practitioner who provides primary care supported by district (community) nurses. Prescribed medicines are heavily subsidised and are free to many with special medical needs.

Most care (nursing) homes for older people are commercial organisations and not part of the NHS. Both residential care homes and social care services require an assessment of income and are not freely available to all people.

PALLIATIVE CARE IN THE UK

Most hospices (80%) are provided by independent local charitable organisations that provide a range of specialist palliative care services supported by NHS provision and enter into various local contracts with the NHS. This annual contracting process is managed in geographical areas by Clinical Commissioning Groups (CCG). Patients and families do not pay for hospice care.

For all patients in need

The first modern hospice, St Christopher's Hospice, was opened in 1967 in South London by Dame Cicely Saunders with the aim of offering excellence in clinical care, education and research, focusing on the needs of dying patients and their families (Clark, 2002). A multidisciplinary and holistic approach forms the core of palliative care practice, although service configuration and funding arrangements vary across the UK.

Ideally services should be available to all patients in need of palliative care wherever they are: in hospitals, at home, nursing homes, prisons and other institutions. However, there remains inequity in provision with the accessibility of services depending on a number of factors including where a person lives.

Availability across the life span

Palliative care is available across the life span (with 40 children's hospices in the UK) and for patients with any advanced or life limiting condition. The provision of support for family members throughout the illness trajectory and during bereavement is a core component of palliative care.

In 2008, the End of Life Care Strategy (DoH, 2008) was published in England, with similar strategies developed for Northern Ireland, Scotland and Wales. These policies aimed to promote high quality care for adults at the end of life by providing more choice about where they would like to live and die. The policies place an emphasis on people's right to a 'good death', whatever this may mean for the individual. Within the UK, there are also a number of quality standards in place which cover the care provided to all adults approaching the end of life (NICE, 2011).

General and specialist palliative care

Two levels of palliative care are defined:

- General palliative care which is provided by the healthcare professionals normally involved in the treatment of the patient and family with low to moderate complexity of palliative care need, who have a good basic knowledge of palliative care (e.g. GPs, community nurses)
- Specialist palliative care services which are provided for patients and their families with moderate to high complexity of palliative care need and delivered by healthcare professionals who have additional training and expertise within palliative care

HOSPICE AT HOME: AN EXAMPLE OF SPECIALIST PALLIATIVE CARE TO A RURAL REGION IN ENGLAND

We have selected an initiative called Hospice at Home, West Cumbria (hereafter: H@H West Cumbria) as an example of delivering specialist palliative care across a large rural area. The initiative was established in September 1987. At this time, a hospice service was needed in a large rural area to cater for the needs of local residents but limited local funds were available to support the development of a hospice building. In addition, a single-site hospice would have been unable to cater for the needs of people located across a wide rural area.

Entrance to Hospice at Home, West Cumbria



A special model of care

An approach was needed which offered an alternative to the provision of specialist palliative care in one building. Practitioners who set up this palliative care initiative knew that many people wish to stay at home for end of life care and to die there. H@H West Cumbria therefore represents a special model of care: one in which people are supported in their usual place of care whether this is their home, a hospital bed, or a nursing home. This service works alongside the NHS who provide specialist palliative care services such as Clinical Nurse Specialists in the community (as described in David's story), in order to augment rather than duplicate existing provision. This maximises resource use and allows flexibility in the targeting of service provision where gaps are identified or develop, over time.

The location of the initiative

The initiative operates throughout West Cumbria, located in the North West of England. Recent data show the population of West Cumbria to be 167,000 people (Cumbria Intelligence Observatory, 2013), which is sparse for a predominantly rural area that covers over 750 square miles (almost 2000 square kilometres). The majority of people in West Cumbria are White British (>97%), with approximately twenty percent of people in the area aged 65 years and over (Cumbria Intelligence Observatory, 2013). Ten percent of people living in the area state that their day-to-day activities are 'limited a lot' as a result of health problems or disability (Cumbria Intelligence Observatory, 2013).

West Cumbria often experiences severe weather and includes one of the wettest places in England (Met Office, 2015). The area has a diverse geographical terrain, including small seaside villages and sandy beaches, along with mountains and hills, making West Cumbria a popular tourist destination. The area is not intersected by any major roads or motorways, with inland areas comprising small market towns linked by a network of minor roads. West Cumbria has a few large towns which developed in response to industries such as shipbuilding, steel making and coal mining. Today these industries no longer exist and most economic activities are related to farming and tourism. The rurality of the area along with industrial decline has resulted in high levels of social and economic deprivation in West Cumbria.

Services offered by the initiative

From the outset, H@H West Cumbria has accepted referrals from patients with all life-limiting conditions including cancer, chronic heart failure and chronic obstructive pulmonary disease. It receives approximately 25% of its funding from the NHS, with the remaining 75% sourced through charitable donations.

H@H West Cumbria offers a range of services, including:

- Home nursing - provided by health care assistants
- A lymphoedema service
- Family and bereavement support - provided by trained volunteers working under the supervision of a paid co-ordinator
- One-to-one support, group support and complementary therapies - provided by volunteers supported by a small number of paid staff

There is no inpatient unit and services such as complementary therapy, counselling and group support are delivered from a town centre building located on a busy shopping street.

Networks of care provision

H@H West Cumbria collaborates with a variety of organisations and individuals, including:

- Five local community hospitals (small hospitals funded by the NHS)
- Nursing and residential care homes for older people
- Local GPs, district nurses and community matrons (funded by the NHS)
- Clinical Nurse Specialists in Palliative Care (funded by the NHS)
- Volunteers

Important role for volunteers

As with many palliative care services in the UK, volunteers provide a large part of the workforce in a variety of roles. Some of them focus upon fundraising such as working in charity shops and others are administrative assistants, for example working on the reception desk or, helping with filing and general office work. Complementary therapies such as massage and other direct services are also often provided by volunteers. H@H West Cumbria offers a bereavement service which is predominantly staffed by volunteers who receive training and supervision from a paid family support coordinator. Volunteers are a key component of the wider hospice workforce in the UK.



I think David enjoys the healthcare professionals coming because he's isolated now, I think they bring him news local or about themselves.
(David's wife, family carer)

STRENGTHS OF THE INITIATIVE

Close collaboration with specialist palliative care and primary care

H@H West Cumbria works in close collaboration with local specialist palliative care and primary care services provided by the NHS. When it began, the agency entered into a formal agreement with the local representatives of the NHS. Currently, H@H West Cumbria has a 'Service Level Agreement' with the NHS organisation who provides community care which is renegotiated each year. Collaboration with a range of other organisations, such as health and social care agencies in the local area, is not formally agreed and occurs on an ad hoc basis as required.

Multidisciplinary approach

A multidisciplinary approach to palliative care is fundamental to the H@H West Cumbria initiative. Professionals working across different organisations and agencies share information, knowledge and expertise in different ways. One way in which this is achieved is through regular multidisciplinary team meetings which includes doctors, community nursing staff and hospice at home staff. Volunteers do not generally attend these meetings, but their paid supervisors do. Two are held each week, with different priorities: in the first meeting, professionals discuss all current patients receiving nursing services at home and all new referrals; the second meeting is a specialist multidisciplinary team meeting with

a focus on patients with more complex problems and needs. Information sharing is also supported through the use of patient-held notes which are kept inside the District Nurse folder within the patient's own home for all professionals to access when they visit the patient.

Information sharing

Other ways in which information, knowledge and expertise are shared between professionals include other face-to-face meetings, by telephone and fax. As a result of the rural location of the initiative, professional teams are small and an emphasis is placed on knowing and understanding patients and well developed inter-professional relationships. Regular meetings between professionals, both formal and informal, provide opportunities to identify patients with whom they need to build and maintain relationships to support palliative and end of life care. Those involved in H@H West Cumbria work hard to deliver integrated palliative care to the people of West Cumbria and are proud of the ways in which they work together to cover such a large rural area.

Strong leadership and local support

H@H West Cumbria itself benefits from strong leadership from the Chief Executive, a nurse with a lifelong attachment to the locality who was instrumental in founding the organisation. The initiative also has enormous ongoing support from people within the local community.

It has actually been an eye-opener how good people can be, how kind people can be.
(patient talking about volunteers)

IMPROVEMENT OPPORTUNITIES

Electronic system for information sharing

One of the factors that hinder the proper delivery of care is that, at present, there is no electronic system for information transfer that enables the sharing of patient information between professionals working across different sites and organisations. As a result, communication and information transfer currently depend on paper-based and oral systems. This can be unreliable and problematic, for example in an emergency situation in which there is no time to find paperwork or where the paper record is elsewhere. Healthcare professionals, however, make use of telephone conversations to maintain personal relationships across the different healthcare providers.

A new electronic medical records system is planned which will enable more reliable and effective sharing of patient information between professionals working across different sites and organisations within West Cumbria. Indeed such a service operates in some parts of the country and has led to large improvements in the electronic communication of patient's records.

Dependency on donations

As with the majority of hospice providers in the UK, H@H West Cumbria operates within a landscape of uncertain funding and is reliant upon local donations and short-term NHS funding. As a result of its geographical location, it can also be difficult to recruit and retain members of staff. At a national policy level, continuing reductions to social care funding have adverse effects on home care, particularly for people who have a longer dying trajectory.

Better integration of services

The service recognises that there is still a challenge in managing the integration of health and social care, particularly from a fiscal point of view.

At the national level, there is a call for better integration of services, in general, from some quarters and research and evaluation of integrated service models is well underway (The Kings Fund 2015; Ham et al., 2011). Some hospices in the UK have started to incorporate the services into their total care package to streamline services.

KEY RECOMMENDATIONS

- H@H West Cumbria exemplifies the integration of the state funded and independent sectors in providing palliative and end of life care services to a scattered rural population
- This responsive and flexible service focusses care in the patient's home, rather than in costly buildings and staffed beds
- As such, this service can more readily individualise care and maximise the use of limited resources – in terms of both people and funds
- Establishing and sustaining inter-professional relationships over time and over distance is key to providing quality palliative and end of life care in a remote, rural context

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Chapter 8

How to ensure best practice: Global recommendations from a European study

JEROEN HASSELAAR, SHEILA PAYNE AND JEROEN VAN WIJNGAARDEN

In this final chapter, we would like to formulate recommendations on how to ensure best practice to further the integration of palliative care in Europe. We categorize the recommendations at four levels, namely at the level of patient and family care, at the organizational level, the regional level, and at a health system level.

AT THE PATIENT AND FAMILY LEVEL

Best practices treat patients and their families as whole persons

This seems an obvious statement. However, throughout the project patients often contrasted palliative care favourably with general healthcare in relation to this. The chapters give numerous examples of how professional palliative caregivers communicate at a personal level and patients recognize this and therefore feel treated as persons, not as numbers. Integration of palliative care therefore starts from the experience of the patient as a whole, using an integrated physical, psychosocial, and an existential viewpoint on suffering. In this regard, palliative care even has the potential to guide general healthcare.

Importantly, integrated care is about patients and their families. Also the role of family members is important in decision making, especially when they are the legal representative of the patient where a patient has decreased cognitive capacities. This seems not always easy and needs careful management of expectations. In addition to that, some centers have developed specific programmes to support bereaved family members after the death of the patient.

Best practices develop integrated care plans and pathways

In the project we did not see many examples of integrated care pathways. Most often, the integration of palliative care was achieved via multidisciplinary meetings or service collaborations. A few examples were noted however, one is described in the Belgian chapter where a home care nurse organization uses a pathway for palliative care. Pathways create the ability to structure the caregiving process and to allocate roles and responsibilities that may stimulate advance care planning. Also timely involvement of palliative care may be supported by the use of pathways. Notwithstanding this, a lot more attention needs to be paid to implementing them.

AT AN ORGANIZATIONAL LEVEL

Best practices integrate palliative care via informal relationships but subsequently provide more formal structures

Palliative care initiatives often started with a lot of volunteering and pioneering by professional caregivers. Palliative care needed to find its position in the medical domains, the nursing domain, and the social care domain. For this, informal relationship building is pivotal to integrate and connect palliative care to all these longer established disciplines and services. For example, it is necessary to start up multidisciplinary patient meetings, to establish referral patterns, and to connect hospice, home, and hospital care for patients with advanced and progressive illnesses. This can be rewarding but also exhausting when the network grows, with a risk that these informal relationships are only accessible via the mobile phones of a few palliative care leaders. In addition, standardization of work processes may be lacking, for example too many informal streams of information between professional palliative caregivers and other healthcare professionals,

and lack of systematically organized shifts and on-duty calls for patient's visits. To become a best practice therefore, informal relationships need to be transformed into more formal patterns and structures including agreed frameworks of care quality, mechanisms to transfer information, and patient referrals.

Best practices have to develop an integrated work plan on human and financial resources

One global theme in all case descriptions concerned the work overload of palliative care professionals. Work overload may have several reasons among these are inefficient work patterns, lack of educated professionals, or lack of budget to attract sufficient employees. Unfortunately, all of these can limit the integration of palliative care. An essential resource is funding. Shortage of budget can put pressure on the employees and finally exhaust them. Most initiatives are confronted with health system limitations when they cross borders between home care, hospice care, and hospital care. Some overcome this by finding creative ways to integrate palliative care in the health system by combining several sources of budgets together, others raise project funding, and others find private donations. In this respect, promising practices from palliative care can also pave the way for health system integration in a broader perspective.

AT A REGIONAL LEVEL

Best practices create a regional information hub for palliative care delivery

Palliative care moves beyond individual professional caregivers and organizations. The WHO definition mentions a multidisciplinary team as a precondition for the delivery of palliative care. If this team works within the same institution, the sharing of information can be done using the structure and information architecture of that institution. However, when individuals come from several institutions, information needs to be transferred across settings. Frequently questions about privacy and protection of data become concerns. Some initiatives leave the information in a diary or handwritten record at the place of residence of the patient. This may help to make the patient or relative the owner of his/her own data. However, in multidisciplinary groups this may be more difficult. In the future, electronic data storage will be increasingly desirable. The final solution is not yet found, but investigations

are ongoing in a number of countries with a patient record where all relevant information can be stored with regulated access for professional caregivers in the palliative care network.

Best practices Integrate palliative care in society as a visible locus of action

Being an information hub also takes on a different meaning. It means that the initiative is known for having expertise and knowledge on palliative care and becomes a natural focus for all palliative care activities in the region, a central visible hub in the regional care network.

Palliative care needs to be visible in the community. Especially in the UK, palliative care is firmly embedded in the local community. These local people raise charity donations and volunteer in their local hospice. The integration of palliative care needs a visible focus of action, whether it is a building, an office or online representation. Visibility creates awareness by society, other professionals and the public as a whole. Without visibility, palliative care stays behind the scenes and will have more difficulties to create a place in the care trajectory.

AT A HEALTH SYSTEM LEVEL

Best practices are not afraid of accountability

Visibility may also include accountability about what is achieved. This can be done using activities such as annual social reports and open visits. However, it can also be done at a societal level for policymakers and funders, by periodically reporting the satisfaction of patients and family members and to measure and report patient reported outcomes to show the effects and results of care delivery. Here, the relation with research becomes apparent.

Best practices have an open mind for future sustainability

In the short term, barriers to integrated care may be fixed and difficult to influence. In the long term however, many elements can be variable. A lack of current educated professional caregivers for example can be influenced by more education activities in the longer term. A lack of current regulations can be influenced after ongoing pressure in the political field. Best practices often take longer practices to be achieved. They do not appear immediately but are gradually built upon previous experiences and results.

In this respect, the integration of palliative care into education and research is important to mention and promising examples were found in this study, two of these are mentioned in the chapters from Hungary and Germany. Research and education need time and resources to develop, but can be very powerful instruments to integrate palliative care in the longer term.

Best practices promote integrated access to palliative care facilities for all patients in need

Current regulations and funding for palliative care are often directed towards terminal care for cancer patients. Prognostication (eg a life expectancy of less than 6 months) is often required to provide access for patients to palliative care facilities in many but not all European countries. In particular access to palliative care teams is severely limited by these restrictions. Interestingly, this seems contrary to the WHO definition that recommends early integration and a holistic approach. For patient groups whose prognostication is more difficult, like COPD and heart failure, promising practices were harder to uncover in our European study and if available, these had often difficulties to position themselves within the trajectory of care. The most promising development for early integration can be found in hospital care, where outpatient clinics can support the early onset of palliative care and access restrictions are less apparent for several disease groups.

CONCLUDING REMARKS

Best practices act on different levels simultaneously

Professionals and policymakers that want to foster the integration of palliative care have to take into account several dimensions, namely (1) the holistic approach to the needs of patients and his/her relatives, (2) the professional and family caregiver network that supports the patient, (3) the operational procedures that organize the work structure, including for example shifts, out of hour arrangements, budgets and human resources, (4) the organizational arrangements between social care, home care, hospice care, and hospital care needed to create a visible space for a palliative care hub, (5) the national or regional health system policy (regulations, health insurance, funding) that supports or frustrates access to palliative care for all who need it. To put it shortly, they need to operate on several levels at the same time, namely

(1) the level of patient and family, (2) the level of the individual institution, (3) the level of regional collaborations, and (4) the level of national health policies. How to bind all these levels together? What capacity is needed to move this complex and dynamic integration of care forward?

Integrated palliative care requires leadership

If the patient and family are taken as the center of caregiving, care arrangements have to assess the patient's needs regularly. Connecting caregivers from several disciplines may easily create an administrative and bureaucratic problem of its own. In particular when palliative care needs to be delivered across home care, hospice care, and hospital care with each sector having their own policies and regulations. Palliative caregivers should ensure that all professionals, settings, and bureaucracies stay directed towards the needs of the patient as a whole. Profound knowledge of the palliative patient population and the local healthcare system is needed together with the courage to develop new and sometimes unexpected care arrangements. The integration of palliative care is therefore also a matter of creative leadership.

A strong motivation to develop palliative care is pivotal, as it requires endurance and patience. None of the promising practices in this book appeared fully developed initially. Best practices need the 'best' leaders. But rather than a strong hierarchical leadership, it needs a creative and collaborative leadership that is able to get people together in a place where they can flourish, to build networks, to informally influence people and structures, and to keep the needs of patient and family at the forefront of care. These sorts of leadership skills can be found in several professions, including medicine, nursing and other allied healthcare professionals.

Coming at the end of this book, we conclude that collaborative leadership skills are needed to integrate palliative care and to act on several levels at the same time. The challenge is daunting but it is worthwhile working on for the benefit of many patients and their family carers in Europe.

Annex

Research methods for INSUP-C project

MARIEKE GROOT

RESEARCH DESIGN

In the INSUP-C project we investigated how patients with advanced cancer, chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF), their family and professional caregivers within a selection of integrated palliative care (IPC) initiatives in Belgium, Germany, Hungary, the Netherlands and United Kingdom, experienced care delivery in the last phase of the patient's disease.

To do so, we devised a so-called 'multiple embedded case study' (see diagram 1). Because retrieving answers to our questions about experiences in integrated palliative care is not a simple one-way task, we had to take contextual conditions into account. The multiple embedded case study design enabled us to do this. The 'cases' were the selected IPC initiatives and the embedded units of analysis were the patients, family caregivers and professional caregivers. Contextual conditions were for example, the organisation of palliative care in the country and/or region in which the initiative is embedded, the network of caregivers involved in the initiative, needs of the patient and family caregiver and severity of the illness. Research ethical approval was obtained to meet the specific requirements for each country.

SAMPLING AND RECRUITMENT OF INITIATIVES AND PARTICIPANTS

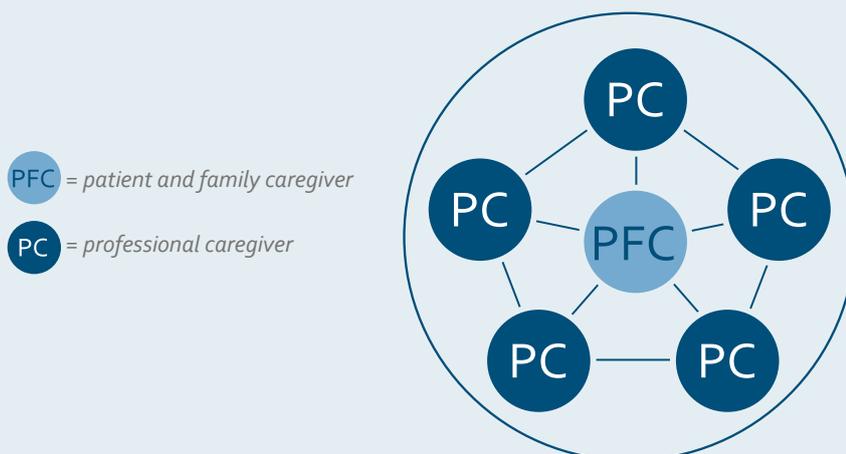
Based on the network of the participating researchers in the various countries and on expert interviews which were performed in an earlier phase of the project, we approached palliative care initiatives and asked if they met the following criteria:

- It is an established local¹ palliative care collaboration
- A hospital can be part of that collaboration
- The collaboration must contain at least two different organizations
- Collaborating healthcare professionals must provide direct patient care (not only an advisory function)
- The collaboration is multidisciplinary (professionals of different professions must be involved, e.g. specialist, GP, nurse (practitioner), social workers, AHP, faith leader, complementary therapist, others)
- The collaboration is supposed to provide palliative care for either one specific diagnostic group (Advanced COPD/CHF/ cancer), or to all three diagnostic groups.

If the initiatives confirmed that they indeed met these criteria, we included them as an Integrated Palliative Care Initiative and made agreements about the research procedures.

In total, 22 IPC initiatives participated in the project, 3 – 5 per country. They started patient inclusion at different times from June 2014 – July 2015. Not all IPC-I were involved in the care of patients with all 3 diagnostic groups; some were dedicated to one patient group, some to all groups but with a variety in proportion per diagnosis.

Diagram 1: Multiple embedded case study: Integrated palliative care in the country



Because of the mainly qualitative nature of the study, there was no need to include large numbers of patients and family caregivers. We therefore came up with a planned sample size of 18-27 patients for Belgium (due to logistic reasons) and 30 - 45 patients for the other 4 countries. In order to achieve this required number, we aimed to recruit up to 60 patients per country (36 in Belgium). In this number, we took account of a 30% attrition rate. We intended to recruit one family caregiver per patient and 8 professional caregivers per IPC initiative for the (group) interviews.

DATA COLLECTION

If a patient and family caregiver had entered the study, there were four consecutive contact moments with an interval of one month (baseline, month 1, month 2, month 3). At baseline and at month 3 there was a face-to-face contact with the patient and his/her family caregiver. During these contacts we conducted semi-structured interviews and assessed the caregiver network analysis with the patient. At baseline, month 1, month 2 and month 3 the patient and family caregiver completed a couple of questionnaires that covered Quality of Life, Satisfaction with care, perceived symptoms, burden and reward of care giving. Weekly, between baseline and month 3, the patient kept a diary. The questionnaires and diary were completed by the patient and/or family caregiver themselves or with the help of a researcher, by telephone. If a patient died during the study period, we contacted the family caregiver to offer our condolences and, dependent on the circumstances of the bereaved carer, ascertained if they wished to have a final semi-structured interview. If so, we contacted them again and made an arrangement for the final interview at a time of their convenience between 4 and 12 weeks afterwards. For each initiative, we conducted one focus group with professional caregivers at the end of the data collection period. The expected duration of the entire study period was 18 months, including recruitment, data collection, and analysis. At the end of July 2015 we ended the inclusion of patients and family caregivers.

¹ With 'local' we mean that such a locally established collaboration is not necessarily nationally acknowledged or formal. It is rather an informal agreement between professional caregivers who aim to provide palliative care for patients in a particular region or network and to improve continuity of care.

DATA ANALYSIS

Performing such a complex international research project, requires all kinds of procedures and agreements, which allows us to finally give valid and reliable answers to the research questions with which we started the project. The majority of the textual data were analysed using qualitative data analysis methods. The procedures and agreements to facilitate data collection and analysis were:

- We organized 5 training meetings, in which we trained the researchers from the 5 countries and discussed with them all aspects of data collection and data analysis. In between these training meetings, the researchers had 'homework' to do. During data-analysis, the research team initially worked together to develop an agreed codebook, and, in between team meetings, researchers worked on analysing their own country data. The codebook was based upon a generally agreed working method.
- Regular skype meetings with all researchers were held in order to discuss current problems and to share experiences related to interviews, coding and other issues.
- Via Google docs, we constructed and maintained a data collection log in which the researchers were able to discuss issues that came up during their work and share topics and experiences about data collection and data analysis. In this way we provided additional opportunities for attuning working methods and discussing issues which are important and therefore did not have delays between meetings.
- In order to monitor the recruitment process in all 5 countries, we developed a screening log. On a regular basis researchers were asked to fill in the form. This form contained information on e.g. number of patients and caregivers included, - finished, - in follow up etcetera
- We used Castor, an online tool for medical research, as a data management programme in our research. Our data could be stored, listed, retrieved and remotely accessed. Castor is a programme which allowed us to process and modify our quantitative data. We can export data directly to SPSS™ and easily see the number of records in our dataset. Every researcher can enter data in Castor even at the same time. We entered the questionnaire data into Castor as well as patient's and family caregiver's data.

TOTAL SAMPLE INCLUDED

In total data was collected from five countries and 22 initiatives, and included 156 patients and 88 family caregivers. We are very proud that we achieved this numbers in a research field in which is known that it is difficult to recruit patients. In every integrated palliative care initiative more patients were

'screened' for participation than the amount we finally managed to include. We do not have the numbers of screened patients as this process was usually performed by local clinicians.

		Cancer	COPD	CHF	Total
The Netherlands	Number of patients included	22	6	3	31 ¹
	Number of family caregivers included				22
UK	Number of patients included	18	7	10	35 ²
	Number of family caregivers included				13
Germany	Number of patients included ³	30	3	0	34 ⁴
	Number of family caregivers included				9
Hungary	Number of patients included	14	17	11	42 ⁵
	Number of family caregivers included				30
Belgium	Number of patients included	11	3	0	14 ⁶
	Number of family caregivers included				14
Total	Number of patients included	95	36	24	156
	Number of family caregivers included				88⁷

Ad¹: 5 initiatives participated, we included 3-12 patients per initiative

Ad²: 5 initiatives participated, we included 1-13 patients per initiative

Ad³: in Germany there is 1 patient with an unknown diagnosis

Ad⁴: 4 initiatives participated, we included 3-12 patients per initiative

Ad⁵: 5 initiatives participated, we included 5-12 patients per initiative

Ad⁶: 3 initiatives participated, we included 3-6 patients per initiative

Ad⁷: 27 (30.7%) of the family caregivers were male, 61 (69.3%) female

Table 2: Characteristics of the patients						
	Total	Belgium	Germany	UK	Hungary	The NL
No. of Patients	156	14	34	35	42	31
Gender						
Male	70 (44.9%)	7 (50%)	16 (47.1%)	13 (37.1%)	17 (40.5%)	17 (54.8%)
Female	86 (55.1%)	7 (50%)	18 (52.9%)	22 (62.9%)	25 (59.5%)	14 (45.2%)
Family Caregiver						
Partner	85 (54.5%)	11 (78.6%)	20 (58.8%)	17 (48.6%)	18 (42.9%)	19 (61.3%)
Child	35 (22.4%)	2 (14.3%)	8 (23.5%)	8 (22.9%)	13 (31.0%)	4 (12.9%)
Other /missing	36 (23.1%)	1 (7.1%)	6 (17.7%)	10 (28.6%)	11 (26.2%)	5 (16.1%)
How much time do you spend in bed or lying down in the daytime?						
Hardly ever	57 (36.5%)	7 (50%)	16 (47.1%)	8 (22.9%)	19 (45.2%)	7 (22.6%)
< half a day	54 (34.6%)	3 (21.4%)	10 (29.4%)	15 (42.9%)	9 (21.4%)	17 (54.8%)
> half a day	34 (21.8%)	2 (14.3%)	5 (14.7%)	12 (34.3%)	11 (26.2%)	4 (12.9%)
All day	11 (7.1%)	2 (14.3%)	3 (8.8%)	-	3 (7.1%)	3 (9.7%)

For further information about the InSuP-C project see www.insup-c.eu and the following publications:

Aldridge, M. D., Hasselaar, J., Garralda, E., van der Eerden, M., Stevenson, D., McKendrick, K., Centeno, C. & Meier, D. E. (2015). Education, implementation, and policy barriers to greater integration of palliative care: A literature review. *Palliative Medicine*, DOI: 0269216315606645.

Ewert, B., Hodiament, F., van Wijngaarden, J., Payne, S., Groot, M., Hasselaar, J., Menten J. & Radbruch, L. (2015). Building a taxonomy of integrated palliative care initiatives: results from a focus group. *BMJ Supportive & Palliative Care*, DOI: 10.1136/bmjspcare-2014-000841.

Garralda, E., Hasselaar, J., Carrasco, J. M., Van Beek, K., Siouta, N., Csikos, A., Menten, J. and Centeno, C. (2016) Integrated palliative care in the Spanish context: a systematic review of the literature. *BMC Palliative Care*, 15, no.1:1. DOI: 10.1186/s12904-016-0120-9.

Hasselaar, J. and Payne, S. (2016) Editorial: Moving the integration of palliative care from idea to practice. *Palliative Medicine*, 30 (3): 197-199. DOI: 10.1177/0269216315626039.

Hughes, S., Preston, N. and Payne, S. (2016) Online learning in palliative care: where are we up to? *European Journal of Palliative Care*, 23, no.5. (in press, Sep 2016). ISSN 1352-2779.

Siouta, N., Van Beek, K., Preston, N., Hasselaar, J., Hughes, S., Payne, S., Garralda, E., Centeno, C., van der Eerden, M., Groot, M., Hodiament, F., Radbruch, L., Busa, C., Csikos, A. and Menten, J. (2016) Towards integration of palliative care in patients with chronic heart failure and chronic obstructive pulmonary disease: a systematic literature review of European guidelines and pathways. *BMC Palliative Care*, 15, 1: 1. DOI: 10.1186/s12904-016-0089-4.

Siouta, N., Van Beek, K., van der Eerden, M., Preston, N., Hasselaar, J., Hughes, S., Garralda, E., Centeno, C., Csikos, A., Groot, M., Radbruch, L., Payne, S. & Menten, J. (2016) Integrated palliative care in Europe: a qualitative systematic literature review of empirically-tested models in cancer and chronic disease. *BMC Palliative Care*, 15:56. DOI: 10.1186/s12904-016-0130-7. Available at: <http://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0130-7>.

Van Beek, K., Siouta, N., Preston, N., Hasselaar, J., Hughes, S., Payne, S., Radbruch, L., Centeno, C., Csikos, A., Garralda, E., van der Eerden, M., Hodiament, F., Radvanyi, I. and Menten, J. (2016) To what degree is palliative care integrated in guidelines and pathways for adult cancer patients in Europe: a systematic literature review. *BMC Palliative Care*, 15, 1:1. DOI: 10.1186/s12904-016-0100.

van der Eerden, M., Csikos, A., Busa, C., Hughes, S., Radbruch, L., Menten, J., Hasselaar J. & Groot, M. (2014). Experiences of patients, family and professional caregivers with Integrated Palliative Care in Europe: protocol for an international, multicenter, prospective, mixed method study. *BMC Palliative Care*, 13(1), 52. DOI: 10.1186/1472-684X-13-52.

Integrated palliative care

This text is a highly readable account of integrated palliative care, illustrated by real-life international stories from patients and family caregivers. Integrated palliative care involves bringing together administrative, organizational, clinical and service aspects in order to achieve continuity of care between all people involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid.

This book is essential reading for all those undertaking studies in palliative care. The book provides:

- European context of palliative care development
- Stories from patients and family caregivers about their experiences of integrated palliative care from five countries
- Highlights of the factors that facilitate and are barriers to integrated palliative care
- Recommendations for policy and practice

"This book provides the impetus for what can be done and what can be changed. The next 20 years for palliative and end-of-life care will be very different to what has gone before. Understanding the value of what integration of care can bring to patients and families is the new horizon for our discipline."

*Professor Phillip Larkin,
President of the European Association for Palliative Care*

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