Quality indicators to facilitate improvements in the organisation of palliative care for people with dementia or cancer in Europe

Jasper van Riet Paap
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For reasons of consistency within this thesis, some terms have been standardised throughout the text. As a consequence the text may differ from the articles that have been published.

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Quality indicators to facilitate improvements in the organisation of palliative care for people with dementia or cancer in Europe

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General introduction
Ageing of the population and higher survival rates of people with chronic diseases result in an increasing number of patients in need for palliative care\(^{1,2}\). At the end of their lives, people with chronic diseases often suffer from symptoms such as pain, dyspnea, depressed mood, or existential problems\(^{3,4}\). Symptoms that not only threaten a patient’s life but also the quality of their remaining lifetime. In daily clinical practice, however, care is often not centered around the patient but around the disease of the patient\(^5\). Many physicians, for example, often continue a curative treatment until late in the disease trajectory\(^5\). Yet, we know that following a palliative care approach alongside usual oncological care is more effective to improve the patient’s quality of life than just oncological care, without shortening it\(^6\). However, many patients still receive sub-optimal palliative care. Not all patients in need of palliative care, for example, have access to palliative care services\(^7\). But as Berwick already stated: “an adequate organisation of care is a prerequisite to good clinical care”\(^8\). To further improve the provision of palliative care, it is important to strengthen the organisation of palliative care. Yet, as the provision of palliative care is different per country, region and setting, an approach is needed that can identify areas for improvement in order to improve the organisation of palliative care at a local level. For that reason, the EU-funded 7th Framework IMPACT project (IMplementation of quality indicators for PAlliative Care sTudy) started in 2011 with the aim to develop quality indicators to assess and improve the organisation of palliative care by implementing improvement strategies in settings that provide palliative care. Researchers from ten countries participated in the IMPACT project to define, develop and implement strategies to improve the organisation of palliative care in different settings across Europe. The scientific work presented in this thesis presents (part of) the results of this IMPACT project.

**Palliative care**

Palliative care began in the hospice movement and originates back to the Roman era, where a hospice was a place of rest for travellers\(^9\). Travellers, but later also (terminally) ill persons were offered special hospitality as they were often far from home. The term ‘hospice’ disappeared for a while, but re-emerged in the 19th century as a sanctuary for the dying. In 1967, the modern hospice movement was founded by Dame Cicely Saunders\(^10\). In 1973, the Canadian physician Balfour Mount did not want to call his unit for terminally ill -dying- patients a ‘hospice’, since this term was already in use for the poor and destitute in French-speaking Canada. Instead, he called his unit ‘palliative care’\(^11\). Palliative care was by that time primarily known as ‘care of the dying’\(^9\), but later also incorporated terms as ‘terminal care’, ‘end-of-life care’, ‘hospice care’ and ‘supportive care’\(^9\). In 1986, the World Health Organisation (WHO) defined palliative care as the “active total care of patients whose disease is not responsive to curative treatment [...]]”\(^12\). This definition was later considered to be too focused at incurable diseases\(^13\). Therefore, in 2002, the WHO updated its definition on palliative care to “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
Palliative care for patients with different incurable diseases

The 2002 WHO definition implies that palliative care is applicable to patients suffering from any life-threatening illness, such as cancer, chronic obstructive pulmonary disease (COPD), coronary heart failure (CHF), kidney failure, dementia, aids or ebola. The WHO estimated that over 20 million people are continuously in need of palliative care worldwide; 69% adults (19 million), of which 13.1 million persons (69%) aged 60 years or older and 4.1 million persons (22%) in Europe. They suffer: cardiovascular diseases (38.47%), cancer (34.01%), COPD (10.26%), HIV/AIDS (5.71%), diabetes mellitus (4.59%), kidney disease (2.02%), cirrhosis of the liver (1.70%), Alzheimer’s and other dementias (1.65%) and other chronic illnesses (1.59%). However, these figures are based on mortality data. We know that for some chronic diseases, such as dementia, often another (acute) cause of death is mentioned. The actual number of persons in need of palliative care will therefore double or even triple compared to what is stated above.

The European perspective

In Europe, cancer is responsible for a large proportion of patients in need of palliative care. In 2008, there were about 3.2 million new cases of cancer and 1.7 million deaths from cancer. It is expected that the incidence of cancer will rise with about 20% in the next decade and the prevalence will rise due to longer survival. Besides, as people are getting older, there will be a rising number of persons with dementia. In 2006, about 7.7 million persons were diagnosed with dementia. This number is expected to double in the next 20 years. Traditionally, older people have received less palliative care than younger people and services focused more on cancer than on dementia care. However, most deaths in Europe concern people aged over 65. These figures underline the need for well-organised services that provide optimal palliative care, not only for patients with cancer but also for those with dementia.

Palliative care for patients with cancer

Cancer is characterised by a predictable decline in physical health over a period of weeks, months, or years (figure 1). Many patients with cancer suffer from pain as well as from fatigue, depressed mood, and non-medical problems that threaten the quality of life such as reduced autonomy. Thereby, many patients with cancer are in need of more professional attention for coping with the unpredictability of the future and a fear of physical suffering. Most weight loss, reduction in performance status, and impaired ability for self care occurs in patients’ last few months. But in general there is time to anticipate on palliative care needs and plans for end-of-life care.
The advantage of palliative care for patients with cancer
It has been shown that early palliative care improves the quality of life in patients with metastatic non-small-cell lung cancer. Temel et al, assigned patients to receive early palliative care integrated with standard oncologic care. After 12 weeks, patients assigned to early palliative care had significantly higher quality of life scores, significantly lower percentage of depressed mood, improved documentation about resuscitation preferences, less aggressive care at the end of life and increased survival in comparison to those assigned to standard care. Thereby, various cost-effectiveness studies showed that palliative care reduced healthcare expenditure.

Palliative care for patients with dementia
Dementia is a clinical syndrome characterised by a decline in cognitive functioning resulting in impairments in daily living and that eventually will lead to death. Dementia is characterised by a slow, progressive deterioration of the condition of the person affected. The period between diagnosis of dementia and death can be two to 20 years. During their illness trajectory, many people with dementia suffer from pain, agitation, dyspnoea, neuropsychiatric symptoms and depression and have reduced cognitive and communicative skills. The disease trajectory is often associated with weight loss, an increasing number of infections, disability and impairment. Birch described that people with dementia may die at any stage during their illness: they may die from another acute or incurable illness, or a combination of dementia and another comorbidity or of dementia itself. Although it is evident that a palliative care approach is also
applicable to persons with dementia it is, because of the unpredictability of the disease trajectory, difficult to determine when to start palliative care.

The advantage of palliative care for people with dementia

Understanding and responding to the needs of people with dementia improves their quality of life\textsuperscript{27}. People with dementia often experience end-of-life related symptoms for a longer period than patients with cancer\textsuperscript{24}. Cognitive, communication, functional and behavioural problems can make palliative care problematic as symptoms are difficult to detect\textsuperscript{26}. Initiating a palliative care approach earlier in the disease trajectory allows to anticipate on future needs and wishes of a person with dementia and facilitates person-centred care\textsuperscript{24}. But, unlike the benefits of early palliative care for patients with metastatic non-small-cell lung cancer, there are few studies that describe the efficacy of palliative care for people with dementia. Sampson et al. conducted a review in which only two out of 885 studies were eligible for inclusion in the final review\textsuperscript{28}: In the study of Ahronheim et al., people with dementia who were hospitalised with acute illness were randomised to receive advice from the palliative care team or to usual care. The intervention had no influence on length of hospital stay or reduction in painful interventions\textsuperscript{29}. In a study of Volicer et al., a traditional long-term care unit was compared with a dementia special care unit. There was higher mortality but lower observed discomfort, costs of medication, radiology and laboratory procedures were significantly less and there were fewer patient transfers to acute medical settings in the dementia special care unit\textsuperscript{30}. Sampson et al. identified another study with a weaker methodology that showed better symptom control.

\begin{figure}[h]
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\caption{Prolonged decline}
\end{figure}
and improved analgesia usage\textsuperscript{28,31}. In addition, Shega et al. described that early stage support for people with dementia was helpful for complying with patients’ wishes and choice of place of death\textsuperscript{32}.

**Provision of palliative care**

Palliative care can be provided wherever the patient resides. Depending on the healthcare organisation per country, different services where palliative care can be provided exist\textsuperscript{33}. The spectrum of services is supposed to cover all the different levels of care needed by the patients, including acute care (hospital), long-term care (nursing home and hospice) and home care (general practitioner and community nurses)\textsuperscript{34,35}. Patients with cancer usually receive palliative care at home and in the hospital; non-cancer patients at home, in the hospital and nursing home; and patients with dementia primarily at home and in nursing homes\textsuperscript{36}.

Another distinction can be made between generalist and specialist palliative care. Generalist services offer a standard of palliative care that can be provided by all healthcare professionals in all services. Specialist services offer a higher standard of palliative care, provided at the expert level, by a trained multi-professional team\textsuperscript{34,35}. Specialist palliative care is in the Netherlands, for example, provided at a palliative care unit, hospice, by a home based palliative care team\textsuperscript{34,35}, or by a telephone support team\textsuperscript{37}.

Many healthcare professionals do not have the adequate knowledge, experience and skills to provide optimal palliative care\textsuperscript{38}. In many countries, the integration of palliative care into the core curricula of medical and nursing education is still lacking\textsuperscript{39}. Consequently, too many patients receive suboptimal or delayed care, leaving many patients suffer from severe physical, psychosocial and spiritual symptoms\textsuperscript{40}.

**Improving the quality of palliative care**

Evidence-based and best practices are often not implemented in daily clinical practice. Healthcare professionals, for example, just don’t have enough time to keep up-to-date with all new evidence\textsuperscript{41}. Thereby, professionals often have a lack of knowledge regarding how to implement scientific evidence. Implementation of scientific evidence can therefore best be guided by a step-by-step approach such as the Plan-Do-Study-Act Model\textsuperscript{42}, Framework for complex interventions\textsuperscript{43}, and Grol’s Implementation of Change Model (figure 3)\textsuperscript{44}. Consequently, using such an approach facilitates the identification of potential barriers and facilitators, allowing to tailor the implementation process to the specific situation. An essential step to ensure the effectiveness of the implementation process.

**Analysis of actual performance**

One of the first steps in the implementation process is to measure the current level of quality of care\textsuperscript{45}. A description of the current level of care can be used to objectively compare the results before and after an intervention study. Such a systematic and transparent data collection can be achieved by using quality
A quality indicator is “a measurable element of practice performance for which there is evidence or consensus that it can be used to assess quality and hence changes in the quality of care provided”\(^{46}\). Donabedian distinguished three types of quality indicators: structure (type and amount of resources), process (activities and tasks) or outcome (effects of healthcare)\(^{47}\).

**Quality indicators**
The structure and process quality indicators proposed by Donabedian can be used to identify potential areas for improvement regarding the organisation of care.
If a quality indicator is used for such a purpose, they are called ‘internal quality indicators’. Quality indicators designed to improve the organisation of care cannot be used for external purposes, as this will make them unfit for their task. Berwick et al. summarised this as “measuring for improvement is not measuring for judgement”. Engels et al., for example, applied a set of quality indicators to assess the organisation of general practices. One of their quality indicators was about the availability of essential medicines in the doctor’s bag. The result of the assessment was used to initiate a stepwise improvement plan to improve the availability of emergency medicines.

In the past few years, several sets of quality indicators for palliative care have been developed. The aim of these studies were mainly to improve clinical care and not the organisation of care. Pasman et al. developed a set of 142 quality indicators, but this set did not focus on the organisation of care, was often restricted to a specific setting like the intensive care unit, was not developed within an international context and was not widely implemented.

In the EU funded ‘Europall’ project (2007-2010), Woitha et al. developed an international set of quality indicators for the organisation of proactive palliative care. However, Woitha et al. focused on palliative care in general, and did not consider specific patient groups such as those with dementia.

Including palliative care for dementia might stimulate the development of collaborative care in these two clinical domains. Knowledge, experience and best practices from both domains can then be shared in order to improve both.

**Implementing change**

Evidence based interventions do not implement themselves, even if new knowledge has been made ready for use by the development of quality indicators. This is particularly the case in the complex organisation of palliative care. However, it is still unclear which implementation strategies are effective to change the organisation of palliative care. Subsequently, it is also unclear which factors influence these strategies. This hampers the actual translation of clinical evidence into daily clinical practice. This is especially true for the different countries in Europe, where differences in the national healthcare system can prevent transfer of successful strategies from one service to another and from one country to another. However, as the European population is ageing, there is much to gain. Palliative care has evolved from care for patients with incurable cancer, to care for patients with all kind of life-limiting chronic diseases. But irrespective of the disease, patients in need of palliative care have a lot in common. They have changing (and often increasing) needs for treatment and support, have multiple (and comparable) problems and symptoms, receive care from a variety of professionals, and often move between services. However, disease features, trajectories over time and dying scenarios differ due to the characteristics of the underlying disease. To further improve palliative care, it is therefore inevitable to increase the transition of evidence based and best practices beyond the borders.
of one medical specialty. For that reason, it is important to develop a tool that can be used by all healthcare professionals across all levels of care to assess whether their service meets a basic quality level of palliative care and that can identify potential areas for improvement.

**Objective of this thesis**

Starting from Grol's Implementation of Change Model\(^4\), we aim to assess whether the first steps of the model are applicable for the organisation of palliative care. Thereby, we aim to add knowledge about the implementation of quality improvement initiatives specifically for the field of palliative care. Secondly, we aim to improve the identification of persons with dementia that are in need of palliative care.

The objective of the present thesis therefore is to develop a generic set of quality indicators that 1) make it feasible to assess the organisation of palliative cancer and dementia care; 2) can be implemented in daily practice; and 3) can initiate quality improvements for the organisation of palliative cancer and dementia care. And secondly, to improve the identification of persons with dementia that are in need of palliative care. Consequently, the following research questions were formulated:

1. Which quality indicators are useful to assess the organisation of palliative cancer and dementia care in different settings and countries?
2. What are the most optimal strategies to implement evidence-based and best practices regarding the organisation of palliative care into daily clinical practice?
3. What are barriers and facilitators regarding strategies aiming to improve the organisation of palliative care as perceived by professionals in five European countries?
4. When do professionals working in long-term care facilities consider a person with dementia in need of palliative care?

**Outline of this thesis**

Chapter 2 provides an overview of the entire IMPACT project. Chapter 3 describes the results of a modified RAND Delphi-procedure used to compose a set of quality indicators specifically for the organisation of palliative care. Chapter 4 describes an integrative review of strategies aimed to improve the organisation of palliative care. Chapter 5 describes the results of a qualitative study to explore barriers and facilitators perceived by professionals when implementing strategies to improve the organisation of palliative care of services in five European countries. Chapter 6 describes the results of a qualitative study in which an international group of experts considered the most optimal strategies to implement evidence-based medicine into daily clinical practice. Chapter 7 describes the results of a qualitative study to explore the opinions of professionals working in long-term care facilities when they considered a person with dementia in need of palliative care. Finally,
chapter 8 summarises and discusses the main findings of this thesis, considers its strengths and limitations, as well as the implications of the findings for the organisation of palliative care in Europe.
References


Improving the organisation of palliative care by implementing quality indicators and national and setting-specific interventions: study protocol of the IMPACT project

Progress in Palliative Care 2014; 22:4

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Abstract

**Background:** There is a wide gap between knowledge about palliative care and its application in everyday clinical practice, affecting many patients in our ageing population. However, changing healthcare practice is a complex and challenging process. Therefore the EU funded IMPACT (IMplementation of quality indicators in PAlliative Care sTudy) project aims to develop optimal implementation strategies to improve the organisation of palliative care for people with cancer or with dementia in Europe.

**Methods and design:** The organisation of palliative care in Europe will be mapped to develop and prepare strategies to improve it, and an overview of barriers and incentives regarding successful organisational changes in palliative care will be undertaken. A pre-test with a set of quality indicators (QIs), developed within the project, will be used to identify aspects of the organisation of palliative care requiring change in hospitals, nursing homes, hospices and primary care in five European countries. Based on the results of the pre-test, each setting will be invited to prioritise and improve aspects of their organisation that appeared weak. The improvement objective they choose will be tailored to national and setting-specific barriers. Finally, a post-test with the same QIs will determine the effectiveness of the strategies used. An extensive process analysis will be conducted throughout the entire study.

**Discussion:** It is expected that the IMPACT project will provide professionals and policy makers useful tools to facilitate effective implementation of high quality palliative cancer and dementia care in different settings in Europe.
Background

Continuous development of health services is required to maintain the highest quality of care\(^1\). However, ‘gaps’ exist between readily available evidence of best practice and its use in everyday care. This is particularly the case for palliative care, which aims to “improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement”\(^2\).

Ageing of the population and higher survival rates of people with life-threatening diseases result in a larger number of patients with multiple and complex health-threatening problems\(^3,4\). Within the next decade, for example, the incidence and prevalence of cancer will increase by about 20%; the prevalence of dementia will double before 2050\(^5-7\). To prevent problems and to provide adequate symptom relief, it is necessary to identify and assess symptoms as early as possible in order to initiate and develop a pro-active palliative care plan. To optimally promote the quality of life of a person affected with a complex, incurable and life-threatening health problem the care pathway should address physical, emotional, psychosocial and spiritual aspects of the patient’s health, as stated in the World Health Organisations (WHO) definition of palliative care\(^8\).

Although the organisation of palliative care has been described\(^9-11\), knowledge about how best to improve it has hardly been studied\(^12\). Quality indicators (QIs) can be used to assess where care can be improved. QIs are evidence-based, explicitly defined and measurable items that evaluate and describe the structure, processes and outcomes of healthcare, and that can indicate either potential problems in or achievement of good quality care\(^13\). They can be used to assess and feed back to professionals their actual performance compared to benchmarks, as a starting point for quality improvement\(^14\). QIs have been used effectively to assess and improve hospital care\(^15\), primary care\(^16\), and dementia care\(^17\). Several international studies have also developed QIs to improve the structures and process needed for the delivery of good quality palliative care\(^18-20\). However, these large sets, with QIs ranging between 56 to 142, are more a tool for research than actually useful in daily practice. These indicator sets have, therefore, not yet been widely applied in everyday clinical practice. This study proposes to implement QIs and strategies into daily practice to improve the organisation of palliative care in Europe. Unlike other studies\(^21\), this study will not only focus at the organisation of palliative care for patients with cancer, but also at the organisation of palliative care for patients with dementia.

Methods and design

Objective

The IMPACT project (IMplementation of quality indicators in PAlliative Care sTudy)
aims to develop optimal strategies to improve the organisation of palliative cancer and dementia care in Europe with the use of QIs. This study will be conducted in five European countries (England, Germany, Italy, Norway, and the Netherlands) and is supported by researchers in another five European countries and Australia.

**Time frame**
This study runs from 2011 to 2015. At the time of publication, the project is in its third year: the mapping exercise has finished and a set of QIs has been developed. These QIs are currently being tested in the pilot study.

**Study design**
The stepwise implementation model of this study is built on the framework for the development and evaluation of complex interventions to improve health of the UK Medical Research Council (MRC). The main tasks in this study correspond with the developmental steps of the MRC framework in that theoretical and modelling activities will be undertaken before the intervention study will be designed and implemented. Table 1 provides a detailed overview of the tasks that will be conducted in the IMPACT project.

**Theory and modelling**
Semi-structured interviews with professional healthcare providers and policy makers will be used to map the different palliative care models in Europe. This mapping exercise will facilitate the development of QIs and strategies to improve the organisation of palliative care. QIs will be selected from existing sets. Only QIs that are related to the organisation of palliative cancer care or palliative dementia care (e.g. process and structure QIs) will enter a modified RAND Delphi-procedure. A purposefully selected panel of about 40 international experts will participate in the modified RAND Delphi-procedure. These panellists have to be either an expert in palliative care, cancer care, or dementia care, and have knowledge about QIs. Panellists will be asked to rate each individual QI on a 9-point Likert scale for clarity and usefulness in two written rounds and one consensus round. QIs with a median rating on the usefulness scale of 7, 8 or 9 without disagreement will be considered face valid. This Delphi exercise will result in one set of QIs that is applicable for the organisation of both palliative cancer and dementia care and can be used in different types of settings. This final set will be structured according to the recommendations for the organisation of palliative care of the Council of Europe.

Strategies to improve the organisation of palliative care will be identified with the use of an integrative review, in order to allow the inclusion of both empirical and theoretical literature on implementation strategies. Subsequently, interviews and focus group interviews with healthcare professionals will be used to adjust the strategies in response to national and setting-specific barriers and facilitators,
in order to develop a toolkit of country and setting-specific strategies to improve the organisation of palliative care.

**Pilot**

**Setting and participants**

Palliative care is provided by a range of professionals in different settings: including, but not limited to specialised palliative care teams in hospitals, palliative home care provided by the general practitioner and community nurses, palliative care wards/teams in nursing homes, and hospice care. The IMPACT project aims to incorporate all of these services. Therefore, QIs and improvement strategies will be implemented in four types of settings (hospitals, nursing homes, hospices and primary care). In each country, a minimum of two services per setting will participate in order to compare the usefulness of QIs in palliative cancer and palliative dementia care services.

The multidisciplinarity of the research team will help recruitment of the study settings. The team includes experts of the pan-European research group on detection and timely INTERvention in DEMentia (Interdem) and the European Association for Palliative Care (EAPC), all of whom are stakeholders in their country in palliative cancer and/or dementia care. The research team will be invited to use their networks to purposefully select settings to take part in the intervention. Services will be excluded from participation in the study if they

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Table 1: Tasks of the IMPACT project

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do not treat palliative patients aged 18 years or above, or when they have not provided palliative care for the last three years. Within these services, healthcare professionals will be selected to participate in the pre-test – intervention - post-test study.

**Implementation**

Professionals from the participating settings will be asked to answer qualitative and quantitative questions derived from the QIs, to identify aspects in the organisation that require change (pre-test). An online survey will facilitate easy use of the QIs, allow early comparison of data between settings and/or countries and provide rapid feedback to participants. Following the feedback, professionals will be stimulated to use the stepwise implementation model to set improvement objectives formulated in a SMART way (Specific, Measurable, Acceptable, Realistic and Timely)\(^4\). These improvement objectives will help professionals to choose specific strategies, adjusted to their situation, to improve the organisation of palliative cancer and dementia care (intervention). During the entire intervention, each service will be regularly visited by a trained consultant to guide them through the stepwise implementation model. After the intervention period, the organisation of palliative care will again be assessed (post-test) with the use of the same QIs as used in the pre-test.

**Evaluation and dissemination**

During the intervention period, a process evaluation will be performed to study actual barriers and facilitators of the implementation process\(^27\). Therefore, the implementation process will be monitored by using an activity report (including but not limited to questions related to the progress, barriers and facilitators, and personal experiences of the improvement strategies). Each time the consultant visits a service, they will fill in an activity report. To get a better understanding of the aspects mentioned in the activity reports, semi-structured individual and focus group interviews will be conducted with professionals from each participating service. Professionals will be purposefully selected based on their participation in and knowledge of the conducted improvement strategies. These interviews will be continued until data saturation is reached. Results of the evaluation will be used to guide professionals introducing changes to improve their daily practice.

**Data analysis**

Quantitative data of the pre- and post-test will be transferred from the web-based data system into a computer program for statistical analysis (SPSS) for descriptive analysis. The degree to which professionals are intending to act according to the recommendations expressed in the QIs will be compared between pre- and post-test. Comparing the results within and between countries and settings will also allow the identification of optimal strategies to improve the organisation of palliative care. Qualitative data, resulting from the individual and focus group interviews, will
be analysed\(^{28}\) using computer software such as Atlas.ti for content analysis\(^{29}\), and (if applicable) grounded theory development\(^{30}\). QIs with low adherence will be omitted from the study, unless individual and focus group interviews identified strong reasons to keep the QI.

**Discussion**

The aim of the IMPACT project is to assess and improve the organisation of palliative cancer and dementia care in Europe. With the use of quality indicators, the current organisation of palliative care will be assessed in order to identify aspects of the organisation that require change. Results from this assessment will be fed back to professionals working in the settings. Next, a consultant will help each setting to start and finish structured improvement projects\(^ {31}\).

We know that using feedback alone results in small to moderate effects on service performance\(^ {32}\). In addition to the feedback, this study will also use other strategies tailored to national and setting-specific barriers and facilitators, to improve the implementation of change. Many of these strategies have been tested before\(^ {3,33}\), but not yet in the complex multidimensional field of palliative care. In conjunction with the WHO definition on palliative care\(^ {3}\), this study will not only focus on palliative care for patients with cancer but will compare the organisation of palliative cancer care and palliative dementia care. This comparison allows for the identification of common strategies (and their barriers) that are suited to improve the organisation of palliative care as well as identify those that are disease specific. These results can be used as a template for further research in other healthcare settings that provide care for chronically ill patients.

Results from the IMPACT project will be provided to stakeholders and decision makers in order to facilitate effective implementation of high quality palliative cancer and dementia care in a variety of settings in Europe.

**Strengths and Limitations**

First, the IMPACT consortium consists of a multidisciplinary research team, including researchers experienced in quantitative and qualitative research and well-known experts in the field of palliative and dementia care. In each country, the research team consists of at least a PhD student for the day-to-day work and one or more senior researchers responsible for the scientific output. Regular face-to-face meetings (at least twice a year with the research team and once a year with the entire consortium) and telephone conferences (at least every two months with the research team) will ensure that the project is conducted simultaneously in the five countries.

Second, a financial incentive will be rewarded for participating services upon meeting specific milestones (e.g. completion of the pre-test), stimulating their motivation to implement strategies to improve their organisation of palliative care.

Third, the stepwise implementation model that will be used in this study allows us
to tailor the intervention at a setting and country level, in other words to translate the intervention to everyday clinical practice\textsuperscript{14}. This will require the use of research methods that are able to cope with the factors that shape palliative care in general and its organisational processes in particular. Controlling these aspects in an international study with strict deadlines would have made a randomised controlled trial impractical\textsuperscript{34-36}. Thereby, randomised controlled trials are usually focused on one setting and often in one country, while this study explores and initiates quality improvements in several settings in different European countries.

Before the start of the project, two potential limitations have been identified. First, time management is a major risk throughout the course of the project. All of the phases of the project depend on each other. Failure in one phase will result in problems in the next. In conjunction with the European Union’s 7\textsuperscript{th} Framework Programme, deliverables (table 2) have been formulated. Each of the work package leaders involved in the IMPACT consortium has to produce deliverables, stimulating them to deliver their results on time. In consequence, strict time management is required by the project coordinator who will actively monitor and stimulate all the researchers involved.

Second, IMPACT is a European project conducted in five different countries, with different cultures, languages, healthcare systems and organisation of palliative care, making it difficult to compare services between countries. These differences have to be taken into account during the entire project. The IMPACT project explicitly tries to overcome this challenge by providing detailed information of each participating service (e.g. number of staff, level of trained staff, etc.). This critical reflection of the differences in service delivery in each country will help to compare the results of the project on an international level.

**Table 2: Scientific deliverables**

<table>
<thead>
<tr>
<th>Deliverable name</th>
<th>Month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analytic framework to characterise palliative care across Europe</td>
<td>12</td>
</tr>
<tr>
<td>Model of the organisation of palliative care related to the national context</td>
<td>14</td>
</tr>
<tr>
<td>(macro-level), the available workforce (meso-level) and the settings and</td>
<td></td>
</tr>
<tr>
<td>professionals level (micro-level)</td>
<td></td>
</tr>
<tr>
<td>Concept set of implementation strategies</td>
<td>24</td>
</tr>
<tr>
<td>Table of strategies used in five countries</td>
<td>36</td>
</tr>
<tr>
<td>Description of factors influencing implementation</td>
<td>36</td>
</tr>
</tbody>
</table>
References

Chapter 2


Consensus on quality indicators to assess the organisation of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts

BMC Health Services Research 2014; 14:369

Jasper van Riet Paap
Myrrha Vernooij-Dassen
Rose-Marie Dröes
Lukas Radbruch
Kris Vissers
Yvonne Engels
Abstract

Background: Large numbers of vulnerable patients are in need of palliative cancer and dementia care. However, a wide gap exists between the knowledge of best practices in palliative care and their use in everyday clinical practice. As part of a European policy improvement program, quality indicators (QIs) have been developed to monitor and improve the organisation of palliative care for patients with cancer and those with dementia in various settings in different European countries.

Method: A multidisciplinary, international panel of professionals participated in a modified RAND Delphi-procedure to compose a set of palliative care QIs based on existing sets of QIs on the organisation of palliative care. Panellists participated in three written rounds, one feedback round and one meeting. The panel’s median votes were used to identify the final set of QIs.

Results: The Delphi-procedure resulted in 23 useful QIs. These QIs represent key elements of the organisation of good clinical practice, such as the availability of palliative care teams, the availability of special facilities to provide palliative care for patients and their relatives, and the presence of educational interventions for professionals. The final set also includes QIs that are related to the process of palliative care, such as documentation of pain and other symptoms, communication with patients in need of palliative care and their relatives, and end-of-life decisions.

Conclusion: International experts selected a set of 23 QIs for the organisation of palliative care. Although we particularly focused on the organisation of cancer and dementia palliative care, most QIs are generic and are applicable for other types of diseases as well.
Background

Europe faces a huge challenge with a population that is rapidly aging in the coming decades. It is estimated that the incidence and prevalence of cancer will increase by about 20% and the prevalence of dementia will double before 2050\(^1\)\(^-\)\(^4\). Although it concerns two totally different diseases with different care needs and disease trajectories, they do have a lot in common: they are often unnecessarily hospitalised\(^5\), have a high need for a multidisciplinary approach\(^6\) and many suffer from symptoms which are partly the same, like pain\(^7\)\(^,\)\(^8\). Higher survival rates of people with life-threatening and progressive chronic diseases will result in a larger number of patients that have multiple and complex health-threatening problems. Therefore, a growing number of patients will be in need of palliative care. However, a wide gap exists between the knowledge of best practice in palliative cancer and dementia care and its application in every day clinical practice\(^9\).

As a first step in bridging this gap, it is important to assess current performance of palliative care in relation to its desired performance. Such an assessment of healthcare can be achieved by using quality indicators (QIs). QIs are evidence based, explicitly defined and measurable items that evaluate and describe structures, processes and outcomes of healthcare\(^10\). As such, they reflect the core elements of good clinical care. In day-to-day terms QIs can, for example, show whether pain is regularly being assessed using a validated tool; or whether a general practitioner is timely informed about a patient’s situation before or directly after discharge from hospital\(^11\)\(^,\)\(^12\). QIs can help trace potential problems or confirm good quality of care and can be used to guide quality improvement processes\(^10\). They have been used effectively to assess and improve hospital care\(^13\), primary care\(^14\), and dementia care\(^15\)\(^,\)\(^16\). Several studies have also developed QIs to improve the structures and process needed for the delivery of good quality palliative cancer or dementia care\(^11\)\(^,\)\(^12\)\(^,\)\(^17\)\(^,\)\(^18\). However, these studies were performed five or more years ago, developed large sets of QIs, ranging from 56 to 142 QIs. Furthermore, none of these sets were widely implemented in everyday clinical practice.

The objective of this study was to integrate existing sets of QIs into one generic set that can be used to assess and improve the organisation of palliative care in different services and countries. The study was conducted within the framework of the European IMPACT project (IMplementation of quality indicators for PAlliative Care sTudy)\(^19\).

Methods

A modified RAND Delphi-procedure was used to develop a set of QIs\(^20\), which is considered an accepted methodology to develop QIs\(^10\). Typically, a RAND Delphi-procedure consists of a written and a face-to-face round\(^20\). In this study, four written rounds and one face-to-face round were performed to reach consensus
about the essential aspects regarding the organisation of palliative care.

**Panellists**

The IMPACT consortium consists of experts of the pan-European research group on detection and timely INTERvention in DEMentia (Interdem) and the European Association for Palliative Care (EAPC), all of whom are stakeholders in their country in palliative cancer and/or dementia care. The research team was invited to use their networks to purposefully select panellists for the modified RAND Delphi-procedure. A key selection criteria was that the expert had to have extensive knowledge about palliative care, cancer care or dementia care. Additionally, experts had to be able to communicate in English (both verbally and non-verbally) and were planning to attend the 2012 Congress of the European Association of Palliative Care (EAPC) in Trondheim, Norway. Project partners nominated national and international experts in palliative cancer and dementia care. All nominated experts were approached via email (n=50), forty experts from twelve countries agreed to participate in the modified RAND Delphi-procedure (table 1). All participants provided written informed consent. About half of them were experts in palliative cancer care and the other half in dementia care. Twenty-two panellists were active clinicians in this field (e.g. physician, nurse, psychologist, etc. currently involved in direct-patient care), the others were researchers.

**Selecting a preliminary set of QIs**

A search for existing sets of QIs was conducted in PubMed. The search strategy was limited to English literature and consisted of various search terms that referred to subject-specific keywords describing palliative care (combined using “or”), as well as (“and”) the assessment of care using QIs (combined using “or”). Synonyms and medical subheading terms were used to fully include relevant literature (see table 2).

![Table 1: Panellists per country](image)

<table>
<thead>
<tr>
<th>Country</th>
<th>Researcher</th>
<th>Clinician</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Belgium</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Canada</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Germany</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Italy</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Netherlands</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Norway</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Poland</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Switzerland</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>United States</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>18</td>
<td>22</td>
</tr>
</tbody>
</table>
Subsequently, references of key papers describing sets of QIs were hand searched. Additionally, consortium members of the IMPACT project were asked to nominate national and international sets of QIs on palliative cancer and dementia care they considered important. Two researchers (YE & JvRP) subsequently reviewed all of the identified QIs independently to determine if the QIs assessed the structure and process of palliative care and to structure them according to the domains of the recommended framework for the organisation of palliative care of the Council of Europe. 

First written Delphi-round
For the first written Delphi-round (April 2012), panellists received a personal invitation for an online questionnaire. To reduce the large number of identified QIs, panellists were asked to nominate one QI per domain of palliative care. Those QIs that were nominated by the panellists were included in the second round of the modified RAND Delphi-procedure.

Second written Delphi-round
In the second round (May 2012), also via an online questionnaire, panellists were asked to rate QIs on a 9-point Likert scale for clarity (1 = not clear at all; 9 = very clear), usefulness (1 = not useful at all; 9 = very useful), to rephrase unclear and to add missing QIs. They were instructed to rate a QI high on usefulness if it: 1) corresponded with a basic quality level; 2) referred to a higher quality level that would be met only in very good practices; or 3) was associated with an innovative quality level which is exceptional at the moment, but could become the optimal quality level in the near future. They were asked to give a low rating on usefulness if a proposed QI: 1) was too ambiguous or represented an unrealistically high quality level; 2) did not correspond with the material, social or cultural conditions of the situation in their country; or 3) was not in accordance with the regulations of palliative cancer and dementia care in their country.

Third interactive Delphi-round
A consensus meeting was organised during the EAPC Congress June 7, 2012 in Trondheim, Norway. The meeting was chaired by an independent researcher with the aim to reach consensus on the QIs on which there was disagreement or where

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**Table 2: Overview of search terms**

<table>
<thead>
<tr>
<th>Search term</th>
<th>Quality indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care</td>
<td>Quality indicators</td>
</tr>
<tr>
<td>Terminal care</td>
<td>Quality assurance</td>
</tr>
<tr>
<td>Hospice care</td>
<td>Quality measurement</td>
</tr>
<tr>
<td>Cancer care</td>
<td>Quality assessment</td>
</tr>
<tr>
<td>Dementia care</td>
<td></td>
</tr>
</tbody>
</table>
the median score was between 4 and 6 in the second Delphi round. Participants received a rating sheet on which the median ratings of the second Delphi-round of all experts were visible. Participants were given 30 minutes to rate the adapted QIs for usefulness. Next, per QI, participants were asked to raise their hand if they had rated usefulness 6 or less. If at least nine (30%) participants raised their hand, the QI was discussed until consensus was reached.

Fourth written Delphi-round
After the consensus-round, the remaining indicators were fed back to the panellist with the purpose to validate the changes that were made (September 2012).

Fifth written Delphi-round
In the final step of the QI development process, QIs were operationalised by the research team into questions that could be used by healthcare professionals to assess their organisation of palliative care and identify areas for improvement. During this process, it appeared that some QIs were inappropriate or not measurable (e.g. too time consuming to answer them appropriately). All QIs were therefore rated for necessity by the IMPACT research team (October 2012), representing both clinicians and researchers that also took part in the modified RAND Delphi-procedure. QIs that were considered not necessary after this round, were omitted from the list.

Analysis
QIs with a median rating on the usefulness scale of 7, 8 or 9 without disagreement were considered to have face validity. Disagreement was defined as: 30% or more of the panellists rated a single QI in the 1-3 tertile and more than 30% in the 7-9 tertile. QIs scored with a median of 1-3 without disagreement were not considered to have face validity. Because panellists had rated QIs high on usefulness, only QIs with median ratings of 8 or 9 were considered face valid for the second Delphi-round. Only QIs that were rated valid by all panellists were included in the final set.

Ethical considerations
The Medical Ethics Committee of the district Arnhem-Nijmegen has declared that this study doesn’t fall within the remit of the Medical Research Involving Human Subjects Act (WMO) (registration number 2012/075). This means that this study can be carried out without an approval by an accredited medical ethics committee.

Results
650 QIs were selected from literature. After having assessed these QIs, 554 were excluded because they were not about the organisation of palliative care or because of overlap; the remaining 96 QIs were included in a preliminary set of QIs (figure 1). Of the 40 experts invited as panellists, 25 (63%) participated.
In the first Delphi round, 65 of the 96 QIs were selected and 13 missing QIs were suggested in an open question in which panellists were asked if they missed any relevant QI. This resulted in an adapted list of 78 QIs, which were included in the second Delphi round.

In the second Delphi-round, 27 (67.5%) of the 40 invited panellists participated. Sixteen QIs were considered to have face validity, 28 were invalid, and six QIs were added to the list based on suggestions made by the panellists. The 40 QIs on which there was no agreement on, were included into the third Delphi round.

In the third Delphi-round, a consensus meeting, 29 (72.5%) of the 40 panellists participated. After having rated 40 QIs, one was excluded and 10 were discussed. Of the QIs that were discussed, six were accepted and four were excluded. Panellists also agreed to merge 11 QIs. Round three therefore resulted in 24 accepted QIs. The total list of QIs (QIs considered to have face validity in round two and three) comprised 40 QIs.

In the fourth Delphi-round, panellist provided feedback to the remaining set of QIs. This resulted in minor linguistic changes and the exclusion of three QIs because they were considered inappropriate by the majority of panellists. The resulting set of QIs, therefore, consisted of 37 QIs. This list was critically assessed by members of the IMPACT consortium for their necessity (round five). Fourteen QIs were considered to be overlapping, inappropriate, or not measurable in palliative care. The final list of QIs, therefore, consisted of 23 QIs, covering seven domains (table 3). Key findings can be summarised as follows:

**Access to palliative care**

The availability of a dedicated palliative care team was considered important by almost all panellists in the Delphi-procedure. They explicitly stated that palliative care services should not only be available during office hours, but at all times (day, evening, night and weekend). Furthermore, specific elements of palliative care were considered important, such as the availability of opioids and anticipatory medications for symptom control, as well as the availability of bereavement support.

Almost all panellists also rated important the accessibility of the medical record to healthcare professionals, timely transfer of information between settings (including when transferring or discharging patients). Panellists also considered an assigned contact person, who maintains regular contact with patients and their families, useful.

**Infrastructure**

The infrastructure of the place where palliative care is provided, such as a single bed hospital room, was rated important. Access to equipment (such as anti-decubitus mattresses, suction equipment, etc.), required to provide palliative care, was considered important. Panellists also rated high consensus for facilities for relatives to visit, stay overnight, and a private area for saying goodbye to the
Figure 1: Modified RAND Delphi-procedure

QI: Quality indicator
1 Equivocal is defined as all QIs on which there was no agreement: e.g. QIs with 30% or more of ratings in both the 1-3 tertile and the 7-9 tertile and all indicators with a median rating in the 4-6 tertile.
2 At the end of round three, panelists agreed that 11 QIs could be merged.
deceased. There was no agreement on QIs that aimed to control waiting time or waiting list, i.e. these aspects were not considered to be unique for palliative care and therefore not important.

**Assessment tools**
Regular assessment of pain and other symptoms was rated as a valid quality criterion, though it was commented that a validated instrument might not always be available, particularly for specific patient groups (e.g. for persons with advanced dementia).

**Personnel**
There was agreement on the need for a multidisciplinary team, which should consist of at least a physician and nurse, and have access to a range of supporting disciplines, such as: physiotherapist, psychologist, occupational therapist, social worker, dietician, and chaplain. Panellists also rated a regular multidisciplinary team meeting important.

**Documentation of clinical data**
Panellists recognised the importance of having a well-structured medical record. However, a QI about the structure of the medical record was not considered important by the panellists. Panellists only considered the inclusion of a medication regimen in the medical record important. They also considered a timely assessment (within 48 hours) of pain and other symptoms, psychosocial and spiritual needs, patient preferences, wishes and needs, and the patient’s capacity to be involved in the decision making process as important.

Furthermore, almost all panellists rated the documentation of communication on the medical condition, goals of treatment, physical, psychosocial, and spiritual needs of the patient and their relatives, intention to return home, advanced directive, and end-of-life decisions as important.

**Quality and safety**
Panellists rated the QI about assessing the experiences of care givers with the palliative care service important. Secondly, a QI about the quality of care, assessing the use of an end-of-life care pathway within the last three days of life, was also considered useful.

**Education**
QIs about the staff’s learning objectives and a program for specialised and/or continuing medical education about the physical, psychosocial, and spiritual needs of a patient in need for palliative care were not rated important. There was also no agreement on disease-specific education for staff members, but panellists considered palliative care training specified to the professional’s background important.
### Table 3: Overview of quality indicators

<table>
<thead>
<tr>
<th>1. Access to palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1a. Access and availability</strong></td>
</tr>
<tr>
<td>1. A specialist palliative care team* is available 24/7.</td>
</tr>
<tr>
<td>2. Specialist palliative care* advice is available 24/7 to professionals delivering palliative care.</td>
</tr>
<tr>
<td>3. Bereaved relatives and/or professionals involved in care of a person in need of palliative care are offered support during the bereavement process if they need or wish to have support.</td>
</tr>
<tr>
<td><strong>1b. Out of hours care</strong></td>
</tr>
<tr>
<td>4. Opioids are accessible and available for persons in need of palliative care 24/7.</td>
</tr>
<tr>
<td>5. Co-analgesics* for symptom control are available to treat persons in need of palliative care 24/7.</td>
</tr>
<tr>
<td><strong>1c. Continuity of care</strong></td>
</tr>
<tr>
<td>6. An (electronic) file of a person in need of palliative care is accessible to professionals in charge of the person 24/7.</td>
</tr>
<tr>
<td>7. At each transition between care settings, comprehensive information (including care goals and care plan) of a person in need of palliative care is transferred to the professional(s) in charge in the next setting.</td>
</tr>
<tr>
<td>8. The professional in charge of the person is informed before a person in need of palliative care is discharged home or sent to the next setting.</td>
</tr>
<tr>
<td>9. Persons in need of palliative care have an assigned contact person who maintains regular contact with the person and their families, and ensures coordinated delivery of health and social care.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Infrastructure</th>
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</thead>
<tbody>
<tr>
<td>10. Specialised equipment (e.g. anti decubitus mattresses, suction equipment, stoma care, oxygen delivery, drug administration pumps, hospital beds, etc.) is available to persons in need of palliative care.</td>
</tr>
<tr>
<td>11. Single bedrooms are available for persons who are dying and who wish to have one.</td>
</tr>
<tr>
<td>12. Family members and friends are able to visit the dying person without restrictions of visiting hours.</td>
</tr>
<tr>
<td>13. There are facilities for relatives to stay overnight with their dying relative.</td>
</tr>
<tr>
<td>14. There is a private area for saying goodbye to the deceased, nearby or on the ward/unit where the person died.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Assessment tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. There is a regular assessment of pain and other symptoms using a validated instrument*.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Personnel</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>4a. Team</strong></td>
</tr>
<tr>
<td>16. The multidisciplinary team* that delivers palliative care services consists of at least: a physician and nurse; and has access to one or more of the following professionals: physiotherapist, psychologist, occupational therapist, social worker, chaplain, dietician.</td>
</tr>
<tr>
<td>17. There is a weekly multidisciplinary meeting with at least the physician and nurse in charge of the person in need of palliative care to review treatment and care plans.</td>
</tr>
</tbody>
</table>
Table 3: Continued

4b. Sharing information
18. The file of the person in need of palliative care contains documentation of a discussion with the person or representative (if the person lacks capacity e.g. is unable to communicate) about:
   - medical condition;
   - goals for treatment;
   - the physical*, psychosocial and spiritual needs of the person and family caregiver;
   - an advance directive or advance care plan;
   - end-of-life decisions*;
   - the intention to return home or to another facility from the place where the person is currently staying.

5. Documentation of clinical data
5a. Clinical records
19. The file of the person in need of palliative care contains a medication list that is accessible to the professionals caring for the person.

5b. Timely documentation
20. Within 48 hours of admission to the service, the file of the person in need of palliative care contains documentation of the initial assessment of:
   - pain and other symptoms, using a validated instrument*;
   - psychosocial and spiritual needs;
   - persons preferences, wishes and needs;
   - capacity to be involved in the decision making process.

6. Quality
21. Family and caregiver experiences of the palliative care service are assessed / evaluated / recorded.
22. An end-of-life care pathway (such as the Liverpool Care Pathway) was used for the last 3 days of life of a person in need of palliative care.

7. Education
23. All professionals that deliver palliative care services receive accredited training in palliative care, appropriate to their discipline.

NB Where person is stated, one can also read patient.

*Glossary

Palliative care team
A home palliative care team provides specialised palliative care to patients who need it at home (or home replacing institute) and support to their families and carers at the patient’s home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home. The core team of a home palliative care team consists of four to five full-time professionals and comprises physicians and nurses with specialist training, a social worker and administrative staff. The home palliative care team works in close collaboration with other professionals so that the full range of multi-professional team work can be realised in the home-care setting. (Source: Radbruch L, Payne S: White paper on standards and norms for hospice and palliative care in Europe: part 2. European Journal for Palliative Care 2010, 17:22-33)
A hospital palliative care support team provide specialist palliative care* advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education, and liaise with other services in and out of the hospital. A hospital palliative care support team is composed of a multiprofessional team with at least one physician and one nurse with specialist palliative care training. The team should have ready access to other professionals working in liaison with it, including bereavement specialists, chaplains, dietitians, therapists, oncologists, pharmacists, physiotherapists, psychiatrists, psychologists, social workers and speech and language therapists. (Source: Radbruch L, Payne S: White paper on standards and norms for hospice and palliative care in Europe: part 2. European Journal for Palliative Care 2010, 17:22-33).

Team

A team is hereby defined as a group of people organised to work together, which consists of at least a nurse and a physician.

Specialist palliative care

Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative services require a team approach, combining a multiprofessional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care. (Source: Radbruch L, Payne S: White paper on standards and norms for hospice and palliative care in Europe: part 2. European Journal for Palliative Care 2010, 17:22-33).

Co-analgesics

An adjuvant (or co-analgesic) is a drug that in its pharmacological characteristic is not necessarily primarily identified as an analgesic in nature, but that has been found in clinical practice to have either an independent analgesic effect or the additive analgesic properties when used with opioids. (Source: Khan MIA, Walsh D, Brito-Dellan N. Opioid and Adjuvant Analgesics: Compared and Contrasted. Am J Hosp Palliat Care 2011, 28(5) 378-383)

Validated instrument

Instruments such as the Visual Analogue Scale (VAS) or the Numeric Rating Scale (NRS) that can be used to indicate the severity of the patient’s pain or other symptom. (Source: Ahmedzai S, Gómez-Batiste X, Engels Y, Hasselaar J, Jaspers B, Leppert W, Menten J, Molland JM, Vissers K: Assessing Organisations to Improve Palliative Care in Europe. Nijmegen: Vantilt Publishers; 2010).

End-of-life decisions

End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness. End-of-life care may also be understood more specifically as comprehensive care for dying patients in the last few hours or days of life. Either way, the patient preserves his/her self-determination regarding the power of decision on place of care, treatment options and access to specialist (palliative) care. End-of-life decisions are all the decisions made by the patient/family and health professionals regarding this last phase of a patient’s life, e.g. decisions that may influence the time of death, either prolonging life (or prolonging dying) or shortening life (or let patients die). (Source: Radbruch L, Payne S: White paper on standards and norms for hospice and palliative care in Europe: part 1. European Journal for Palliative Care 2010, 16(6):278-289).

Physical needs

For example if the patients physical symptoms require certain needs, such as special bed...
Discussion

With the help of a modified five-round RAND Delphi-procedure, we were able to develop an internationally validated set of QIs for the organisation of palliative care with high face validity as judged by experts in the field of cancer and dementia care. The final set provides 23 quality aspects regarding the accessibility of the service, its infrastructure, the use of symptom assessment tools, management of personnel, documentation of clinical data, quality of care, and education. Of these 23 QIs, one was identical to the original one (Family members and friends are able to visit the dying person without restrictions of visiting hours)\(^{12}\), two were new (Family and caregiver experiences of the palliative care service are assessed / evaluated / recorded and An end-of-life care pathway (such as the Liverpool Care Pathway) was used for the last 3 days of life of a person in need of palliative care) and 20 were rephrased QIs. Panellist agreed not to formulate disease-specific QIs for the organisation of palliative care, since our set of QIs provide information about the organisation of services and not about the care provision itself. This might explain why so many QIs were rated face-valid for as well the organisation of cancer as dementia palliative care: regarding aspects as access to and 24h availability of specialist palliative care or transferring information between settings, the specific condition of the patient (advanced cancer, dementia, or even COPD or heart failure) is not relevant, making our set of QIs much more broadly applicable. Therefore, these QIs are generically applicable and can be used in different settings. Thereby, they can also be used for (cross-)national comparisons and to identify best practices regarding the organisation of palliative care in other services and countries.

In the recent literature several sets of QIs for palliative care have been identified\(^{11,12,17,38,55}\). For example, Pastrana et al. used a nominal group technique to identify indicators for the assessment and evaluation of palliative care\(^{38}\). However, they primarily focused on the German healthcare system, which makes this set difficult to apply in an international context\(^{38}\). Pasman et al. conducted a literature review, and identified 142 QIs in 16 studies\(^{11}\). However, this set also has not been developed within an international context and it does not focus on the organisation of palliative care\(^{11}\). An update of this review, published in 2013, included a further 187 QIs, bringing the total to 326 QIs, with still few QIs about the organisation of palliative care\(^{55}\). Around the same time, Woitha et al. developed a set of 56 QIs\(^{12,17}\). Woitha et al. conducted two written Delphi rounds, leaving little room for discussion, while we conducted a consensus round with extensive opportunity to discuss the QIs. Secondly, they included professionals from different European countries only, while we also included professionals from countries such as Canada, Australia and the USA, making the set of QIs presented here globally applicable. Thirdly, they focused on the organisation of palliative care in general and did not specifically consider the organisation of palliative care for patients with dementia, like was done in the present study.
A recently published White paper defining optimal palliative care in older people with dementia, described several recommendations on palliative care treatment for persons with dementia. All of their recommendations that can be translated to the organisation of care, like the use of assessment tools, multidisciplinary meetings, bereavement support and about specialist palliative care teams, are represented in our QI set.

Another quality indicator, suggested by the World Health Organisation as part of the framework programme on non-communicable diseases has been the focus of attention recently. This QI is being proposed to describe access to palliative care by assessing morphine equivalent consumption per death from cancer. However, this QI has been criticised as it might have provided flawed information due to inaccuracies in the underlying data base and the unavailability of national cancer registries. Instead of assessing palliative care on a global level, we aim to assess whether palliative care services meet a basic quality level or higher quality level that would be met only in very good practices. Our set of QIs can therefore be used as internal QIs by healthcare providers (professionals and managers) to monitor and improve their service. They can also be used to describe and rank services according to performance, but this should not lead to a quality rating, as there may be good reasons for the differences in performance with the QI (e.g. different organisational structure).

Using our QIs as an external quality assessment tool will therefore make them unfit for their task. Berwick et al. summarised this as ‘measuring for improvement is not measuring for judgement’. An ongoing intervention in 40 palliative care services in Europe, including hospitals, hospices, nursing homes and primary care settings, performed as part of the IMPACT project, in which this set of QIs is used as starting point to assess the organisation of palliative care, will evaluate the feasibility and discriminatory power of the QIs in relation to improving the organisation of palliative care in the participating services.

**Strengths and limitations**

Strengths of this study were that we used a large international group of panellists for our Delphi-procedure, who were actively involved in palliative care (such as members of the European Association for Palliative Care). Secondly, by organising our consensus meeting during the EAPC Congress in Trondheim, Norway, key persons active in this fields of palliative care and dementia care were able to contribute extensively to the discussion for the Delphi-procedure. Thirdly, the multidisciplinary character of palliative care was represented by the panellists (e.g. physicians, nurses, psychologists) involved in the Delphi-procedure. Furthermore, half of them were professionals active in dementia care. Fourth, combining QIs for the organisation of services that provide care to palliative patients with cancer and those that provide such care to patients with dementia is unique. Our QIs can therefore be used in different settings.
A limitation of this study is that this set of QIs might not be comprehensive. Because an international, generic set of QIs was developed, some QIs that were important in only one or a few countries were excluded from the list. For that reason, important national or setting-specific QIs must be added when the set is used in a specific country. Secondly, this set of QIs is only related to the organisation of palliative care. Outcome and patient-related outcome measures were not included because they address a distinct purpose in measuring quality of palliative care. Thirdly, participants of the modified RAND Delphi-procedure were selected because of their knowledge about palliative care, cancer care or dementia care. Because some experts of two large European networks (EAPC and InterDem) are part of the IMPACT consortium, they were also selected as participant for the modified RAND Delphi-procedure (n=18). Although not all countries were represented (like France) and others were overrepresented (like the Netherlands), the experts covered 12 countries from three continents, covering different healthcare systems and types of organisation of palliative care. Pilot testing the set of QIs in those countries and continents that were not represented in this study will reveal whether they are applicable in these countries too. Fourthly, unfortunately, there were no patient representatives involved as panellist. Testing the final set of QIs will therefore also have to incorporate their views on the basic quality level or higher quality level that would be met only in very good services.

**Conclusion**

International experts selected a set of 23 QIs for the organisation of palliative care that can be implemented in daily practice in order to demonstrate that organisations are providing high quality and effective palliative care or to identify areas for improvement.
References


Implementation of improvement strategies in palliative care: an integrative review

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Abstract

Background: The European population is ageing, and as a consequence, an increasing number of patients are in need of palliative care, including those with dementia. Although a growing number of new insights and best practices in palliative care have been published, they are often not implemented in daily practice. The aim of this integrative review is to provide an overview of implementation strategies that have been used to improve the organisation of palliative care.

Methods: Using an integrative literature review, we evaluated publications with strategies to improve the organisation of palliative care. Qualitative analysis of the included studies involved categorisation of the implementation strategies into subgroups, according to the type of implementation strategy.

Results: From the 2379 publications identified, 68 studies with an experimental or quasi-experimental design were included. These studies described improvements using educational strategies (n = 14), process mapping (n = 1), feedback (n = 1), multidisciplinary meetings (n = 1) and multi-faceted implementation strategies (n = 51). Fifty-three studies reported positive outcomes, 11 studies reported mixed effects and four studies showed a limited effect (two educational and two multi-faceted strategies).

Conclusions: This review is one of the first to provide an overview of the available literature in relation to strategies used to improve the organisation of palliative care. Since most studies reported positive results, further research is needed to identify and improve the effects of strategies aiming to improve the organisation of palliative care.
Background

The European population is ageing, and as a consequence, an increasing number of patients are in need of palliative care, including those with dementia. The World Health Organisation has defined palliative care as an ‘approach to improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement’\textsuperscript{1-3}. Although a growing number of new insights and best practices in palliative care are being published, knowledge translation into daily practice is lacking\textsuperscript{4}. Study results in both the USA and the Netherlands suggest that up to 40\% of patients in need of palliative care do not receive evidence-based care\textsuperscript{5}. Apparently, there is a wide ‘gap’ between the available scientific evidence and its use in daily practice\textsuperscript{5}.

The implementation of new evidence into daily practice is particularly challenging when complex changes are needed, cooperation between disciplines is required, or behaviour needs to be changed\textsuperscript{6}. The use of traditional implementation strategies to convince professional care providers to use new evidence (such as identifying, synthesising and disseminating evidence in journals, guidelines, continuing medical education and conferences) is apparently not sufficient to engineer changes in the complex systems of palliative care\textsuperscript{5}.

Yet, many studies that aim to improve palliative care have been performed. Often, these studies require much time investment and money from both the professional workforce as well as patients, which raises cost-effectiveness questions. It is therefore of utmost importance to synthesise and disseminate state-of-the-art scientific knowledge\textsuperscript{5,7}. The aim of this integrative review is to provide an overview of effective implementation strategies that have been used to improve the organisation of palliative care. As such, results of this review have been used in the EU-funded Seventh Framework IMPACT project (IMplementation of quality indicators for PAlliative Care sTudy) which aims to develop and tailor national and setting-specific strategies to improve the organisation of palliative care in Europe\textsuperscript{8}.

Methods

A review of available research literature was considered important to identify current knowledge about this topic.

The integrative review methodology summarises past empirical and theoretical literature that uses diverse methodologies and study designs from a variety of sources in order to provide a comprehensive understanding of a complex healthcare problem\textsuperscript{9}. Therefore, an iterative comparison and analysis of relevant publications about the implementation of strategies to improve the organisation
of palliative care was conducted.

**Search strategy**

A comprehensive literature review was conducted, including Medline, CINAHL, British Nursing Index, PsycINFO, and by searching for grey literature\(^{10}\) (e.g. literature that has not been published in peer-reviewed literature). The search strategy was limited to English literature only, to publications that concerned palliative care for adults (aged 18 or above) and to publications that were published between 2000 and August 2011. Various search terms were used that referred to subject-specific keywords describing palliative care, as well as the type of implementation strategy and outcomes of the implementation, including synonyms and Medical SubHeadings (MeSH) to include all relevant literature. Table 1 provides an overview of the search terms (the search string is available in appendix 1). Disease-specific search terms, such as cancer or dementia, were not included because the organisation of palliative care goes beyond a specific disease\(^{11}\).

<table>
<thead>
<tr>
<th>Search terms</th>
<th>implementation strategy</th>
<th>outcomes of implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>palliative care</td>
<td>health plan implementation</td>
<td>quality of health care</td>
</tr>
<tr>
<td>hospices</td>
<td>program development</td>
<td>program evaluation</td>
</tr>
<tr>
<td>hospice care</td>
<td>quality indicators</td>
<td>quality</td>
</tr>
<tr>
<td>end of life care</td>
<td>implementation strategy</td>
<td>improvement</td>
</tr>
<tr>
<td>comfort care</td>
<td>program evaluation</td>
<td>change</td>
</tr>
<tr>
<td>supportive care</td>
<td>information dissemination</td>
<td></td>
</tr>
<tr>
<td>cancer care facilities</td>
<td>information distribution</td>
<td>organisation change</td>
</tr>
<tr>
<td>oncology service, hospital</td>
<td>diffusion of innovation</td>
<td>educational models</td>
</tr>
<tr>
<td></td>
<td></td>
<td>organisational models</td>
</tr>
<tr>
<td></td>
<td></td>
<td>quality improvement</td>
</tr>
</tbody>
</table>

**Inclusion and exclusion criteria**

Publications were included when they described (1) improvements to the organisation of palliative care, (2) which implementation strategies were used, (3) how these strategies were implemented and (4) the effectiveness of these strategies. Publications were excluded when (1) no abstract was available, (2) the implementation strategies were not directed at healthcare professionals or volunteers, (3) they were not directed at adult healthcare services or (4) educational curricula were developed.
Data extraction and analysis
Two of the authors (JvRP and RS, one with a background in nursing and health sciences and the other in sociology) independently screened title and abstract and reviewed the full-text articles of the included studies to identify implementation strategies to improve the organisation of palliative care. A data collection form was used to extract information about the country and year in which the study was published, study design, setting, type of disease, healthcare professionals involved, and type, description and impact of the implementation strategies used. Subsequently, implementation strategies were categorised into subgroups, according to the type of implementation strategy, similar to the approach of Grol and Grimshaw. Data from the subgroup classification was coded and compiled into a matrix, whereby the effect of each implementation strategy was summarised as a significant improvement (++), improvement (+), mixed or limited effect (+/−) or no effect (−). To ensure the trustworthiness and rigour of the analysis, peer debriefing took place with the other authors throughout the entire process of data analysis.

Results
Study selection
Of the 2379 initially identified publications, 241 were selected for full-text assessment (figure 1). A first assessment of the full-text of these publications revealed that 156 publications could be excluded, as they did not meet the inclusion criteria (for example, because there were no details given about the improvement strategy used). Reference lists of all publications eligible for inclusion as well as a hand search in grey literature databases revealed an additional 27 publications eligible for inclusion. The remaining publications represented a wide variety of research methods and designs: interviews, focus groups, strategy development designs, case descriptions, surveys, process evaluations, RCTs, pre-post-test interventions, review papers as well as theoretical papers. Because of the large number of identified studies, of which many were of low scientific quality and with incomparable outcome measures, only studies with an experimental (n = 12) or quasi-experimental (n = 56) study design were selected for further analysis.

Characteristics of included studies
A total of 17 single intervention studies and 51 multi-faceted intervention studies were identified. Most studies were conducted in the USA (n = 29), UK (n = 19) and Australia (n = 8), but studies were also included from countries such as Japan, Taiwan, Italy and the Netherlands. Studies were conducted within the entire range of palliative care services, from home care services to advanced palliative care units in hospitals. Fifty-one studies were conducted in one setting (primary care: n = 2, hospital: n = 38, nursing home: n = 9, hospice: n = 1 and other: n = 1) and 11 were conducted in multiple settings. For six studies, the type of setting could not be identified. Within the included studies, a large variety of professionals
Chapter 4

2877 potentially relevant publications

498 duplicate publications

2379 relevant publications

20 not about the organisation of palliative care

25 not directed at healthcare professionals

42 not directed at adults

114 educational curriculum development

1366 no improvement strategies described

350 other (i.e. not available in English)

462 publications included

2 not directed at adults

10 not about the organisation of palliative care

13 not directed at healthcare professionals

15 educational curriculum development

67 no abstract available

104 no improvement strategies described

10 other (i.e. not available in English)

241 publications included

156 no improvement strategies described

85 publications included

112 publications describing 104 studies

12 experimental studies

56 quasi-experimental studies

29 non-experimental studies

7 case-report studies

Focus of review

Figure 1: Flowchart
participated. Thirty-five studies were directed at a single type of professionals (e.g. nurses only), 29 at two or more different groups of professionals (e.g. nurses and physicians), and four studies did not report the target group of professionals.

**Strategies and its impact**
Appendix 2 provides a summarised description of the methodology, setting and country, number and type of participants, the implementation strategy and the impact of the strategy of each individual study. Table 2 provides an overview of the results of studies with an experimental or quasi-experimental study design.

**Educational strategies**
Two experimental and 12 quasi-experimental studies used different types of educational strategies to improve palliative care, including lectures\(^{12-14}\), study days\(^{15,16}\), role play sessions\(^{17,18}\), interactive education\(^{19,20}\), educational outreach visits\(^{21}\) and computer-facilitated education\(^{22-25}\). Eight studies were targeted at a single profession, while six were targeted at multiple professionals. Four studies reported significant improvements, eight reported improvement, and two studies had limited or no effect.

**Process mapping**
One study used process mapping to improve the organisation of palliative care in a nursing home\(^{26}\). Before implementing the Liverpool Care Pathway, nursing home staff organised interdisciplinary team discussions where they answered the question, ‘If your patient is diagnosed as dying at 10 am on Monday morning and they are in pain, what happens?’ or in other words, ‘What is the process?’ in order to identify bottlenecks to be expected\(^{26}\). A repeated process measure post-implementation reduced the numbers of expected bottlenecks.

**Feedback**
One study addressed feedback to improve the organisation of palliative care\(^{27}\). In an RCT, patients completed a health-related quality of life questionnaire. In the intervention group, hospital physicians received automated feedback upon completion of this questionnaire. The RCT showed improved health-related quality of life in the intervention group compared to the control group.

**Multidisciplinary meetings**
One quasi-experimental study performed by Lilly et al. described family and multidisciplinary meetings to improve the communication and shared-decision making at the intensive care unit (ICU) in a hospital\(^{28,29}\). Pre- and post-intervention measurements showed that the use of such meetings reduced length of ICU stay.

**Mixed interventions**
Fifty-one studies used a combination of strategies. Half of these studies used a combination of solely educational strategies (for example, lecture combined with
<table>
<thead>
<tr>
<th>Strategy</th>
<th>#</th>
<th>Primary care</th>
<th>Hospital</th>
<th>Nursing home</th>
<th>Hospice</th>
<th>Other, multiple or unknown settings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Lecture</strong></td>
<td>3</td>
<td></td>
<td>Ke, 2008 (++)</td>
<td></td>
<td>Schim, 2006 (+)</td>
<td>Ersek, 2006 (++)</td>
</tr>
<tr>
<td><strong>Study day</strong></td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Role-play</strong></td>
<td>2</td>
<td></td>
<td>Hales, 2008 (+)</td>
<td></td>
<td>Carr, 2003 (+)</td>
<td>Dryden, 2009 (+)</td>
</tr>
<tr>
<td><strong>Interactive education</strong></td>
<td>2</td>
<td></td>
<td>Bruneau, 2004 (-); Cooke, 2004 (+)</td>
<td></td>
<td>Back, 2007 (+)</td>
<td></td>
</tr>
<tr>
<td><strong>Outreach visit</strong></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Computer facilitated education</strong></td>
<td>4</td>
<td></td>
<td>Hulsman, 2002 (-); Jarabek, 2008 (++)</td>
<td></td>
<td>Newton, 2009 (+)</td>
<td>Ersek, 2008 (++)</td>
</tr>
<tr>
<td><strong>Process mapping</strong></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Feedback</strong></td>
<td>1</td>
<td></td>
<td>Velikova, 2004 (+)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Multidisciplinary meetings</strong></td>
<td>1</td>
<td></td>
<td>Lilly, 2000 and Lilly, 2003 (++)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Multi educational interventions</strong></td>
<td>25</td>
<td>Reymond, 2005 (++)</td>
<td>Bylund, 2010 (+/-); Furman, 2006 (+/-); Betcher, 2010 (+); Hall, 2007 (+); Kinnane, 2009 (+); Razavi, 2002 and Delvaux, 2004 (+); Fischer, 2007 (+); Kruse, 2008 (++); Bailey, 2005 (++); Fallowfield, 2001 (++); Gueguen, 2009 (++); Sutherland, 2007 (++); Yamagishi, 2009 (++);</td>
<td>Weissman, 2000 (+); Weissman, 2001 (+);</td>
<td>Bravemen, 2001 (+/-); Razavi, 2003 and Lienard, 2006 and Lienard, 2008 and Merckaert 2008 (+/-); Wilkinson, 2008 (+); Finset, 2003 (+); Favre, 2007 (++); Quinn, 2008 (++); Sullivan, 2005 (++); Wilkinson, 2002 (++); Wilkinson, 2003 (++; Stacey, 2008 (++);</td>
<td></td>
</tr>
<tr>
<td><strong>Mixed interventions</strong></td>
<td>26</td>
<td>Boakes, 2000 (++)</td>
<td>Butow, 2008 (+); Curtis, 2011 (-); Fallowfield, 2002 and Jenkins, 2002 and Shilling, 2003 and Fallowfield, 2003 (+/-); Hansen, 2009 (+/-); Hills, 2009 (+/-); Jacob, 2002 (+/-); McCormick, 2010 (+/-); Morgan, 2010 (+/-); Rola, 2004 (+/-); Kinley, 2004 (+/-); Lankshear, 2010 (+); Miranda, 2005 (+); Monteleoni, 2004 (+); Okon, 2009 (+); Smith, 2009 (+); Bookbinder, 2005 (++); Dauer, 2006 (++);</td>
<td>Hanson, 2005 (+); Hockley, 2010 (+); Lyon, 2007 (+); Reynolds, 2004 (+); Strumpf, 2004 (+); Keay, 2003 (++);</td>
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</tr>
</tbody>
</table>

++ significant improvement, + improvement, +/- mixed or limited effect, - no effect
Overview of improvement strategies

role play sessions\(^{30-58}\), while the other half combined a variety of strategies (for example, education combined with feedback and reminders\(^{59-86}\). Nine studies had an experimental design. Based on the conclusions of the authors, there were 13 studies that had no or a limited effect on the specified outcomes, 21 studies that had a positive effect, and the remaining 17 studies reported a significant improvement.

Discussion

We made a comprehensive overview of the available literature in relation to strategies used to improve the organisation of palliative care. In total, 68 studies, representing an experimental or quasi-experimental study design, were discussed. These studies included educational strategies, process mapping, feedback, multidisciplinary meetings as well as mixed interventions.

For this review, all reported outcome measures in the identified studies were extracted. These measures included several patient outcome data items (e.g. assessment of the percentage of patients in pain following an educational session about pain treatment) as well as data concerning the process of care (e.g. the frequency of patient referral to specialist care following the introduction of a new referral form), making comparisons of outcomes impossible. However, the aim of all included studies was to improve the organisation of palliative care. We therefore generalised the outcomes to the degree in which they aimed to improve the organisation of palliative care.

Fifty-three studies, covering all strategies identified, reported that their study resulted in improving the organisation of palliative care. Eleven studies showed improvements for some of the characteristics targeted (four multi-educational and seven multi-faceted strategies), and four studies reported limited or no improvements (one using interactive education, one using computer-facilitated education and two multi-faceted strategies). The studies with a mixed or limited result on improving the organisation of palliative care were primarily conducted in one setting (hospital) and directed at one professional group. This stipulates the challenges that are encountered when implementing new evidence in complex environments such as a hospital as well as the importance of the multidisciplinary and interdisciplinary character of palliative care.

The different strategies identified in this review have been described in other fields in healthcare. In a review by Grol and Grimshaw, for example, large conferences and courses showed mixed effects, small group interactive education showed positive effects, educational outreach showed positive effects, feedback showed mixed effects and the use of mixed interventions often resulted in better results compared to single intervention studies\(^5\). Reviews that focused on one strategy type, for example, on audit and feedback\(^{87}\), printed educational materials\(^{88}\) or
educational outreach visits\textsuperscript{89}, all had similar findings. One reason for the primarily positive findings of the studies identified in this review might be the fact that participants in a quality improvement project perform better as a result of knowing they are a study object (Hawthorne effect)\textsuperscript{90}. Another reason might be that effects were often measured immediately after the intervention, so we do not know if the effects were sustained. Finally, only a few studies (n = 12) used a randomised controlled design, which is often considered to be the gold standard in research \textsuperscript{91}, compared to other designs. RCTs require significant time and funding and expert research guidance, and particularly, in palliative care populations, they are scarce because of recruitment restrictions, high attrition, (selection) bias, lack of blinding, confounding and small sample sizes\textsuperscript{91,92}. Many of these aspects, however, are also relevant in studies with a quasi-experimental, non-experimental or case-study design. The studies that were included in this review might, therefore, not represent the strongest designs to test improvement strategies.

The included studies were conducted in a variety of settings (e.g. hospitals, nursing homes, hospices and primary care facilities). The provision of palliative care within these settings may vary depending on the patient group. Patients with cancer, for example, have a different disease trajectory, and other symptoms and needs than persons with dementia\textsuperscript{93,94}. Despite these differences, there are many similarities regarding the organisation and multidisciplinary character of palliative care. For all chronic, life-threatening conditions, palliative care entails a patient-centred approach in which multidimensional interventions related to actual and future problems, needs and preferences are made.

The WHO definition of palliative care is therefore applicable for all patient groups \textsuperscript{3}. The European Association of Palliative Care illustrates this by recommending a common approach for palliative care across settings\textsuperscript{95,96}. In addition, 40 international experts agreed that there is no need to formulate disease-specific quality criteria for the organisation of palliative care\textsuperscript{97}. However, this does not mean that there is ample evidence regarding effective strategies to improve (the organisation of) palliative care in the different settings. Hall et al., for example, described that there is limited evidence for palliative care service delivery for residents of care homes for older people\textsuperscript{98}. This illustrates the necessity to further improve the field of implementation science, in particular, in underdeveloped areas such as palliative care for persons with dementia.

Quality improvement projects often require investments of time and money from both the professional workforce and patients. It is important that the evidence of effective strategies is used to improve daily clinical practice. However, researchers and professionals often have different cultures, values, timelines, goals and rewards\textsuperscript{99}. Even when the intervention is well-designed, real-world contextual factors may prevent the intervention from being realised. Implementation of evidence-based and best practices should therefore always be guided by a step-by-
Overview of improvement strategies

step model in order to identify the problem, barriers and facilitators and tailored strategies to solve the problem. Integrated knowledge translation can then be used as a bridge in closing the gap between what we know and what we do.

The results of this review were used in the EU-funded Seventh Framework IMPACT project. An intervention study investigating improvement projects with pre- and post-test evaluations was performed in 40 services providing palliative care across Europe (including hospitals, nursing homes, hospices and primary care facilities). In this study, quality indicators were used to identify potential areas to improve the organisation of palliative care. Subsequently, Grol’s Implementation of Change model was used to guide the services in their quality improvements. The strategies described in this review were used as an example and if possible also as actual strategies regarding how to change the organisation of palliative care.

Strengths and limitations
This is one of the first reviews that provides an overview of implementation strategies used to improve the organisation of palliative care. The results of this review can be used as a starting point for further research. However, some limitations should be taken into account. Firstly, this review used the integrative review methodology. Although this approach allows for the combination of diverse methodologies (including non-experimental research), only studies with an experimental and quasi-experimental design were included because of the unexpected high number of publications on the highest evidence level. Since a variety of methods was used in these studies, a quantitative comparison of effect size was considered impossible. Secondly, because it was the aim of this review to provide an overview of strategies used to improve the organisation of palliative care rather than the effectiveness, we did not assess each individual study for risk of bias or effect estimates. The effects of the strategies presented in this paper should therefore be interpreted with caution. Thirdly, we have limited the search strategy to English literature only. Although publications have been included from non-English speaking countries such as Japan and Italy, it is likely that we have missed potentially interesting publications from countries that often publish in their own language. Fourthly, there is no generic set of search terms to identify literature about improvement strategies, despite the fact that improvements are now being recognised as a science. Although we have captured a broad selection of literature with our search strategy, it is possible that it did not identify all available publications on this topic.

Conclusion
This review provides an overview of the available literature in relation to strategies used to improve the organisation of palliative care. The identified studies described educational strategies, process mapping, feedback, multidisciplinary meetings and multi-faceted interventions. Future research, with more rigid designs, proper duration, control and blinding are necessary to identify and improve scientific
evidence regarding the optimal strategies to improve the organisation of palliative care.
References


Overview of improvement strategies

63. Rolla F. Transferring scientific evidence to oncological practice: a trial on the impact of three different implementation strategies on antiemetic prescriptions. Support Care Cancer.
Chapter 4


Appendix 1

Search string

**BNI**
palliat*.ti,ab. or exp Terminal care/ or terminal care.ti,ab. or Terminal Care : Hospices/ or Terminal care : nursing/ or Terminal care : services/ or Cancer : services/ or hospic*.ti,ab. or end of life care.ti,ab. or comfort care.ti,ab. or supportive care.ti,ab.

**AND**
implement*.ti,ab. or program development.ti,ab. or “Standards and guidelines”/ or Audit/ or “Care plans and planning”/ or Health service planning/ or Management information systems/ or quality indicator*.ti,ab. or program evaluat*.ti,ab. or information disseminat*.ti,ab. or information distribut*.ti,ab. or organi?ational innovat*.ti,ab. or organi?ational chang*.ti,ab. or “Models and theories”/ or Quality assurance/

**AND**
Exp Quality assurance/ or quality*.ti,ab. or Management information systems/ or program evaluat*.ti,ab. or improv*.ti,ab. or chang*.ti,ab. or Evidence based practice/

**Limitation**
not (child* OR neonat* OR infant* OR pediatr* OR paediatr*).ti.
yr=”2000 to current”

**CINAHL**
MH “Palliative Care” or TI palliat* OR AB palliat* OR MH “Terminal Care” or TI “terminal care” OR AB “terminal care” or MH “Hospice and Palliative Nursing” or MH “Hospices” or MH “Hospice Care” or MH “Hospice patients” or TI hospic* or AB hospic* or TI “end of life care” or AB “end of life care” or TI “comfort care” or AB “comfort care” or TI “supportive care” or AB “supportive care” or MH “Cancer Care Facilities”

**AND**
MH “Program development+” or MH “Patient care plans+” or TI “health plan implement**” or AB “health plan implement**” or TI “program implement**” or AB “program implement**” or TI “program development” or AB “program development” or MH “Clinical indicators” or TI “quality indicator**” or AB “quality indicator**” or TI “clinical indicator**” or AB “clinical indicator**” or MH “Quality improvement” or TI “quality improvement**” or AB “quality improvement**” or TI “implementation strateg**” or AB “implementation strateg**” or TI “program evaluat**” or AB “program evaluat**” or TI “information disseminat**” or AB “information disseminat**” or TI “information distribut**” or AB “information distribut**” or MH “Organizational change” or TI “organis?ational innovat**” or AB “organis?ational innovat**” or TI “organis?ational chang**” or AB “organis?ational chang**” or MH “Diffusion of innovation” or MH “Models, educational” or MH
“Quality of care research”

AND
MH “Quality of Health Care+” or TI quality* or AB quality* or MH “Program Evaluation” or TI “program evaluat*” or AB “program evaluat*” or TI improv* or AB improv* or TI chang* or AB chang*

Limitation
not (MH child+ not MH adult+)
Published Date from: 20000101-20111231

MEDLINE
exp palliative care/ or palliat*.ti,ab. or terminal care/ or terminal care.ti,ab. or exp hospices/ or exp hospice care/ or hospic*.ti,ab. or end of life care.ti,ab. or comfort care.ti,ab. or supportive care.ti,ab. or exp cancer care facilities/ or exp oncology service, hospital/

AND
exp health plan implementation/ or health plan implement*.ti,ab. or exp program development/ or program development.ti,ab. or exp quality indicators, health care/ or quality indicator*.ti,ab. or implementation strateg*.ti,ab. or exp program evaluation/ or program evaluat*.ti,ab. or exp information dissemination/ or information disseminat*.ti,ab. or information distribut*.ti,ab. or exp organizational innovation/ or organi?ational innovat*.ti,ab. or organi?ational chang*.ti,ab. or exp diffusion of innovation/ or exp models, educational/ or exp models, organizational/ or Quality improvement/

AND
Exp Quality of health care/ or quality*.ti,ab. or program evaluat*.ti,ab. or improv*.ti,ab. or chang*.ti,ab.

Limitation
not ((exp child/ or exp adolescent/) not exp adult/)
yr=“2000 -Current”

PsycINFO
Exp Palliative care/ or palliat*.ti,ab. or terminal care.ti,ab. or Exp hospice/ or hospic*.ti,ab. or end of life care.ti,ab. or comfort care.ti,ab. or supportive care.ti,ab.

AND
health plan implement*.ti,ab. or exp Program development/ or program development.ti,ab. or exp Program evaluation/ or program evaluat*.ti,ab. or quality indicator*.ti,ab. or implementation strateg*.ti,ab. or Information dissemination/ or information disseminat*.ti,ab. or information distribut*.ti,ab. or organi?ational innovat*.ti,ab. or exp Organizational change/ or organi?ational chang*.ti,ab. or diffusion of innovation.ti,ab. or Organizational development/ or organi?ational develop*.ti,ab. or Organizational learning/ or organi?ational learning.ti,ab.

AND
Exp Quality of services/ or quality*.ti,ab. or exp Program evaluation/ or program
evaluat*.ti,ab. or improv*.ti,ab. or chang*.ti,ab. or Evaluation/ or evaluat*.ti,ab.
or Professional standards/ or professional standards.ti,ab. or Best practices/ or
best practices.ti,ab.

Limitation
Yr=”2000-current”
### Description of studies

<table>
<thead>
<tr>
<th>Source</th>
<th>Study methodology</th>
<th>Setting / country</th>
<th>Participants in intervention (n)</th>
<th>Description of strategy</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schim, 2006</td>
<td>Experimental study</td>
<td>Hospice / USA</td>
<td>Administration, clergy, nurse,</td>
<td>One-hour educational session on cultural considerations adapted from the End-of-Life Nursing Education Consortium Training Materials Module.</td>
<td>Pre- (n=130) and post-intervention (n=107) cultural competence assessment showed that cultural competencies improved.</td>
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<tr>
<td>Ke, 2008</td>
<td>Experimental study</td>
<td>Hospital / Taiwan</td>
<td>Nurses (n=88)</td>
<td>Intervention group received a 50-minute lecture on artificial nutrition and hydration.</td>
<td>Pre (n=88) and post-intervention (n=88) structured questionnaires showed a significant improvement in knowledge, attitudes and</td>
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<tr>
<td>Ersek, 2006</td>
<td>Quasi-experimental study</td>
<td>Nursing home, hospice / USA</td>
<td>Administrators, Director of nursing, Staff development/educators, Social workers, Staff nurses, Coordinators, Others (n=87)</td>
<td>A two-day palliative care educational resource team train-the-trainer workshop was provided. The workshop consisted of 16</td>
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<td>modules (from the philosophy of end-of-life care to ensuring quality end-of-life care) and were conveyed through didactic presentations. Participants received a manual and CD with all course information.</td>
<td>Changes in knowledge and attitude were significantly different between experimental and control group. Changes of behavioural intentions</td>
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<td>between experimental and control group were not significant.</td>
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**Single intervention studies**

**Large scale educational methods**
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<thead>
<tr>
<th>Source</th>
<th>Study methodology</th>
<th>Setting / country</th>
<th>Participants in intervention (n)</th>
<th>Description of strategy</th>
<th>Results</th>
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</thead>
<tbody>
<tr>
<td>Carr, 2003</td>
<td>Quasi-experimental study</td>
<td>Setting unknown / UK</td>
<td>Nurses, physicians, physical therapists, occupational therapists, pharmacist (n=on average 18 per session)</td>
<td>4 half-day study days were conducted. For each session, 2 cases were identified by charge nurse and a team member presented each case. Discussion was used for problem solving. Sessions were facilitated by 2 or 3 members of the steering committee.</td>
<td>Average pain scores decreased from pre-intervention 2.9 (n=30) to 2.0 (n=28) as there was an increase in pain assessment, discussion about pain and requests for transcutaneous electrical nerve stimulation (TENS) machines. Decrease in referrals to acute pain team. Post intervention evaluations showed that sessions on chronic pain were considered more useful compared to session on acute pain. All participants indicated that learning with other professions and gaining new knowledge and ideas was particularly valuable.</td>
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<tr>
<td>Dryden, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital, Hospice &amp; Nursing home, and Community &amp; Day care / UK</td>
<td>Healthcare assistants and social care officers (n=52)</td>
<td>A study day (including lecture and group work) was used to teach healthcare assistants how to help patients cope with the symptoms of advanced disease.</td>
<td>Post-intervention evaluation forms (n=47) and pre and post-test self-report questionnaires (n=42) showed improvements in knowledge and self-confidence.</td>
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<tr>
<td>Small scale educational methods</td>
<td>Role play</td>
<td>Unknown</td>
<td>Oncology fellows (n=115)</td>
<td>A biannual, 4-day residential communication skills workshop for 20 fellows per workshop was provided. Content of the workshop was focused on: 1) developing a relationship and dealing with uncertainty, 2) giving bad news, 3) discussing transition to palliative care, and 4) discussing DNR orders. The workshop was organised around 5 simulated patients (actors) and most of teaching done in small groups of 5 participants and 1 facilitator.</td>
<td>A preretreat questionnaire, and 2 preretreat and 2 postretreat patient encounters (n=106 pairs) showed improved communication skills in the postretreat encounters.</td>
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<td>Source</td>
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<td>Hales, 2008</td>
<td>Quasi-experimental study</td>
<td>Hospital / Canada</td>
<td>Intensivist, nurse, social worker, respiratory therapist, clinical nurse educator (n=36)</td>
<td>Teams of 3-6 professionals rotated through six 45-minute stations, enacting scenarios with trained actors.</td>
<td>Pre and post-test questionnaires (n=18) showed improved ethical and legal knowledge and confidence in communication.</td>
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<tr>
<td>Bruneau, 2004</td>
<td>Quasi-experimental study</td>
<td>Hospital / UK</td>
<td>Nurses (n=18)</td>
<td>Two sessions of 2-hours each. First session explored participants’ knowledge and experience of stress. Second session reviewed the issues explored in the first session and provided an opportunity to practice relaxation techniques.</td>
<td>Pre and post-test questionnaires and interviews (n=18) indicated no conclusive evidence that the stress-reduction programme had any impact on participants’ stress levels or their capacity for coping with stress.</td>
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<tr>
<td>Cooke, 2004</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Nurses, psychologists, physical therapists, occupational therapists, social workers, physicians, administrators (n=unknown)</td>
<td>1-hour, rotating, monthly program of case presentations and analysis to assist clinical nurses in translating research and ongoing knowledge into practice: facilitator introduced purpose of presentation, staff nurse presented the case study. 5-minute presentation about evidence based practice was given, 3 team members presented for 10 minutes on relevant nursing issues using EBP from the literature, a 20-30 minute discussion followed.</td>
<td>Pre-post intervention evaluation revealed that confidence in knowledge increased by almost one point on a five-point scale.</td>
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<td>Source</td>
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<td><strong>Outreach visit</strong></td>
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<td>Implementation of the preferred place of care document, including a 1-3 hour face-to-face educational contact with each study site, prior to the commencement of the preferred place of care document.</td>
<td>Assessment of preferred place of care document and periodic questionnaire showed that 85% of the nurses using the document stated that it had affected their practice, because it helped raise awareness. The document was initiated later in the patient trajectory than recommended. 71% of the patients during the study period died at their PPC.</td>
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<tr>
<td>Newton, 2009</td>
<td>Quasi-experimental study</td>
<td>Community care, Hospital, Hospice &amp; Nursing home / UK</td>
<td>Nurses (n=33)</td>
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<td><strong>Computer facilitated education</strong></td>
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<td>Ersek, 2008</td>
<td>Quasi-experimental study</td>
<td>Home care, Nursing home, hospice &amp; hospital / USA</td>
<td>Nursing assistants (n=65)</td>
<td>Six hours of nursing assistant computerised education programme was used over a six week period, which was based on the palliative care educational resource team programme and the core curriculum for the hospice and palliative nursing assistant.</td>
<td>Evaluation questionnaire, and pretest-posttest end-of-life care knowledge exam and self-evaluations showed a significantly increased knowledge and improved perceived skills in caring for patients at the end of life.</td>
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<tr>
<td>Hulsman, 2002</td>
<td>Quasi-experimental study</td>
<td>Hospital / the Netherlands</td>
<td>Physicians (n=21)</td>
<td>A 4 hour computer assisted communication skills training, consisted of 4 modules. Module 1: focused on basic communication skills regarding verbal and non-verbal behaviour of physician and patient. Module 2: breaking bad news. Module 3: providing information effectively, based on two-way interaction. Module 4: dealing with patients’ emotions. In each module, video examples were used to present poor and adequate communication.</td>
<td>Pre and post intervention videotaped patient interviews and patient satisfaction ratings showed a positive course effect on rating of the quality of physicians’ performance. No course effect were found on the frequencies of physicians’ communication behaviours and on the patient satisfaction rating.</td>
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<td>Jarabek, 2008</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Internal medical house staff (n=144)</td>
<td>Implementation of palliative care order set: An educational e-mail was sent which outlined each section within the order set with links to internal and external web sites referencing palliative management of pain, sedation, delirium, secretions, dyspnoea, code status, nutrition and fluids. The e-mail was only sent once, when the order set was introduced.</td>
<td>Pre-intervention (n=97) and post-intervention (n=76) evaluation showed a significant increase in the percentage of residents comfortable with regard to the four aspects of symptom management.</td>
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<td>Smith, 2010</td>
<td>Quasi-experimental study</td>
<td>Various / UK</td>
<td>Nurses (n=30)</td>
<td>Six week, online communication and end-of-life assessment skills training.</td>
<td>Pre and post-test self-assessment questionnaire, post-intervention candidate evaluation, and post-intervention moderator evaluation showed improvements in participants' confidence.</td>
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<td>Non education interventions</td>
<td>Process mapping</td>
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<td>Taylor, 2007</td>
<td>Quasi-experimental study</td>
<td>Nursing home / New Zealand</td>
<td>Manager, care manager, senior nurse, pharmacist, LCP facilitator, LCP consultant pharmacist (n=unknown)</td>
<td>A meeting was arranged with members of the interdisciplinary team to map the process of care in order to implement the Liverpool Care Pathway. The second part of the meeting involved looking at the bottlenecks.</td>
<td>After six months, the process was remapped, demonstrating a distinct reduction in bottlenecks and improved pre-emptive prescribing.</td>
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<td>Feedback</td>
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<td>Patients were allocated to intervention group (completion of touch-screen health related quality of life questionnaire and feedback of results to physician), attention-control group (completion of touch-screen health related quality of life questionnaire, without feedback to physician), and control group (no touch-screen measurement of health related quality of life).</td>
<td>Physicians referred explicitly to the health related quality of life data in only 64% of the encounters. However, a larger proportion of patients in the intervention group showed clinically meaningful improvement in HRQL compared with patients in attention-control and control groups. Routine use of HRQL information during the encounters had an impact on physician-patient communication without prolonging the interviews. Chronic nonspecific symptoms were discussed more frequently.</td>
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<tr>
<td>Velikova, 2004</td>
<td>Experimental</td>
<td>Hospital / UK</td>
<td>Physicians (n=28)</td>
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<td>Multidisciplinary meetings</td>
<td>Quasi experimental study</td>
<td>Hospital / USA</td>
<td>Physicians, nurses (n=54)</td>
<td>In the preintervention period, formal family meetings were usually held after the provider team had reached consensus that restoration of function or survival was unlikely. In the intervention period, an initial formal multidisciplinary meeting with the patient, family or both was held within 72 hours after admission to the ICU. Purpose of the meeting was: 1) review medical facts and options for treatment; 2) discuss patients’ perspectives; 3) to agree on care plan; and 4) to agree on criteria by which the success or failure of this care plan would be judged. Weekly multidisciplinary case reviews were held to ensure that all relevant patients had sessions.</td>
<td>Preintervention (n=134) compared to intervention (n=396) demonstrated a significant increase in physician-led meetings, length of stay in the ICU was reduced from 4 days to 3 days (after 4 years, this was still 3 days) and there was a decrease in unadjusted overall mortality (p=0.02) and a trend toward reduced mortality during the ICU stay. The rate of provider non-consensus days decreased from 65 days per 1,000 patient-days to 4 days per 1,000 patient-days. The rate of family non-consensus decreased from 171 days 1000 patient-days to 16 days per 1000 patient-days.</td>
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<td>Lilly, 2000 &amp; Lilly 2003</td>
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<td>Kruse, 2008</td>
<td>Experimental study</td>
<td>Hospital / USA</td>
<td>Nurses (n=81)</td>
<td>Control group received an article to read. Intervention group 1 received a 3-hour didactic presentation, including case study, presentation and discussion. Intervention group 2 received 3-hour didactic presentation + 4-hour bedside clinical experience at a local hospice.</td>
<td>Pre and post-test questionnaire showed no significant differences in perception of end-of-life care were found between control and intervention groups.</td>
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<tr>
<td>Razavi, 2003 &amp; Lienard, 2006 &amp;</td>
<td>Experimental study</td>
<td>Setting unknown</td>
<td>Physicians (n=72)</td>
<td>Physicians received a basic communications skill training (2-hour lecture and 17-hour small group role-playing sessions). Subsequently, physicians were randomly selected to receive 6 3-hour workshops (same program as basic training) or were placed on the waiting (consolidation workshop started 2 months later).</td>
<td>Consolidation workshop improved communication skills. Simulated interviews (n=62) showed: significant increase in open and open directive questions and utterances alerting patients to reality. Significant decrease in premature reassurance. Patient interviews (n=59) showed: significant increase in acknowledgements, emphatic statements, educated guesses, negotiations. No significant correlations were observed at baseline between pre-post consultation evolution of patients’ anxiety and physicians’ assessment. No significant effect group by time on changes in patients’ and relatives’ anxiety following a three-person consultation was observed. No significant changes were noted in physicians’ ability to detect relatives’ distress. However, there was an effect of the workshops on physicians’ ability to detect patients’ distress when they are accompanied by a relative.</td>
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<td>Razavi, 2002 &amp; Delvaux, 2004</td>
<td>Experimental study</td>
<td>Hospitals / Belgium</td>
<td>Nurses (n=116)</td>
<td>Nurses of the intervention group participated in a three week communication skills training (one week for each of the three consecutive months). The programme included theoretical information (30h), experiential exchange (case presentations) and role-playing exercises (75h). Each subject participated in 4 role-play exercises. Nurses in the control group, were trained after having completed all their assessments.</td>
<td>Nurses completed recorded interviews (one role-play and one clinical interview) at baseline (n=114), one week after the end of training (n=111) and three months later (n=110). Results show that professional empathy increased (professionals use more emotional words after training). Compared to control, trained nurses reported positive changes on their stress level and attitude (both significant). Significant effect was found for communication skills, but no training effect was observed on nurses’ satisfaction levels. However, a positive training effect was found on patients’ satisfaction levels. Audio-taped nursing assessment before (85 in control arm, and 82 in intervention group) and after (82 in control arm, and 72 in intervention group) the training demonstrated significant improvement in communication skills and coverage and confidence of nurses. Patient satisfaction was also greater in the intervention group.</td>
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<tr>
<td>Wilkinson, 2008</td>
<td>Experimental study</td>
<td>Community nursing service, hospices / UK + Ireland</td>
<td>Nurses (n=170)</td>
<td>Nurses completed an audio-taped nursing assessment after which they were randomly included in a) control group, or b) intervention group. The intervention consisted of a 3-day communication skills training, which included a didactic overview, exploration of communication behaviours, interactive demonstrations, facilitated role-play, constructive feedback, discussion, consolidation materials (handouts, references, etc.).</td>
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<td>Source</td>
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<td>Bailey, 2005</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Physicians, nurses and other staff (n=unknown)</td>
<td>1 hour educational sessions in 3 cycles of 16 weeks each were conducted to teach staff communication skills and how to identify patients in need of end-of-life care and implement care plans. After these educational sessions, more informal case-based teaching was undertaken. Verbal reminders and laminated pocket cards were used to assist and remind staff to identify patients who were near the end of life. A set of comfort care plans was also developed and condensed into a laminated pocket card. New nursing and pharmacy policies were issued to ensure the implementation of the care plans.</td>
<td>Pre and post-test record review indicated increased documentation and care plans for 12 of the 13 end-of-life symptoms. Significant increase in number of symptoms documented, number of care plans, availability of opioid pain medication, Do-not-resuscitate (DNR) orders, palliative care consultations and use of restraints. Significant decrease in resuscitation attempts. Non-significant decrease in withdrawal of nasogastric tubes.</td>
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<tr>
<td>Betcher, 2010</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Nurses (n=8)</td>
<td>45 minute lecture followed by role-play with simulation and discussion to improve communication skills of nurses.</td>
<td>Pre and post-test caring efficacy scales indicated improved confidence in the ability to portray caring attitude and helped to improve communication skills with patients and their families.</td>
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<tr>
<td>Brave- men, 2001</td>
<td>Quasi-experimental study</td>
<td>Hospice, home care / USA</td>
<td>Unknown</td>
<td>1st intervention: Education of staff about pain management via two 1-hour in-service training sessions of physical, psychosocial, social and spiritual manifestations of pain and pain interventions. This education consisted of an introductory lecture, discussions and role-playing. A laminated pocket-card and checklists were developed which included the most important information, and all staff were given a set of guidelines. A pain expert was created at each site. 2nd intervention: weekly pain newsletter</td>
<td>Pre and post-test competency assessment and chart audits indicated for the 1st intervention: Some improvements in documentation. Little improvements in staff competency. And for the 2nd intervention: great improvement in staff competency.</td>
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<td>Bylund, 2010</td>
<td>Quasi-experimental study</td>
<td>Hospital/USA</td>
<td>Physicians (n=36)</td>
<td>Six 3-hour training sessions, consisting of didactic presentation to review evidence and introduce communication skills, a demonstration video, small group role-play to practice skills, and feedback related to their role-play sessions.</td>
<td>Pre and post-test assessment of video recorded consultations (n=112) showed significant improvements in two communication skill sets (establishing consultation framework and checking). Some change (though limited) in questioning, empathic communication and information organisation skills. No improvement in shared decision making skills.</td>
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<td>Favre, 2007</td>
<td>Quasi-experimental study</td>
<td>Setting unknown/Switzerland</td>
<td>Physicians, nurses (n=10)</td>
<td>A 2-day communication skills training consisted of case-history discussion, analyses of videotaped interviews with simulated patients, and structured role-play. Follow-up consisted of four to six individual supervisions. After 6-months, another half-day training session including role-play (videotaped interviews) took place.</td>
<td>Observer-rated videotaped interviews before and after the course showed significantly increased overall defensive functioning, significant decrease of immature defences, significant decrease in borderline defence and, on the individual level, the overall defensive functioning improved for 8 out of 10 clinicians.</td>
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<tr>
<td>Fallowfield, 2001</td>
<td>Quasi-experimental study</td>
<td>Hospital/UK</td>
<td>Nurses (n=129)</td>
<td>A two-day communication skills training was given to small groups (12 persons per session). Participants worked on specific skills in small groups of four or less, using video review of role-play with standardised patients. Interactive group demonstrations, small group discussion of prepared video materials and a resource file of selected key reading provided a conceptual framework and expansion of participants’ knowledge of the literature.</td>
<td>Before and 3-months after the course (n=92), nurses filled in a questionnaire. Posttest data showed that nurses reported significantly greater confidence in handling 14 common communication problem areas in cancer and in 8 different areas of teaching. Three months post-course 91% reported changing their own teaching practice and 85% had initiated new communication skills teaching.</td>
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<td>Finset, 2003</td>
<td>Quasi-experimental study</td>
<td>Setting unknown / Denmark, Finland, Iceland, Norway and Sweden</td>
<td>Physicians (n=219)</td>
<td>A communication skills course, consisting of three modules. Module 1: three seminars of 3 hours at two week intervals about interview techniques, psychological defence mechanisms and crisis reactions, using instructional videos and self-study materials. Module 2: a boarding course lasting for 3 days, including experiential learning in the form of role-play, which was videotaped to stimulate discussion. Module 3: three seminars of 3 hours aimed at how doctors experienced their work with cancer patient and testing new skills.</td>
<td>Physicians filled in a questionnaire before, at the completion, and 2 to 6 years after course completion (n = 155). 94% of the physicians reported high degree to fairly large extent of satisfaction of the course content. The course improved all communication learning needs, except applying knowledge of defence mechanisms, meeting depression in patients, meeting withdrawal in patients, and meeting suicidal patients. Participants described that communication in challenging situations is easier than before the course.</td>
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<tr>
<td>Fischer, 2007</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Internal medicine interns (n=51)</td>
<td>A 3-hour communication skills workshop was provided. The workshop consisted of group discussions, a brief lecture, videotape review, and role-playing.</td>
<td>Pretest (n=43) and posttest (n=29) survey showed an increase in overall knowledge, bad news subscore, and advance care planning subscore. There was also an increase in participants’ confidence in ability to discuss advance care planning and limitations of treatment, delivering bad news and handling emotional responses from patients. There was no significant differences in attitude before and after the workshop.</td>
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<tr>
<td>Furman, 2006</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Physicians (n=8)</td>
<td>Participants attended a morning report consisting of both didactic training and three-person role-played discussion in order to improve discussion of advance directives.</td>
<td>Pre (n=44) and post (n=35) intervention chart audit, showed that 32% of the patients had a documented advance directive discussion before intervention compared to 34% after the intervention. Results were not statistically significant. Anonymous, post-test evaluation forms showed that the confidence in conducting family meeting increased significantly from retrospective pre-test evaluation.</td>
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<tr>
<td>Gueguen, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Physicians, nurses, nurse practitioners, physician assistants (n=40)</td>
<td>Didactic presentation, including exemplary video clips, followed by role-play with discussion and feedback to improve communication skills. Participants were also given an educational booklet.</td>
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<td>Hall, 2007</td>
<td>Quasi-experimental study</td>
<td>Palliative care unit / Canada</td>
<td>Physicians, nurses (n=17)</td>
<td>Four-hour education sessions for nurses and case study and role-play were used by physicians to review communication strategies, shared decision-making and care planning concepts. An advanced practice nurse was available on the unit every day when the pilot began to support staff with the change process.</td>
<td>Daily logs of activities and satisfaction, pre and post-test questionnaires, interviews, and focus groups indicated improved communication between physicians and nurses and the increased assessment responsibility of nurses reduced physician time on the ward.</td>
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<tr>
<td>Kinnane, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital / Australia</td>
<td>Volunteerd and volunteer coordinators (n=8)</td>
<td>3-day training, including classroom and group activities (e.g. role-play) about the service, communication skills, support and self-care.</td>
<td>Pre-post intervention (n=8) showed improvements in: communication skills, offering support, knowledge of available service, confidence. Most valued aspect of training: role-play, learning communication skills, information of the services.</td>
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<tr>
<td>Quinn, 2008</td>
<td>Quasi-experimental study</td>
<td>Hospital, Nursing home, General practitioner, hospice / Australia</td>
<td>Allied health-care professionals, physicians, nurses, personal care attendant (n=495)</td>
<td>Nine sessions presented by specialist palliative care clinicians. Sessions consisted of didactic lectures, question and answer sessions, workshops and panel/ case discussions. Participants were also given educational material.</td>
<td>Pre and post-test questionnaire, post-test evaluation, and a focus group showed a significant improvement in ability to identify palliative care patients, relationship and roles, providing support services, communication skills, symptom and pain management, legal and ethical issues, spiritual and cultural aspects and grief and bereavement.</td>
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<td>Reymond, 2005</td>
<td>Quasi-experimental study</td>
<td>Primary care / Australia</td>
<td>GP, nurse, nurse assistant, personal care worker, indigenous health worker, respite care worker, diversional therapist, Physiotherapist, social worker, pastoral worker (n=149)</td>
<td>3-hour workshop consisting of introductory didactic teaching on participant nominated topics, small group case management discussion, and a session devoted to psychosocial and counseling inputs.</td>
<td>Pre and post-workshop questionnaires (n=116) showed that GPs’ confidence increased significantly in knowledge and skill levels in managing common symptoms (nociceptive tissue pain, neuropathic pain, dyspnoea, constipation, and delirium). Other primary healthcare workers had a significant improvement in rated knowledge of treatment of pain and dyspnea (constipation was not significant), and rated skill level was statistically increased for pain management in dementia. Their confidence in developing management plans and communicating with patients also increased significantly.</td>
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<td>Sullivan, 2005</td>
<td>Quasi-experimental study</td>
<td>Setting unknown / USA</td>
<td>Physicians, nurses, social workers, pharmacists, ethicists, and other healthcare professionals (n=149)</td>
<td>Palliative Care Education and Practice was delivered in two, one-week, full-time, on-site sessions, separated by 6-months that included an interim distance-learning component. Session 1 focused on fundamental clinical and educational aspects of palliative care. Session 2 included experiential learning in clinical and teaching skills and training in leadership and organisational change. During the interim period, participants worked on individual projects, developing a clinical or educational program and contributed to weekly e-mail case discussions.</td>
<td>Self-administered questionnaires before (n=149) and after (n=113) the training demonstrated statistically significant improvements on nearly all measures, including knowledge skills and confidence levels.</td>
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<td>Sutherland, 2007</td>
<td>Quasi-experimental study</td>
<td>Hospital / Australia</td>
<td>Physicians (n=93)</td>
<td>A 4.5 hour workshop on breaking bad news started with the theoretical underpinnings of communication skills. Subsequently, group based activities, including role-play, and discussions were used to practice and understand how evidence-based theory translated to practice. Participants received a booklet with guidelines, information, a glossary and bibliography.</td>
<td>Pre (n=54) and post (n=34) workshop questionnaires demonstrated significant improvements in confidence and in 3 out of 8 items assessing subjective reports of clinical behaviour.</td>
</tr>
<tr>
<td>Weissman, 2000</td>
<td>Quasi-experimental study</td>
<td>Long term care facilities / USA</td>
<td>Unknown</td>
<td>Four educational programs, one every 3 months (20 contact hours), included lectures, demonstrations, small group case-based discussions, role-play and panel discussions to teach and practice pain assessment. Participants received a resource pack that included content outline, overheads and supporting material (national pain management treatment guidelines, sample pain assessment tools, and pain management policies).</td>
<td>Assessment of pain policies before and chart review after the training demonstrated improved pain practice: at baseline 14% of facilities had &gt;51% of the indicators in place; at conclusion 74% of facilities had &gt;51% of indicators in place.</td>
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<tr>
<td>Weissman, 2001</td>
<td>Quasi-experimental study</td>
<td>Long term care / USA</td>
<td>Nurses, different levels of management (n=unknown)</td>
<td>Four educational workshops, consisting of lectures, group workshops, role-play exercises and case studies, spread over a one-year period.</td>
<td>Pre-test needs assessment and post-test chart review indicated improved knowledge and confidence in participants’ own practice. On the organisational level, an improvement on number of target indicators that were reached was reported.</td>
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<td>Wilkin-son, 2002</td>
<td>Quasi-experimental study</td>
<td>Various settings / UK</td>
<td>Nurses (n=308)</td>
<td>A 3-day communication skills training was delivered over a 3-month period. The training consisting of 26 hours and included attitudes to cancer, communication with patients, relations and colleagues, nonverbal communication skills, assessing psychological distress, strategies for handling difficult situations, and stress and survival in cancer nursing settings. Teaching methods included audiotaped feedback, demonstration videos and role play discussions.</td>
<td>Pre and post course tape recorded nursing assessment, questionnaire (pre course only) and written self critique (post course only) demonstrated significant improvement on all 9 individual areas of the communication skills assessment.</td>
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<tr>
<td>Wilkin-son, 2003</td>
<td>Quasi-experimental study</td>
<td>Hospital, hospice, community care / UK</td>
<td>Nurses (n=108)</td>
<td>3-day communication skills training, using a teaching pack, verbal and written feedback on audio recording of nursing assessment, video and audio demonstration tapes, didactic sessions, discussions, and role-play with feedback.</td>
<td>Pre and post-test assessment of audio tape recording (n=101) showed significant improvements in assessment skills, confidence in communication skills and perceived confidence in teaching communication skills.</td>
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<tr>
<td>Yamagishi, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital / Japan</td>
<td>Nurses (n=81)</td>
<td>Educational session about artificial hydration therapy for terminally ill cancer patients, which consisted of a 10-minute lecture, four interactive 60-minute seminars and discussion.</td>
<td>Pre and post-test (n=76) knowledge, confidence, self-reported practice, and overall evaluation showed that knowledge and confidence scores significantly increased.</td>
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<td>Butow, 2008</td>
<td>Experimental study</td>
<td>Hospital / Australia</td>
<td>Physicians (n=30)</td>
<td>Two groups of physicians, one intervention group and one control group. The intervention group received a booklet summarising the evidence underpinning the recommendation before the workshop. Then they underwent a 1.5-day intensive face-to-face communication skills training with 3-6 participants each time, including presentation of principles, a DVD modelling ideal behaviour and role-play practices, followed by four 1.5 hour follow-up video-conferences incorporating role-play. The participants conducted the role-play with actors, while the facilitator joined in through video-conference.</td>
<td>Simulated patient interviews and questionnaire were administered to all physicians, including those from the control group. The intervention group was also assessed immediately after the training, and at 6 and 12 months. Results show that physicians displayed more creating environment and fewer blocking behaviours at follow-up, but were not significant. Physicians valued the training highly, but did not report substantial reduction in stress and burnout.</td>
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<tr>
<td>Curtis, 2011</td>
<td>Experimental study</td>
<td>Hospital / USA</td>
<td>Physicians, nurses, respiratory therapists, social workers and spiritual care workers (n=unknown)</td>
<td>Clinician education about palliative care using grand rounds, workshops, academic detailing and video presentations. Training of champions for palliative care. Identification of ICU-specific barriers to palliative care. Feedback of ICU-specific family satisfaction data. Implementation of system supports such as the palliative care order forms.</td>
<td>Pre and post-test patient, caregiver, and staff questionnaires showed that the intervention was not associated with significant changes in any of the family-assessed or nurse-assessed outcomes. Also, no changes in length of stay in ICU before death or change in time from admission to withdrawal of life-sustaining measures (mechanical ventilation).</td>
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<td>Fallowfield, 2002</td>
<td>Experimental study</td>
<td>Hospital / UK</td>
<td>Oncologists (n=160)</td>
<td>Oncologists were randomly assigned to four groups: 1) written feedback followed by course, 2) course only, 3) written feedback only, 4) control (no feedback and no course). Feedback consisted of comprehensive written feedback on videotaped consultations based on analysis of the doctor’s communication skills, patients’ satisfaction scores, comments after consultation, doctor’s rating of patients’ distress and understanding of information. The 3-day course consisted of reviewing assessments and small group role-play simulations in order to improve oncologists’ communication skills.</td>
<td>Differences between baseline assessment (n=320) and 3 months after the course (n=320) showed a significant improvement in the number of focused and open questions, expressions of empathy, and appropriate responses to patients’ cues for oncologists who had been on the course compared to those who had not. There was little evidence for the effectiveness of written feedback.</td>
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<td>Jenkins, 2002</td>
<td>Experimental study</td>
<td>Hospital / UK</td>
<td>Physicians (n=93)</td>
<td>See Fallowfield, 2002</td>
<td>Pre-and post intervention questionnaire and videotaped patient interview showed significantly improved attitudes and beliefs toward psychosocial issues compared with controls.</td>
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<tr>
<td>Shilling, 2003</td>
<td>Experimental study</td>
<td>Hospital / UK</td>
<td>Oncologists (n=160)</td>
<td>See Fallowfield 2002</td>
<td>Patient and clinician satisfaction were measured before (n=464) and 3 months after (n=439) the course and before (n=491) and after (n=422) the course for the control group. Despite the measureable changes in clinicians’ behaviour, the communication skills training had no significant effect on either patient or doctor satisfaction with the consultation.</td>
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<tr>
<td>Fallowfield, 2003</td>
<td>Experimental study</td>
<td>Hospital / UK</td>
<td>Oncologists (n=160)</td>
<td>See Fallowfield, 2002</td>
<td>12 month follow-up assessments of videotaped patient interviews, showed that the effect recorded after 3 months was still in effect after 12 months. There were fewer interruptions evident and summarising of information increased, responses to patient-led cues improved while the number of inappropriate responses decreased.</td>
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<td>Hanson, 2005</td>
<td>Experimental</td>
<td>Nursing home / USA</td>
<td>Directors of nursing, nurses, nursing assistants, social workers, staff development coordinators, MDS coordinators, administrators, activities directors, Nurse practitioner or physician assistant, other nursing home staff (n=unknown)</td>
<td>One-day conference about hospice enrollment and service, pain management, advanced care planning, communication, and quality improvement techniques. Monthly on-site education about quality improvement techniques. These sessions were videotaped to facilitate delivery to evening and night staff. The palliative care leadership team participated in monthly strategy meetings to design and implement stepwise organizational changes. They received and responded to performance data recorded at baseline, month 3 and month 6.</td>
<td>Pre and post-test (n=41) knowledge test and pre and post-test chart reviews indicated improved knowledge and confidence to provide good quality palliative care. Increased hospice enrollment, number of pain assessments, non-pharmacological treatment and in-depth discussions about end-of-life care with residents. The prevalence of pain and the use of pain medication did not change.</td>
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<tr>
<td>Roila, 2004</td>
<td>Experimental</td>
<td>Hospital / Italy</td>
<td>Oncologists (n=unknown)</td>
<td>Group 1: Diffusion of guideline, group 2: Diffusion of guideline + audit and feedback, group 3: Diffusion of guideline + audit and feedback + educational outreach visit.</td>
<td>Monitoring of the antiemetic prescription showed that a simple diffusion of guideline was not very effective. Simple diffusion of guideline + audit and feedback also resulted in poor results. Combination of diffusion of guideline, audit and feedback, and education outreach visit had a positive impact on antiemetic prescription, but inferior to what was expected.</td>
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<tr>
<td>Okon, 2009</td>
<td>Quasi-experimental</td>
<td>Hospital / USA</td>
<td>Nurses (n=364)</td>
<td>A hospital-wide, computer-based clinical documentation of pain system (including a delayed reassessment alert intervention) was implemented using a detailed printed explanation, brief group training sessions and feedback reports.</td>
<td>Pre and post-test chart audits revealed a reduced delay in pain reassessment time to resolution of severe pain and hospital-wide administration of naloxone.</td>
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<td>Boakes, 2000</td>
<td>Quasi-experimental study</td>
<td>Primary care / Australia</td>
<td>GPs (n=22)</td>
<td>GPs attended weekly patient case conferences to review their own practice, they were asked to keep a diary of patient related activities, they were also required to take part in the hospice team’s normal on-call roster, they participated in tutorial-type educational sessions (covering: pain management, symptom control, oncology, and psychosocial and ethical issues in palliative care), and they held a weekly discussion with a mentor.</td>
<td>Pre and post-intervention questionnaires indicated statistical significant improvement in the GPs perceived level of knowledge, skills and confidence in providing palliative care.</td>
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<tr>
<td>Bookbinder, 2005</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Nurses (n=unknown)</td>
<td>To introduce a care pathway, consisting of interdisciplinary care path, nurses’ daily flow sheet, and a standardised physician order sheet, nurses received educational session about end-of-life care and house staff and physician assistants received a case-based teaching round. On each study ward, a nurse leader acted as liaison to the project. Evaluation tools were used to assess and feedback the progress made.</td>
<td>Pre and post-intervention chart abstraction (n=101;156), process audit, and knowledge questionnaire (n=138) indicated that the mean number of symptoms assessment increased significantly; Significant decrease in the number of problematic symptoms identified and interventions employed in the palliative care unit; Significant increase in the number of inpatient consultations; Increased discussion of patient’s goals of care and patient preferences; Increased use of palliative care in vocabulary of physicians; Increased collaboration between hospice and hospital. Morphine infusion and DNR orders were more likely in study units. Although mean knowledge scores improved, no significant changes were found. Number of patients placed on care pathway: 9 of 27 in Oncology/Geriatric units, all 50 in PC unit</td>
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<td>Dauer, 2006</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Nurses (n=113)</td>
<td>Radiation safety training consisting of revised nursing radiation safety procedures, radiation safety core concepts video, interactive nurse leadership in-service training, didactic nursing staff in-service training, and improved radiation precaution information signs/labels.</td>
<td>Pre and post-test (n=113) assessment showed significant improvements in nurses’ cognitive knowledge and attitude towards radiation safety.</td>
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<td>Hansen, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital / Country unknown</td>
<td>Nurses (n=91-127)</td>
<td>A nurse-developed bereavement program for patients’ families, collaboration with/use of a palliative medicine and comfort care team, use of preprinted orders for the withdrawal of life-sustaining treatment, hiring of a mental health clinical nurse specialist and staff education in end-of-life care.</td>
<td>Pre (n=91) and post-test (n=127) questionnaire showed that the perception of work environment, staff support, patient, and family support and work stress improved. Perception of knowledge and ability did not differ significantly over time.</td>
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<tr>
<td>Hills, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital / UK</td>
<td>Nurses (n=unknown)</td>
<td>Audit to assess aftercare, development of last offices policy, interdisciplinary workshops and teaching sessions (including a DVD on the principles and standards of aftercare).</td>
<td>Pre (n=43) and post-test (n=42) audits showed improvements in care and raised the profile of aftercare. Improvements achieved following the audit were modest.</td>
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<td>Hockley, 2010</td>
<td>Quasi-experimental study</td>
<td>Nursing home / UK</td>
<td>Nurses and caring staff (n=unknown)</td>
<td>1-3 key champions in each service (who received 4 workshops and a 4-day training course) implemented a list of all permanent residents with prompts for monthly discussions around advanced care planning, DNAR status, family and resident communication, and symptom assessment control. Staff received a 2-hour scenario-based training. Each service also had an outreach visit from the project facilitator every 10-14 days.</td>
<td>Retrospective review of clinical notes before (n=95) and during the intervention (n=133) and post-intervention staff audit (n=68) showed that documentation of DNAR instructions rose from 15% to 72%. Evidence of conversations about advanced care planning rose from 4% to 53%. The use of the adapted Liverpool Care Pathway rose from 3% to 30%. Hospital deaths reduced from 15% to 8% and number of hospital bed-days reduced by 38%. Improvement in staff confidence in addressing psycho-social and emotional needs and talking with patients and relatives about dying.</td>
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<tr>
<td>Jacobs, 2002</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Physicians and nurses (n=unknown)</td>
<td>To improve end-of-life care physicians and nurses were given biannual feedback through a palliative care report card. These reports were also presented to the medical director. Other interventions included palliative care social work consultations and educational sessions about symptom management, psychological/social concerns, bioethical and legal issues.</td>
<td>Medical record review (n=194), family interviews (n=133), and a physician survey (n=8) showed significant improvement in the management of respiratory symptoms, but no changes in other indicators. However, the project led to some changes being initiated in institutional policies and clinical management.</td>
</tr>
<tr>
<td>Kinley, 2004</td>
<td>Quasi-experimental study</td>
<td>Palliative care unit / UK</td>
<td>Nurses and medical staff (n=33)</td>
<td>Oral care documentation, including an assessment tool, oral care plan, and protocol of care were implemented. Staff received a refresher training on oral care, including feedback from baseline audit, teaching about oral care, discussion about products, demonstration of oral care, discussion and a video. An information leaflet (in the form of a bookmark) was also developed.</td>
<td>Pre (n=50) and post-test (n=47) retrospective review of patient records and pretest-posttest staff knowledge questionnaire (n=23) showed improvements in awareness and knowledge.</td>
</tr>
<tr>
<td>Keay, 2003</td>
<td>Quasi-experimental study</td>
<td>Nursing home / USA</td>
<td>Physicians (n=12)</td>
<td>A half-day, educational outreach programme based on a curriculum for educating nursing home physicians in palliative and hospice care. Programme included audit &amp; feedback, use of opinion leaders and review of guidelines.</td>
<td>Pre and post test questionnaires and terminal care audit forms showed that the intervention was associated with significant improvements in terminal care outcomes: improved pain control, better control of shortness of breath, better control of uncomfortable symptoms, more attention to hygiene and bereavement. Increased use of WHO class 3 medications. Decrease in WHO class 1 medication. Number of unexpected deaths dropped from 36% to 5%. More documentation of comfort measures. Better documentation of residents’ advance directives.</td>
</tr>
<tr>
<td>Source</td>
<td>Study methodology</td>
<td>Setting / country</td>
<td>Participants in intervention (n)</td>
<td>Description of strategy</td>
<td>Results</td>
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<tr>
<td>Lanksheer, 2010</td>
<td>Quasi-experimental study</td>
<td>Hospital / Canada</td>
<td>Physicians (n=96)</td>
<td>Full-day orientation for clinician mentors, regional education session for clinicians and administrators, presentations at rounds and department meetings were used to launch the project. Clinician mentors held educational information seminars for small groups and individual physicians. Update on project was a standing agenda item at regular meetings in the centers. Monitoring and feedback, including monthly conference calls and monthly quality assurance reports on both center and individual physician level, were used to facilitate ongoing dialogue and motivate physicians to improve documentation of cancer stage.</td>
<td>Pre (n=52) and post-test (n=42) questionnaire indicated that documentation of cancer stage improved on both organisational and provincial levels.</td>
</tr>
<tr>
<td>Lyon, 2007</td>
<td>Quasi-experimental study</td>
<td>Care homes / Australia</td>
<td>Nurses and medical staff (n=unknown)</td>
<td>An audit-feedback approach was used to implement 1) Monthly meetings, 2) External assistance: 2.1) assistance with the development of an implementation strategy and assistance with system changes, 2.2) two-day training and additional one-to-one assistance with an experienced mentor, 3) Information sessions on advanced care planning including introductory discussion and information kits for doctors who were not able to attend the sessions, and 4) Documenting and implementing guidelines. During the course of the project, regular but optional support meetings were used to discuss personal encounters. At the end of the project, a short session about advanced care planning was added to a mandatory study day.</td>
<td>Pre and post-implementation audit of residents’ files (n=46) indicated improvements in documented evidence that the resident has been involved in advanced care planning, significant others have had the opportunity to be involved in advanced care planning and there is evidence of ongoing assessments. Pre- and post-implementation audit of staff (n=6) indicated that advanced care plans are more regularly completed and implemented after receiving training.</td>
</tr>
<tr>
<td>Source</td>
<td>Study methodology</td>
<td>Setting / country</td>
<td>Participants in intervention (n)</td>
<td>Description of strategy</td>
<td>Results</td>
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<tr>
<td>McCor- mick, 2010</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Social workers (n=35)</td>
<td>Social workers participated in clinician education, local champion development and feedback of family satisfaction data.</td>
<td>Pre (n=66) and post-test (n=60) family satisfaction questionnaire and pre and post-test (n=15) questionnaire for social workers indicated decreased family satisfaction (not significant). Increased years as a social worker had a significant and positive effect on family satisfaction and increased caseload had a significant and negative effect on family satisfaction with social workers. Significant increase in 4 of the 14 reported activities: discussing spiritual/religious needs with the family, talk with family about touching their loved one, talk with family about disagreements in the plan of care, and assuring the family that the patient would be kept comfortable. No improvement in social workers’ satisfaction with meeting families’ needs or family ratings of social workers.</td>
</tr>
<tr>
<td>Mirando, 2005</td>
<td>Quasi-experimental study</td>
<td>Hospital / UK</td>
<td>Nurses, physicians, housekeeping staff, porters, administrative and clerical staff (n=unknown)</td>
<td>A care pathway was introduced to 12 clinical areas of a hospital via multidisciplinary training, audit and feedback and reminders and support from the project nurse.</td>
<td>Medical record audit, monitoring variances, and evaluation of training and field notes showed a 20% increase in information-sharing, documentation of do not resuscitate orders, prescription of medications, recording of vital signs being discontinued, discontinuation of nonessential oral drugs, and communication with the family. Following each training session, a short questionnaire showed that the confidence of nurses to prompt a review of clinical situation improved over time.</td>
</tr>
<tr>
<td>Source</td>
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<td>Participants in intervention (n)</td>
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<tr>
<td>Monteleoni, 2004</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Unknown</td>
<td>A palliative care team was established, this team instituted 4 educational programmes: 1) a geriatrician gave a medical grand round. The other 3 programmes involved: rotation of 12 sessions on pain management consultation, participation in presenting modules of the EPEC curriculum, and spend one month on geriatrics rotation.</td>
<td>Chart review showed that the total number of tubes inserted and the number of tubes placed in patients with dementia both decreased significantly. No reduction in proportion of tubes placed in patients with an advance directive refusing artificial nutrition.</td>
</tr>
<tr>
<td>Morgan, 2010</td>
<td>Quasi-experimental study</td>
<td>Hospital / UK</td>
<td>Nurses and other staff (n=unknown)</td>
<td>Before the implementation of an end-of-life care pathway, regular informal meetings were used to teach professionals the principles of the pathway. Champions, continued education and feedback were used during the implementation phase.</td>
<td>A post-intervention audit (n=20) showed that the pathway is being used during decision-making and has facilitated improvement in the quality of End-of-Life Care, but documentation of bereavement care that was present pre-implementation was absent after implementation.</td>
</tr>
<tr>
<td>Reynolds, 2004</td>
<td>Quasi-experimental study</td>
<td>Nursing home / USA</td>
<td>Unknown</td>
<td>Clinical leadership team visited two conferences: one pre-intervention and one post-intervention. A 3-person multidisciplinary team met monthly for 6 months with the leadership team for technical assistance. During the same 6 months, a hospice led team held on-site educational sessions. Audit and feedback of quality indicator scores were given three times, once every two months.</td>
<td>Residents’ charts were reviewed to identify changes in advance care planning, pain management, and hospice use. This showed that four out of eight nursing homes were largely successful in improving their palliative care service.</td>
</tr>
<tr>
<td>Source</td>
<td>Study methodology</td>
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<td>Participants in intervention (n)</td>
<td>Description of strategy</td>
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<tr>
<td>Smith, 2009</td>
<td>Quasi-experimental study</td>
<td>Hospital / USA</td>
<td>Nurses, nurse practitioners, and nursing assistants (N=33)</td>
<td>Nursing assistants received a case-based training to practice the use of scripted screening language. Nurses received identical basic training with educational content on a more advanced level. Nurse practitioners received case-based didactic sessions as well as hands-on training in neuropathic pain-specific neurological examination. Following the educational sessions, all nurse participants received a pocket-sized laminated card of the treatment algorithm and assessment tool. Internet-based distant learning was used to provide education and project updates. Screening adherence was audited and fed back to the participants.</td>
<td>Pre and post-test knowledge questionnaires and (neuropathic) pain screening indicated that knowledge regarding neuropathic pain screening improved for all nurse groups. Screening adherence rate also improved.</td>
</tr>
<tr>
<td>Stacey, 2008</td>
<td>Quasi-experimental study</td>
<td>Cancer call center / Australia</td>
<td>Nurses, psychologists, and other allied healthcare professional (n=34)</td>
<td>1) A decision coaching protocol was introduced to provide a stepped approach to assessing callers needs; 2) Online decision support tutorial to be able to recognise decisional conflict, describe concepts of decision support, tailor decision support callers needs, be aware of decision aids and use the decision coaching protocol; 3) 3-hour skill-building workshop to further develop the participants skills, via: role-play using the protocol, feedback, and discussing a real patient-nurse call; 4) Training of supervisors in decision support; 5) Having the director of the helpline to address workshop participants the importance of decision support.</td>
<td>Pre-post intervention evaluations (n=32) showed an increase in knowledge (from 61% to 84%) and quality of decision support (from 56% to 86%).</td>
</tr>
<tr>
<td>Source</td>
<td>Study methodology</td>
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<td>Participants in intervention (n)</td>
<td>Description of strategy</td>
<td>Results</td>
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<tr>
<td>Strumpf, 2004</td>
<td>Quasi-experimental study</td>
<td>Nursing home / USA</td>
<td>All staff (n=unknown)</td>
<td>Four nursing homes formed the intervention group, and four the control group. The intervention consisted of a training of key staff (administrator, director, nurse, social worker) on five modules: introduction to palliative care, advance care planning, pain and symptom management, psychosocial support, and the palliative care delivery process. Following this training, the nurse and/or social worker became coordinators and delivered the same formal in-service training over a 3-month period for all disciplines. During the study, a nurse consultant was available for support on a weekly basis. In two nursing homes, an interdisciplinary palliative care team was launched that held a weekly discussion about its’ residents in need of palliative care.</td>
<td>Assessment - which focused on advance care planning, pain and symptom control, and psychosocial concerns - demonstrated increasing number of residents with advance care plans, pain management, higher rates of identification, assessment and treatment of symptom in the last weeks of life, and higher rates of physician visits and x-rays.</td>
</tr>
<tr>
<td>Woo, 2011</td>
<td>Quasi-experimental study</td>
<td>Rehabilitation and convalescence unit, Geriatrics Day Hospital, Palliative Day Hospital / Hong Kong</td>
<td>Nurses, physicians and junior medical staff (n=118-121)</td>
<td>Senior geriatricians gave seminars about definitions and trajectories of various end-stage diseases, common end-stage symptoms, and their management. An end-of-life care manual was placed in each nursing station. Forms to guide symptoms monitoring, interventions, and investigations were included in patients’ files. A care pathway was developed with ongoing review and consultation with staff. Forms and electronic alerts were used to inform staff about discharge options and end-of-life-care status. Workshops including role-play and interactive discussions were also conducted.</td>
<td>Pre (n=80 and post-test (n=89) patient symptoms and caregiver assessment showed a reduced duration of stay, fewer investigations, and fewer transfers back to the acute care hospital. Improvement in patient symptoms was achieved for pain and dizziness. Caregiver and patient satisfaction improved after the initiative. Pre- (n=118) and posttest (n=121) staff evaluations showed no significant differences regarding burnout and anxiety.</td>
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Improving the organisation of palliative care: identification of barriers and facilitators in five European countries

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Myrra Vernooij-Dassen
Frederike Brouwer
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Wojciech Leppert
Birgit Jaspers
Elena Mariani
Ragni Sommerbakk
Kris Vissers
Yvonne Engels
Abstract

Background: Interventions to improve palliative care encounter challenges beyond the usual implementation problems because of palliative care’s complex and changing characters. In this study, we explored barriers and facilitators faced by healthcare professionals in five European countries (England, Germany, Italy, Norway, and the Netherlands) with regard to improving the organisation of their palliative care service.

Methods: Semi-structured individual and focus group interviews were conducted with purposefully selected health-care professionals. The constant comparative method was used to analyse the data.

Results: Professionals working in hospitals, hospices, nursing homes and primary care facilities who provide palliative care to adult patients, were interviewed (n=40) or participated in ten focus group interviews (n=59). Barriers and facilitators were inductively grouped into 16 categories and arranged into five themes: innovation, individual professional level, group dynamics, organisational context and local political-economic context. Although the barriers and facilitators identified differed in scope, context, strength and provenance, they were shared by professionals from different European countries.

Conclusion: This study identified barriers and facilitators to organisational change in palliative care. Some of these barriers and facilitators were experienced by professionals in almost all countries and are therefore prerequisites to change. Understanding the barriers to and facilitators of change will help tailor organisational improvements to the needs of individuals and organisations.
Background

Palliative care aims to preserve the best possible quality of life of the patient whose disease is not responsive to curative treatment. Improvements in palliative care usually focus on pain and symptom control, use of standardised assessment tools, care in the last days of life and the quality of dying. To date, improving specific organisational aspects of palliative care has received less attention. Interventions to improve the organisation of palliative care encounter challenges beyond the usual problems of implementation of change in healthcare. Patients in need of palliative care often move between services, have changing (and often increasing) needs for treatment and support, have multiple problems and symptoms and receive care from a variety of professionals. This requires optimal collaboration between patients, informal carers and a range of professionals and healthcare organisations. In order to overcome these challenges and improve the organisation of palliative care, systematic implementation to translate the results of clinical research into everyday clinical routines is necessary. A first step in a systematic implementation process is the identification of barriers and facilitators. Recent studies have provided some insights in possible barriers and facilitators related to changing the organisation of other fields in healthcare, for example in the handover of care, case management and the introduction of nursing guidelines. However, studies on improving the organisation of palliative care are still lacking.

For this reason, the objective of this study was to identify barriers to and facilitators of improvements in the organisation of palliative care in Europe. The results from this study will be used in the European Seventh Framework IMPACT project (IMplementation of quality indicators for PAlliative Care sTudy) to develop and tailor national and setting-specific strategies to improve the organisation of palliative care in England, Germany, Italy, Norway and the Netherlands.

Methods

A qualitative design, with semi-structured individual and focus group interviews, was used. Individual interviews were conducted in order to gain professionals’ understanding of barriers and facilitators to improve the organisation of palliative care. Focus group interviews were used to reflect the social and cultural contexts of barriers and facilitators to improve the organisation of palliative care.

Participants and settings

The study took part in England, Germany, Italy, Norway and the Netherlands. Participants of the individual and focus group interviews were purposefully selected healthcare professionals working in services providing palliative care. Besides professionals working in hospitals, hospices and primary care settings, also nursing home professionals were included because of the growing population.
in such settings in need of palliative care. Services which have been providing palliative care for adult patients for at least 2 years were eligible for this study. In each country a snowballing method was used to select professionals for the individual and focus group interviews: all professionals approached were asked to nominate other professionals. Professionals were included if they were either clinically involved in palliative care (e.g. nurses and physicians) or in the organisation of palliative care (e.g. managers of a specific palliative care service) and if they had at least 1-year professional experience in palliative care. Recruitment continued until no new themes or information was coming out of the interviews.

**Data collection**

A semi-structured interview guide, based on the literature and previous experiences of the research team, was developed and used to guide both individual interviews and focus groups. Questions of the interview guide were refined during an international research meeting with researchers of the IMPACT project (appendix 1). To test the interview guide, at least two pilot interviews were conducted per country. Interview and focus groups were recorded with either written or verbal consent of the participants, and transcribed verbatim using an agreed transcription format. All focus group interviews were led by experienced moderators.

**Data analysis**

Analysis started after the first interview. In each country, researchers (see appendix 2) condensed data and suggested codes closely related to the text fragments by using a constant comparative method. To control for subjectivity, two researchers per country independently coded the data. Software for the analysis of qualitative data (such as Atlas.ti and MAXQDA) was used to facilitate the coding process. Codes and associated text fragments were translated into English and shared between the researchers. At an international IMPACT research meeting, the interview guide was evaluated and adapted where necessary and a consensus codebook was made. Next, this codebook was used by the researchers for the analysis of the remaining interview and focus group data: two researchers in each country discussed the codes until consensus was reached. When no consensus could be reached, a third researcher was consulted. Categories were derived from the codes and discussed between the researchers in the five countries via email and Skype meetings. Per country, a report was produced, summarising the barriers and facilitators to improve the organisation of palliative care in the respective countries. Two researchers (JvRP and FB) compared all these reports of the individual countries, applying an adapted version of the Grol and Wensing model for understanding change at different levels of healthcare in order to organise the barriers and facilitators into categories. The adapted model consisted of five themes instead of six: innovation, individual professional level, group dynamics, organisational context and local political - economic context. Categories were fed back and checked with researchers from each country.
Ethical considerations
The Medical Ethics Committee of the district Arnhem-Nijmegen has declared that this study does not fall within the remit of the Medical Research Involving Human Subjects Act (WMO) (registration number 2012/075). This means that this study can be carried out without an approval by an accredited medical ethics committee.

Results
In total, 40 professionals were interviewed and another 59 participated in 10 focus group interviews (table 1). They were spread evenly in all major services providing palliative care, including hospitals, hospices, nursing homes and primary care facilities.

Barriers and facilitators were inductively categorised into 16 categories and organised into themes, using the adapted model for understanding change at different levels of healthcare\textsuperscript{16}. Table 2 provides an overview of the framework with categories, barriers and facilitators, and associated quotes in each theme. Table 3 provides an overview of the categorised barriers and facilitators per country. The themes and categories are summarised below.

<table>
<thead>
<tr>
<th>Table 1: Interviewee characteristics</th>
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<tbody>
<tr>
<td># Interviews</td>
</tr>
<tr>
<td>Male</td>
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<tr>
<td>Female</td>
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<tr>
<td>Physicians</td>
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<tr>
<td>Nurses</td>
</tr>
<tr>
<td>Social worker</td>
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<tr>
<td>Psychologist</td>
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<tr>
<td>Managers</td>
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<tr>
<td># Focus groups</td>
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<tr>
<td>Male</td>
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<tr>
<td>Female</td>
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<tr>
<td>Physician</td>
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<td>Nurses</td>
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<td>Social worker</td>
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<tr>
<td>Psychologist</td>
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<tr>
<td>Manager</td>
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<tr>
<td>Other</td>
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</tbody>
</table>

EN: England; DE: Germany; IT: Italy; NO: Norway; NL: The Netherlands
* In both Norway and the Netherlands, two interviews were conducted with two interviewees. The number of interviews (n=36) is therefore lower than the actual number of interviewees (n=40).
<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Codes</th>
<th>Associated quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Innovation</td>
<td>Accessibility</td>
<td>Time of training, Availability of education, Frequency of contact</td>
<td>[...] we are trying to organise different moments during the year when all our professionals come here [...] to update all together their training program (psychologist, primary care, Italy).</td>
</tr>
<tr>
<td>Attractiveness</td>
<td>Method of presentation, (lack of) tailoring, Extrinsic motivation, Extrinsic incentives</td>
<td>Cases were presented, cases from our own organisation, cases which really increased motivation of the staff (manager, hospice, The Netherlands).</td>
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<tr>
<td>Usefulness of change</td>
<td>Usefulness, Impact of research, Use of new knowledge</td>
<td>[...] it is important that you will also see the results of what you are doing (nurse, hospice, The Netherlands).</td>
<td></td>
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<tr>
<td>Individual professional level</td>
<td>Attitude</td>
<td>Intrinsic interest, Intrinsic motivation, Decision making process</td>
<td>[...] I say ‘interest’, I don’t know - but maybe it is more interest in end of life care or dementia or whatever and that obviously makes life a lot easier when new initiatives and services are available (nurse, hospice, England). Not all professionals have the proper motivation, time, availability or willingness to involve themselves in something that goes beyond their daily work (psychologist, primary care service, Italy).</td>
</tr>
<tr>
<td>Professional skills</td>
<td>Practitioner autonomy, Placing responsibility, Stepwise introduction of new responsibilities</td>
<td>We [physicians] used to administer the chemotherapy. This has now been completely delegated to the nurses. [...] the doctor became more an observer. [...] the number of patients has increased, so you could not sit there and watch the treatment proceed for 3 hours, so things had to change. The nurses’ competence is much, much more extensive than before (physician, hospital, Norway).</td>
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<tr>
<td>Knowledge</td>
<td>Level of knowledge, Knowledge of palliative care services, (lack of) skills, (lack of) experience</td>
<td>If you only experience 20-25 deaths per year within the entire organisations, it is difficult for the individual nurse to maintain the necessary skills to care for these patients (physician, nursing home, The Netherlands). Nurses need to know what they can improve before they can improve [...] (physician, nursing home, The Netherlands).</td>
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<tr>
<td>Awareness</td>
<td>(lack of) awareness of palliative care</td>
<td>We should make professionals understand that palliative care doesn’t represent the last step [...] (physician, hospice, Italy). Despite all our efforts and education provided, there isn’t a culture about palliative care in everyone yet. For example, it is frustrating when GPs don’t refer their patients to us because they are still conscious (nurse, hospice, Italy).</td>
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### Table 2: Continued

<table>
<thead>
<tr>
<th>Group dynamics</th>
<th>Team climate</th>
<th>(lack of) group support, Culture of change, Fear and avoidance, Participation</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td>The team doesn’t support each other, [...] those who are motivated to change are so few that it is too difficult for them to stand up against those who are against changes (manager, hospice, The Netherlands). We were trained so traditionally that most of the time, the doctors led the meetings. The others who were present just sat there and answered the questions they were asked, instead of considering themselves as equal members of the team with an active role in the meeting (manager/nurse, palliative care unit, Norway). [...] there is an increasing number of services and offers, meaning it is becoming much more complicated [...] (social worker, palliative care unit, Germany). [...] within such a network, people interact who cannot stand each other, but we ask them to do so (physician, nursing home, The Netherlands).</td>
</tr>
</tbody>
</table>

| Network        | Forced network, Knowing other professionals / services, Competition between services | We have a retired GP who is really good, [...] who goes out to see the GPs in [...] that worked really well, he was well regarded in his role. So, of course, him going back to the GPs, they think that’s marvelous, you know, they respect him (nurse, hospice, England). With that colleague I took the time to discuss what the possibilities were and showed him what he could improve. This practical contact really made a difference (physician, hospital, The Netherlands) |

| Professional guidance | Role modeling, Mentoring, Feedback | [...] we need to work a lot with temporary personnel, which brings along the problem that they cannot take part in meetings of quality circles. This means that it is extremely difficult to implement agreed standards (head nurse, primary care, Germany). |

<table>
<thead>
<tr>
<th>Organisational context</th>
<th>Organisational processes</th>
<th>Physical structures, Managing complexity, Extrinsic interest, Use of technology</th>
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</thead>
<tbody>
<tr>
<td></td>
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<td>[...] the hospital itself has changed from being one big building to several big buildings. We used to meet colleagues in the cantina. But now we’re too busy, so we never go to the cantina and if you do, you go to different cantinas, so you don’t meet colleagues like you used to. The lobbying you could do earlier, you can’t do that anymore (physician, hospital, Norway).</td>
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<table>
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<tr>
<th>Organisational structures</th>
<th>Structure of organisation, Place of care</th>
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<tbody>
<tr>
<td></td>
<td>[…] the hospital itself has changed from being one big building to several big buildings. We used to meet colleagues in the cantina. But now we’re too busy, so we never go to the cantina and if you do, you go to different cantinas, so you don’t meet colleagues like you used to. The lobbying you could do earlier, you can’t do that anymore (physician, hospital, Norway).</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff</th>
<th>Staff size, Staff turnover, Availability of staff, Hiring new staff, Depletion of other service,</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>[…] sometimes you have to deal with a culture that is very much dependent on the persons working there. If some of these persons leave, it becomes very difficult to maintain innovations (physician, nursing home, The Netherlands). [...] there are only few people interested in qualifying, choosing this profession is becoming increasingly unattractive [...] (physician, palliative care unit, Germany).</td>
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<table>
<thead>
<tr>
<th>Time</th>
<th>Time constraints, Burden of information</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>[…] so busy with caseload stuff that you haven’t got the time or as much time as you’d like to do that education bit and training (nurse, hospice, England). [...] you are so busy every day that you don’t find the time to meet people (physician, palliative care unit, Norway).</td>
</tr>
</tbody>
</table>
Innovation
Three categories emerged: (1) accessibility of improvement strategies, (2) attractiveness of improvement strategies and (3) usefulness of change.

Accessibility of improvement strategies
Interviewees in Italy, Norway and the Netherlands stated that it is important that improvement strategies (such as education) are arranged in a way that as many professionals of the same team as possible can participate. Professionals in the Netherlands also stated that they perceived restricted access to the improvement strategies as a barrier, for example when the training frequency was low.

Attractiveness of improvement strategies
Professionals in Italy, Norway and the Netherlands considered the attractiveness of improvement strategies important. They stated that the perceived attractiveness of an improvement strategy increases when it is tailored to the needs of the service in question. Interactive educational methods and enthusiasm and motivation of those responsible were considered important contributors to the attractiveness of an improvement strategy. The attractiveness of quality improvement projects was also facilitated by certifying participants for their participation, e.g. for having received education.

Usefulness of change
Perceived usefulness of quality improvement projects was mentioned as an important facilitator by professionals in all countries except England. Professionals...
Table 3: Overview of barriers and facilitators of strategies to improve the quality of palliative care

<table>
<thead>
<tr>
<th>Themes</th>
<th>Facilitators</th>
<th>Barriers*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>EN: Usefulness</td>
<td>DE: Attractiveness</td>
</tr>
<tr>
<td></td>
<td>IT: Accessibility, attractiveness, usefulness</td>
<td>IT: Attractiveness</td>
</tr>
<tr>
<td></td>
<td>NO: Accessibility, attractiveness, usefulness</td>
<td>NO: Attractiveness</td>
</tr>
<tr>
<td></td>
<td>NL: Accessibility, attractiveness, usefulness</td>
<td>NL: Attractiveness</td>
</tr>
<tr>
<td>Innovation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual professional level</td>
<td>Attitude, professional skills</td>
<td>Attitude, knowledge, awareness</td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Team climate, professional guidance, network</td>
<td>Team climate, network</td>
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<td></td>
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<tr>
<td></td>
<td>Professional guidance</td>
<td>Network</td>
</tr>
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<td></td>
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<td></td>
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<tr>
<td></td>
<td>Organisational processes, organisation</td>
<td>Anatomy, professional awareness, structure</td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Financial arrangement, regulations</td>
<td>Regulations</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* For the readability of the table, the ‘lack of’ has been left out in the description of barriers. However, each barrier should be read as if there is a lack of it, e.g. lack of attractiveness, lack of time, etc.

EN: England; DE: Germany; IT: Italy; NO: Norway; NL: The Netherlands
were, for example, more motivated to collect data to measure the quality improvement or use specific tools when these activities benefitted their own clinical practice.

**Individual professional level**

Four categories were related to this theme: (1) professional skills, (2) attitude of professionals, (3) knowledge and (4) awareness of palliative care.

**Professional skills**

The introduction of new professional skills, which are expected to become part of behavioural routines, was mentioned as an important facilitator for the success of quality improvement projects by professionals in all countries but the Netherlands. A Norwegian professional, for example, clarified that the education nurses receive now is much more extensive than it used to be, enabling task delegation from physician to nurse.

**Attitude of professionals**

A positive attitude of professionals regarding improvements was considered an important factor for the success of quality improvement projects by professionals in all countries. Participation in staff training is, for example, facilitated when staff members are motivated and have an interest in the topic. Professionals in England, Germany, Italy and the Netherlands also stated that reluctance of professionals, as well as of organisations, to participate contributes to erroneous beliefs about palliative care, adherence to obsolete routines and may be due to the pressure on the organisation to participate in many improvement projects.

**Knowledge and awareness of palliative care**

Knowledge and awareness of palliative care were mentioned by professionals in Germany, Italy, Norway and the Netherlands. Professionals in Italy, for example, described that there is a general lack of awareness about palliative care, and professionals in the Netherlands stated that their managers considered palliative care unimportant, because they were not aware of what palliative care actually is. However, they also stated that by improving their knowledge, their motivation and interest to change increased.

**Group dynamics**

Three categories emerged: (1) professional guidance, (2) team climate and (3) participation in a network.

**Professional guidance**

Professionals in England, Norway and the Netherlands mentioned that professionally guiding people in their practice and performance, such as role-modelling and mentoring, has a positive effect on their performance, and was therefore perceived as facilitator for many change strategies.
Barriers and facilitators to change

Team climate
The importance of a positive team climate was mentioned by professionals in Germany, Italy, Norway and the Netherlands. Top-down implementation, for example, was not considered to be effective. A well-balanced team with the involvement of staff in decision making regarding implementation of changes was in general considered more effective. Also, several interviewees reported that some of their colleagues were reluctant to change, which decreased the motivation of the team to change. Existing norms and values which were difficult to change were the underlying reasons for this reluctance. In the Netherlands, being involved in too many improvement projects at the same time was perceived as an exhausting factor for the team.

Participation in a network
Being part of a palliative care network was an important facilitator in Italy, Norway and the Netherlands. Professionals involved in a network mentioned that it helped them to know other professionals in their organisation, making it easier to initiate quality improvement projects. However, participation in networks was also perceived as a barrier since issues of collaboration and communication took up too much time at the expense of other improvement strategies (in Norway), involved cooperation with people that sometimes was perceived as difficult (in the Netherlands) and resulted in competition between services to get funded (also in the Netherlands).

Organisational context
There are four categories in this theme: (1) organisation of care processes, (2) organisational structure, (3) availability of staff and (4) availability of time to implement improvement strategies.

Organisation of care processes
Professionals in England, Germany, Italy and the Netherlands stated that it is easier to implement changes when they are in harmony with the general principles of care of their institution. It was also mentioned that having access ‘to the right people’ (e.g. management) made it easier to initiate quality improvement projects.

Organisational structure
The infrastructure of a service (e.g. physical and spatial structure of the building where it is located but also the hierarchical structure of the organisation) was mentioned as a barrier by German, Norwegian and Dutch professionals. For example, spending too much time travelling within or between buildings and a shortage of facilities such as rooms for educational activities, were perceived as barriers.

Availability of staff
Staff shortages were especially experienced in England, Norway and the
Chapter 5

Netherlands. Not having enough staff to allow training without disruption of clinical care created difficulties in improving the organisation of palliative care. High staff turnover results in a never-ending need for training while the services do not have the resources to supply this demand, resulting in professionals having little time to update themselves professionally. However, in services with extra financial resources, hiring extra staff to work shifts for the permanent employees, facilitated their participation in educational sessions. Norwegian professionals commented that recruiting experienced personnel is a rather quick way of increasing palliative care expertise amongst staff. However, they also stipulated that this is not always a good solution since it will deplete other services.

**Availability of time**

Lack of available time to participate in improvement projects was perceived as an important barrier in all countries, but mentioned from two perspectives. Firstly, professionals are faced with extreme time constraints in their clinical work, which limits their availability for training, participation in improvement projects and keeping up to date with new knowledge. Secondly, quality improvement projects may require strategies that take a considerable amount of time to implement, which consequently puts an additional burden on the professionals and organisation. In Germany, lack of time was also considered a facilitator if the innovation would result in saved time, as it helped to focus on the benefits of change.

**Local political-economic context**

Two categories emerged: (1) financial arrangements and (2) effective organisational regulations.

**Financial arrangements**

In all countries, interviewees mentioned that extrinsic financial incentives are crucial for the effectiveness of implementation strategies designed to promote service improvement. For example, there has been a lack of recruitment in services in England and Norway due to financial barriers, because specialist staff were considered too expensive. Financial constraints also resulted in truncation of quality improvement projects, limiting their effect.

**Organisational regulations**

Interviewees in all countries except for Germany reported that they experienced existing regulations on a national, regional and local level both as a facilitator as well as a barrier to changing practice. Professionals considered them a facilitator because clear organisational regulations facilitated participation in quality improvement projects and ensured the quality of care. However, interviewees in the Netherlands perceived them as a barrier because new regulations caused them a lot of extra work. In Italy, some professionals mentioned that the fixed number of certain staff in nursing homes (e.g. not enough staff in relation to the
number of patients) negatively affected their work and consequently the success of improvement projects. Professionals in England and Norway also mentioned that policies and guidelines in place to protect patient information can, for example, also limit the use of innovative quality improvement strategies, such as the use of an electronic patient file.

Discussion

This study identified barriers and facilitators to improve the organisation of palliative care. They could be arranged in five themes as described by Grol, being the innovation itself, the individual professional level, group dynamics, the organisational context and the local political-economic context. All themes appeared to be related to structures and processes of care, as described in the Donabedian Model. Although the barriers and facilitators differ in scope, context, strength and provenance, most of them were shared by professionals from different European countries. However, when comparing barriers and facilitators cross-nationally, differences in the provision of palliative care should be considered. For example, the national health-care system and organisation of palliative care differs in the five participating countries. As shown elsewhere, all five countries have legislation about palliative care. Despite broadly similar legal frameworks, access to palliative care services differs between countries.

There are, for example, cultural barriers in Italian society that refrain patients from receiving adequate and timely palliative care. Although such barriers were not reported by professionals in the other countries, some of them experienced a lack of awareness, but then primarily caused by a lack of knowledge about palliative care of their superiors. Furthermore, the availability of palliative care services also differed between countries. However, even though, hospices are not available in Norway and Italy does not have palliative care units in hospitals, patients receive palliative care in other types of services, whereby most services provide palliative care in agreement with the World Health Organisation’s definition of palliative care.

Differences were found not only between countries but also within countries, such as regional or setting-specific regulations. Sometimes, the same aspect appeared to be a facilitator in one service and a barrier in another. In the Netherlands, for example, networking was considered a facilitator in one service as it resulted in knowing other professionals, but a barrier in another service, as economic regulation caused competition between services.

Despite these national differences, it appeared that similar barriers and facilitators regarding the organisation of palliative care existed in different countries. For example, team climate was mentioned as an influential factor by professionals in all countries but England, and organisational processes were mentioned by professionals in Germany as well as in the Netherlands. Financial resources and
a positive attitude to change were mentioned by professionals in all countries, suggesting that, for example, sufficient funding and the motivation of staff are a prerequisite to change. Facilitators that were mentioned as a barrier when absent (e.g. attractiveness of improvement strategies) could also be considered as an essential requirement to change.

Several facilitators identified in this study are comparable to those found in other studies in healthcare, like flexibility of timing educational sessions, enthusiastic and active initiators and intrinsic motivation of the team members. Comparable barriers are lack of awareness, lack of training and guidance, fear of change, time constraints, staff shortages, lack of funding and lack of adherence to guidelines. The factors identified in our study are therefore not unique to palliative care, but it appears that there are similarities between the organisation of care in different services and countries. Even though the factors may not be unique, the combination of them is relevant because of the complexity of palliative care. Patients in need of palliative care, for example, have multiple problems and symptoms resulting in changing (and often increasing) needs for treatment and support. Consequently, they receive care from a variety of professionals in different types of services. This requires multidisciplinary teamwork and a good division of tasks and responsibilities. However, the multidisciplinary approach in palliative care is also what makes it more difficult to change the organisation of palliative care. In our study, a Norwegian interviewee, for example, pointed out that because staff were trained so traditionally, physicians led the team meetings, while the other staff present did not participate. West et al. described ‘participation safety’ as defined by the extent to which a team participates in making decisions and whether team members feel psychologically safe in proposing new ideas, as a factor that can influence teamwork. In this case, ‘participation safety’ was not possible because of the attitude of the nurses and the social pressure of the physicians. Together with self-efficacy, attitude and social-influence are the main determinants of the ASE-Model (Attitude, Social-influence and self-Efficacy), which in itself is derived from the theory of planned behaviour. Knowing these determinants can facilitate adaptation of improvement strategies in order to achieve the planned behaviour of the nurses. However, only few implementation models translating the results of research into clinical routines recommend to perform a detailed analysis of barriers and facilitators before starting the intervention. For example, the widely used framework for the development and evaluation of complex interventions to improve health of the UK Medical Research Council, does not consider such uncertainties until the pilot testing of the intervention. The PDSA-cycle (Plan-Do-Study-Act) does not even explicitly mention a barriers and facilitators analysis. Although most implementation studies refer to one of these models, only few studies actually perform a barrier and facilitator analysis before starting to implement an intervention. The barriers and facilitators identified in this study will be used in the IMPACT project to tailor country and setting-specific intervention strategies to improve the organisation of
palliative care in 40 services across Europe.

Strengths and limitations
A strength of this study is that it is a large study, conducted with individual and focus group interviews in five European countries. Professionals working in the field of palliative care in hospitals, hospices, primary care settings and nursing homes were included. The results of our study can therefore be used in a variety of services, addressing not only patients with cancer, but also patients with dementia in need of palliative care. A limitation of this study is that the interviews were conducted in five different languages. Although a common format was used for transcription and translation and meanings were reviewed in consensus meetings, different native languages may have caused differences in interpretation. Second, the aim of this study was to identify barriers and facilitators to improve the organisation of palliative care in different European countries. A second limitation is therefore that factors shaping strategies for service changes may be system-specific and not identified in our sample.

Conclusion
This study identified barriers and facilitators to organisational change in palliative care. Some of these barriers and facilitators were experienced by professionals in almost all countries and are therefore prerequisites to change. In order to promote successful implementation of change, it is important to tailor an organisational improvement to the needs of individuals and organisations. Understanding the barriers to and facilitators of change is essential for such tailoring.
References

Barriers and facilitators to change


29. West MA. The social psychology of innovations in groups. In Innovations and creativity at work: Psychological and Organizational Strategies. Edited by West MA, Farr JL. Chishester: John Wiley and Sons; 1990: 309-333


## Interview guide

<table>
<thead>
<tr>
<th>Theme</th>
<th>Aim</th>
<th>Questions / probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Identifying known improvement strategies</td>
<td>To identify strategies that have been recently used to improve (the organisation of) palliative care in the particular setting.</td>
<td>Tell me about the organisation you are in. Probes: • How does the organisation differ from the organisation in the past? • Can you give an example... • What was changed • How was it changed</td>
</tr>
<tr>
<td>2. Identifying barriers and facilitators</td>
<td>To identify factors (barriers and facilitators) that influence strategies to improve palliative care in the setting.</td>
<td>What are barriers/is helpful to improvement strategies used in your setting to improve palliative care? Probes: • Can you tell more about... • How does that influence daily work? • Can you give examples... • What is your experience with... • Are there any other influencing factors you can think of?</td>
</tr>
<tr>
<td>3. Identifying potential strategies</td>
<td>To identify potential (future) strategies to improve the organisation of palliative care in the setting, taking the factors that influence the provision of palliative care into account.</td>
<td>So what are you going/do you like to do next in your service? Probes: • Why this strategy? • Can you think of the consequences of such a strategy being used? • What do you need to improve palliative care? • Would [example strategies] work in your setting? If so why?; If not why?</td>
</tr>
<tr>
<td>4. Supplement</td>
<td>To identify important aspects in the provision of palliative care that have not been discussed yet.</td>
<td>What do you think is really good? If you can recommend to other settings or countries a strategy to improve palliative care that works well in your setting, what would that be? If you can think of existing strategies to improve palliative care that you wouldn’t recommend to other settings or countries, what would that be? Is there anything else you would like to discuss?</td>
</tr>
</tbody>
</table>
# Appendix 2

## Researcher information

<table>
<thead>
<tr>
<th>Country</th>
<th>Researcher</th>
<th>Professional Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>ND</td>
<td>Researcher (PhD student) at University College London, with a professional background in psychology. Responsible for the interviews and analysis in England.</td>
</tr>
<tr>
<td>Germany</td>
<td>BJ</td>
<td>Senior researcher at the Universities of Bonn and Göttingen, with a professional background in philosophy. Responsible for the interviews and analysis in Germany.</td>
</tr>
<tr>
<td>Italy</td>
<td>EM</td>
<td>Researcher at the University of Bologna, with a professional background in psychology. Responsible for the interviews and analysis in Italy.</td>
</tr>
<tr>
<td>Norway</td>
<td>RS</td>
<td>Researcher (PhD student) at the Norwegian University of Science and Technology, with a professional background in sociology. Responsible for the interviews and analysis in Norway.</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>JvRP</td>
<td>Researcher (PhD student) at the Radboud university medical center, with a professional background in health sciences and nursing. Responsible for the interviews and analysis in the Netherlands, and for the comparison of data between countries.</td>
</tr>
</tbody>
</table>
Strategies to implement evidence into practice to improve palliative care: recommendations of a nominal group approach with expert opinion leaders

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Steve Illife
Lukas Radbruch
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Rabih Chattat
Myrra Vernooij-Dassen
Yvonne Engels
Abstract

Background: In the past decades, many new insights and best practices in palliative care, a relatively new field in healthcare, have been published. However, this knowledge is often not implemented. The aim of this study therefore was to identify strategies to implement improvement activities identified in a research project within daily palliative care practice.

Methods: A nominal group technique was used with members of the IMPACT consortium, being international researchers and clinicians in cancer care, dementia care and palliative care. Participants identified and prioritised implementation strategies. Data was analysed qualitatively using inductive coding.

Results: Twenty international clinicians and researchers participated in one of two parallel nominal group sessions. The recommended strategies to implement results from a research project were grouped in five common themes: 1. Dissemination of results e.g. by publishing results tailored to relevant audiences, 2. Identification and dissemination of unique selling points, 3. Education e.g. by developing e-learning tools and integrating scientific evidence into core curricula, 4. Stimulation of participation of stakeholders, and 5. Consideration of consequences e.g. rewarding services for their implementation successes but not services that fail to implement quality improvement activities.

Discussion: The added value of this nominal group study lies in the prioritisation by the experts of strategies to influence the implementation of quality improvement activities in palliative care. Efforts to ensure future use of scientific findings should be built into research projects in order to prevent waste of resources.
Background

Palliative care is an approach that aims to improve the quality of life of patients facing problems associated with life-limiting illnesses, and their relatives\(^1\). A growing numbers of new insights and best practices in palliative care are being disseminated via scientific publications and presentations, yet they are often not implemented in daily practice\(^2\). Failure to implement research findings leads to bias, unnecessary duplication of studies and suboptimal patient outcomes\(^3,4\). In the USA, for example, only about 55% of the patients received recommended care\(^5\).

Chalmers et al. state that about 85% of the global annual investment in biomedical research is currently wasted\(^6\), even though effective strategies and models for stepwise implementation of new evidence exist. Examples of such strategies and models include the UK Medical Research Council’s framework for the development and evaluation of complex interventions to improve health\(^7\), the Plan-Do-Study-Act cycle\(^8\), or the stepwise implementation model of Grol et al.\(^2\). Yet the use of such implementation models is often restricted to the time frame after a research project closes. It is a challenge to continue implementation of new evidence and best practices in daily clinical practice after the research or implementation project has been completed, and it is not always seen as the role of researchers\(^4\).

An example of such a project is IMPACT (Implementation of quality indicators in Palliative Care Study). In this EU funded 7\(^{th}\) Framework project, quality indicators (QIs) for the organisation of palliative care were developed, and used to assess and improve the organisation of 40 palliative care services across Europe\(^9\). The results and tools of this project, even though it is built around implementation may not be further disseminated, adopted and implemented as soon as IMPACT finishes, without further action.

The aim of this study was to identify strategies that can facilitate the implementation of scientific output to improve the organisation of palliative care after a large research project like IMPACT has ended.

Method

A nominal group technique was used. This technique follows a structured and evaluative methodology, developed to facilitate group or team decision making\(^10\). As such, they can be used to analyse healthcare problems\(^11\), and bridge the gap between researchers and healthcare professionals\(^12,13\). A nominal group differs from focus group interviews as these are often used to explore what individuals believe or feel as well as why they behave in the way they do\(^14\).

Participants

Participants were members of the IMPACT consortium, all internationally (European) recognised researchers and clinicians (including physicians, nurses,
social workers and psychologists) in cancer care, dementia care and palliative care, including (former) board members of the European Association of Palliative Care (EAPC - http://www.eapcnet.eu/) and of Interdem (http://www.interdem.org), an international research group on early detection and timely intervention in dementia. Participants were divided by profession and field of interest to create two groups of similar size and with an equal balance of clinicians and researchers. All participants were aware of the results of the IMPACT project prior to the nominal group sessions, which were: a generic model of palliative care, a set of quality indicators to evaluate the organisation of palliative care, strategies to improve the organisation of palliative care, and an overview of barriers and facilitators of such improvement strategies. At the start of the nominal group sessions, all participants were asked for their consent to participate.

**Conduct of the groups**

Both nominal groups were conducted during the annual consortium meeting of the IMPACT project, one day before the EAPC research congress in Lleida (Spain) in June 2014.

Both nominal groups were led by an experienced moderator (YE and MVD, coordinators of the IMPACT project), and an observer was present in each group to take notes. To ensure comparability of the two nominal groups, the moderators discussed the protocol of the nominal group approach prior to commencing the nominal group sessions. As a first step, the moderators invited group members to individually write down strategies for implementing the results of a research project (such as IMPACT) in daily practice, with no limit to the number of strategies. Secondly, the moderators asked each group member to list the strategies in order of importance. These strategies were documented on a flipchart (or laptop and projector) in full view of all participants. Subsequently, the moderators invited the other group members to react to these strategies in order to initiate a discussion. During these discussions, common themes were identified, which allowed the moderators to combine overlapping strategies. When all participants had mentioned their strategies and no further discussion was necessary, the moderators invited each participant to rank their five most important themes (1 being the most important and 5 the least important) and subsequently the feasibility of each theme (1 being most feasible and 5 least feasible). Feasibility was defined as the likelihood that the theme can be operationalised as concrete actions. The ratings provided by the participants were again documented in full view of all participants.

**Analysis**

Data resulting from the nominal group technique was analysed using a qualitative approach. In order to merge the recommendations mentioned by participants in the two nominal group sessions, all items mentioned by the participants were independently coded and subsequently compared by two researchers (JRP and YE). They discussed the codes until consensus was reached. When no consensus
could be reached, a third researcher was consulted. When all items were coded, categories and themes were derived from the codes. As participants ranked their five most important strategies, this helped in identifying top themes.

**Ethical considerations**

The Medical Ethics Committee of the district Arnhem-Nijmegen has declared that this study does not fall within the remit of the Medical Research Involving Human Subjects Act (registration number 2012/075). This means that this study could be carried out without an approval by an accredited medical ethics committee.

**Results**

Twenty participants took part in the nominal group (table 1).

In one nominal group, 21 potential strategies were mentioned and in the second nominal group 31. These strategies could be ranked and combined into the following themes (table 2):

**Dissemination of the results**

Participants considered conferences, and in particular publications tailored to specific audiences, to be important. For example, results should also be published in ‘policy language’ for policy makers, ‘professional language’ in newsletters of
professional scientific organisations and in ‘laymen language’ for the general public (e.g. by using social media).

**Unique selling points**
Participants considered a unique selling point or sales pitch a prerequisite to promote quality improvement activities to services. They argued that quality improvement activities should highlight those aspects that are unique, known to be attractive or solve a problem or barrier. Secondly, participants also considered the collaboration between researchers and clinicians an important unique selling point, as this already shows that clinicians have been involved from the start.

**Educational activities**
In both nominal groups, participants mentioned using specific e-learning tools as well as mass-learning (e.g. YouTube) for dissemination. They also suggested integration of training activities with daily routines and inclusion of quality improvement activities with the core curricula used by teaching staff.

**Participation of stakeholders**
Participants mentioned that it is important to involve different types of stakeholders (patients, professionals, policy makers, insurers and funders). Professionals of a (scientific) organisation can, for example, acknowledge quality improvement

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**Table 2: Strategies mentioned by the participants of both nominal group sessions (themes and categories)**

<table>
<thead>
<tr>
<th>Dissemination of the results</th>
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<tbody>
<tr>
<td>Presentations at conferences</td>
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<tr>
<td>Publications (e.g. in scientific peer-reviewed journals, in professional journals, via policy channels but also (international) professional organisations, newspapers)</td>
</tr>
<tr>
<td>Social media (e.g. websites, YouTube, Twitter)</td>
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<table>
<thead>
<tr>
<th>Unique selling points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sales pitch (focus on facilitating factors / preconditions/ user friendliness/ visibility)</td>
</tr>
<tr>
<td>The impact of using unique selling point/strategy/sales pitch</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integration of training activities into daily scheme</td>
</tr>
<tr>
<td>User friendly format (e.g. e-learning modules, mass learning via YouTube, downloadable slides)</td>
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<tr>
<td>Train the trainer</td>
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<table>
<thead>
<tr>
<th>Participation of stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expert organisations (e.g. those responsible for implementation)</td>
</tr>
<tr>
<td>Patients, relatives, professionals and policy makers</td>
</tr>
<tr>
<td>Healthcare insurers and funders</td>
</tr>
<tr>
<td>Early adopters: staff in pilot services</td>
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<tr>
<th>Consideration of consequences</th>
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</thead>
<tbody>
<tr>
<td>Rewards (e.g. financial, certificates)</td>
</tr>
<tr>
<td>Negative consequences (e.g. no accreditation)</td>
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</tbody>
</table>
Recommended strategies to implement evidence activities and include them in their protocols. Therefore, it is important to identify those stakeholders who can and will contribute to quality improvement activities. Participants suggested using local expert organisations, but also ‘early adopters’ derived from the network of the services itself.

**Consequences**

Participants mentioned that services can be stimulated to implement quality improvements when they are rewarded for their activities, for example with certificates of best practice. However, they also stated that quality improvement activities require commitment from the service. Services can therefore also be held responsible for failure to implement quality improvement activities. For example, participants suggested threats to the accreditation of services as a sanction for not implementing quality improvement activities.

The strategies mentioned by the participants of both nominal groups led to the following recommendations about implementation strategies to improve the organisation of palliative care (table 3).

**Discussion**

This study identified specific strategies to implement the results of research projects in the field of palliative care. The nominal group technique allowed international clinicians and researchers to prioritise five common themes: dissemination of the results, unique selling points, educational activities, involvement of stakeholders and the consideration of consequences. These strategies are in line with those found in literature\(^4,17-21\). For example, in an overview by Grol and Grimshaw\(^18\), in which they included 54 reviews about the effectiveness of different interventions to change clinical practice, they described dissemination activities, educational activities and financial interventions. In another overview, Grimshaw et al. described educational activities as well as

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**Table 3: Recommendations based on the strategies to facilitate implementation**

- Publish results regarding the implementation of quality improvement activities tailored to its audience (e.g. patients, professionals caregivers, policy makers and researchers)
- Identify and disseminate unique selling points to implement quality improvement activities
- Develop e-learning tools (e.g. via YouTube)
- Integrate scientific evidence into the core curricula (of practitioner disciplines)
- Stimulate the active participation of important stakeholders to engage and initiate quality improvement activities (e.g. professional (scientific) organisations)
- Reward services that successfully implemented quality improvement activities (e.g. financial incentive)
- Restrict services that provide suboptimal palliative care and do not implement quality improvement activities (e.g. no accreditation)
disincentives. In a review, Giguere et al. described the effect of different strategies using printed educational materials. In a report for the Danish Institute for Health Services Research and Development, Thorsen et al. described dissemination strategies, educational activities and incentives and sanctions. And in his ‘Diffusion of Innovations’, Rogers described the involvement of stakeholders. However, several of the strategies identified have yet to be applied to improve daily clinical practice. For instance, identifying the unique selling points of studies, and using negative consequences for services are methods that are not frequently used. As for negative consequences, in the USA the Centers for Medicare & Medicaid Services applied financial penalties to hospitals that did not improve their hospital acquired infection rate, and as a result infection rates declined in many hospitals. Regarding the participation of stakeholders, it is known that ‘early adopters’ are important: Rogers described that they show a high degree of innovativeness, are a role model for others and help trigger the critical mass when adopting an innovation. But ‘early adopters’ hardly appear to be used when introducing changes into daily clinical practice.

Participants also considered the social media as agents of change that could be used more often. However, various healthcare organisations, scientific journals, researchers and healthcare professionals use different kind of social media to communicate about palliative care and disseminate new evidence into daily clinical practice. Examples are the EAPC blog (https://eapcnet.wordpress.com/) and reviews of palliative care services (such as available for the Netherlands: https://palliatief.tevreden.nl/). Furthermore, palliative care knowledge networks (such as CareSearch in Australia: http://www.caresearch.com.au/) can contribute to the dissemination and implementation of new evidence in daily clinical practice.

The added value of our study is that all these strategies have been considered together and prioritised by experts.

Surprisingly, de-implementation and mandating quality improvement projects were not mentioned. De-implementation, meaning stopping ineffective or harmful interventions is particularly important as there are many suboptimal forms of care in use. In palliative care, for example, the use of artificial hydration was recently discussed in a paper by Nakajima et al. They showed that artificial hydration did not improve dehydration symptoms, quality of life, or survival in terminally ill cancer patients. The continuation of such ineffective and sometimes even harmful medical practices is undesirable and may result in rising healthcare costs in addition to the increased burden on patients and care givers. Mandating quality improvement projects is important because without the full support of the scientific and professional organisations, the implementation of quality improvement projects will not progress.

However, as the participants in our study emphasised, using only one strategy to implement quality improvement activities in daily clinical practice is not sufficient. Participants recommended, in line with Grol and Grimshaw, the use
of a combination of strategies. It appears to be important that, for each quality improvement activity a theoretically grounded structured procedure, like the framework for the development and evaluation of complex interventions of the UK Medical Research Council\(^7\), the Plan-Do-Study-Act cycle\(^8\), or the Stepwise Implementation Model of Grol et al.\(^2\), is used. These implementation models facilitate both researchers and professionals in a step-by-step guide to implement evidence based best practices into daily clinical routine. Such models also may provide users with a detailed description of the current situation, preferred situation, reasons why the preferred situation has not been reached, factors that could be used to reach the preferred situation, etc. This information facilitates the development of specific actions necessary to initiate change. For example by following the steps described in the theory of planned behaviour or behaviour change wheel\(^{27,28}\). The recommendations stipulated in this paper can be used to tailor quality improvement activities specifically for palliative care. For example one of the recommendations has already been carried out by organising the Palliative Care 2020 conference at which stakeholders were invited to discuss the future of palliative care in Europe and which resulted in the European Declaration on Palliative Care\(^{29}\).

**Strengths and limitations**

Strengths of this study were that the IMPACT consortium consisted of an international, multiprofessional group of professionals (including nurses, physicians, social workers and researchers). The mix of researchers with a background in implementation science, professionals active in daily clinical practice and members involved in national policy making, facilitated the identification of optimal implementation strategies. This study allowed the members of the IMPACT consortium to think about future implementation strategies while the study was still ongoing. However, this also shows a limitation of this study; as no patients or informal caregivers were involved.

**Conclusion**

Research projects generate a growing amount of new knowledge. Often this new knowledge is not implemented in daily practice, particularly in an environment as complex as palliative care. Timely efforts should be made to ensure that the future application of scientific findings is integrated into the research itself, to prevent wasting resources and as an endpoint for better healthcare for patients. The recommendations reported here may be of particular use in promoting quality improvement activities in palliative care. Important stakeholders, such as scientific and professional organisations and leaders on the level where the actual implementation takes place, can perform a key role in the wider implementation of new evidence.
Chapter 6

References

Identification of the palliative phase in people with dementia: a variety of opinions between healthcare professionals

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Abstract

Background: People with dementia can benefit from a palliative care approach. Recommendations, such as those of the EAPC have been proposed to strengthen the provision of palliative care for this group of patients. Yet, it remains challenging for professionals to identify when a person with dementia is in need of palliative care. The objective of this study therefore was to explore when professionals in long-term care settings consider a person with dementia in need of palliative care.

Methods: Teams with in total 84 professionals working in 13 long-term care settings from 6 countries (France, Germany, Italy, Norway, Poland and the Netherlands) received a case-vignette concerning a person with dementia recently admitted to a nursing home. Teams were asked to discuss when they considered people with dementia eligible for palliative care. The constant comparative method was used to analyse their answers.

Results: Three different time points in the disease trajectory when people with dementia were considered to be eligible for palliative care were extracted: (1) early in the disease trajectory; (2) when signs and symptoms of advanced dementia are present; and (3) from the time point that curative treatment of co-morbidities is futile. Yet, none of these time points was uniformly considered by the professional teams across Europe. In some cases, professionals working in the same nursing home didn’t even reach consensus when considering persons with dementia eligible for palliative care.

Conclusion: The results of the study identified that professionals across Europe have different opinions regarding the time point when to consider a person with dementia in need of palliative care.
Background

Worldwide, about 36 million persons have dementia\(^1\). People with advanced stages of dementia have complex physical and psychological needs\(^2,3\). Many suffer from symptoms such as pain, agitation, dyspnea, neuropsychiatric symptoms and depression\(^4\), which threatens the quality of their lives as well as that of their relatives. Appropriate palliative care can deal with the needs and preferences of people with dementia and their families\(^5\). However, access to palliative care services for people with dementia is less defined than for patients with cancer\(^5\). Professionals in dementia care often lack the necessary skills to anticipate the changing palliative care needs of a person with dementia\(^5-7\). Therefore, people with dementia are more frequently hospitalised and too often receive burdensome interventions\(^8\). Moreover, compared to patients with other life-threatening diseases, they are less likely to receive advance care planning\(^6\), are less frequently referred to palliative care teams or hospice care\(^6\) and more often experience symptoms for a longer period of time\(^9\).

Dementia is more and more acknowledged as a life-threatening disease\(^5\). Time from diagnosis until death varies from two to 20 years\(^2,10\). This protracted course of dementia makes it difficult for persons with dementia and their families, as well as for professionals to discuss end-of-life issues, such as advance treatment decisions, preferred place of care and death or lasting power of attorney\(^2,4,5\). Consequently, people with dementia are often not involved in discussions about preferences and needs early in the disease\(^11\), when their cognitive impairment does not yet impede their participation in the decision-making process.

Recently, the European Association for Palliative Care published a white paper on defining palliative care in dementia\(^12\). One of the recommendations is to consider the time point of the diagnosis of dementia as the starting point of palliative care\(^12\). However, there is still an ongoing discussion on the identification of the palliative phase in dementia. Besides, people with dementia have unequal access to palliative care services compared to patients with cancer\(^13\). Therefore, the aim of this study was to explore when professionals in long-term care (LTC) facilities across Europe consider a person with dementia in need of palliative care.

Methods

The EU-funded Seventh Framework IMPACT project (IMplementaton of quality indicators in PAlliative Care sTudy) aims to develop and tailor national and setting-specific strategies to improve the organisation of palliative care in several European countries. As part of this study, a pre-post test was conducted in 40 services across Europe to assess the organisation of palliative care of long-term care settings, in which also a case-vignette was used. Case-vignettes have been used in a variety of settings\(^14-18\), and they offer a promising alternative for the assessment of the
performance of healthcare professionals. Case-vignettes consist of ‘text, images or other stimuli to which research participants are asked to respond’\textsuperscript{16}. In this study, the case-vignette was created in a way that it explicitly excluded clinical details of the depicted subject (e.g. about the prognosis, symptoms, etc.) in order to stimulate discussion. The present paper presents the results of the case-vignette about identifying the palliative phase in people with dementia.

**Case-vignette**
Specific characteristics of a person with dementia were drafted by a general practitioner (Professor of Primary Care for Older People, SI), and used to develop a case-vignette in English. The case-vignette was presented to the IMPACT project team (consisting of 14 clinicians and researchers). After having fine-tuned the concept case-vignette with their feedback (table 1), the English case-vignette was translated into the local languages of the participating countries involved in the project, using a forward-backwards translation. Subsequently, researchers were asked to pilot test the translated case-vignette with at least two professionals in their country. These professionals were asked to evaluate the comprehensiveness and clarity of the vignettes.

<table>
<thead>
<tr>
<th>Table 1: Case-vignette of a person with dementia.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mrs. White is 83 years old. She has been married for 56 years to Charles. They have one child, Lucy, who is 47, and who keeps in regular contact with them.</td>
</tr>
<tr>
<td>Mrs. White was diagnosed with dementia about 9 years ago. Until recently, she lived with her husband in a house in the country. Because Mrs. White can get quite aggressive when she does not understand what is going on, her husband can no longer deal with her at home. Therefore Mrs. White recently moved to a nursing home.</td>
</tr>
<tr>
<td>Question: Please explain if and when you would consider Mrs. White as a person in need of palliative care?</td>
</tr>
</tbody>
</table>

**Setting and participants**
At least two LTC settings for people with dementia were purposefully selected per country. These LTC settings had to have at least one year of experience in the provision of palliative care. Each of the selected LTC settings recruited members from their multidisciplinary team (table 1). Selection criteria for these team members were being involved in direct patient care or, at least, having knowledge of direct patient care. In each setting, one professional was appointed by the researchers as contact person.
Data collection

The multidisciplinary teams participated in a meeting in which the case vignette was presented. In each setting, the contact person chaired this meeting. This person was instructed about the purpose of the meeting. The participants did not receive a definition of palliative care as this would have biased the results. In this study, participants were stimulated to share their own definitions and clinical perceptions about palliative care. Participants were also instructed to consider the depicted person as one of their own residents and were asked: ‘Please, could you explain if and when you would consider Mrs. White as a person in need of palliative care?’ Instructions also stated that consensus within the multidisciplinary team was not important; different opinions could exist. Within each multidisciplinary group, the chair person summarised and documented the answer(s) according to a predefined template divided into three main sections: job titles of participants; outcomes of the discussion; observational analysis of the discussion process. The chair person was asked to translate the answers into English and to provide detailed information about the process how they came to their answers (e.g. specifying if there was immediate consensus, whether there was a long discussion, if requests of clarifications occurred and reactions of the participants ). Subsequently, the chairpersons submitted their answer(s) as open text into an online data-registration tool (a web-based data registration tool based on LimeSurvey). If any of the information was unclear, the chair person was contacted to provide further explanations.

Analysis

In each non-English country, the researcher translated the answers of the vignette into English. Two researchers (JvRP and EM) independently coded the data by using a constant comparative method\(^9\). First, each researcher conducted the comparison within single interviews, developing and labeling categories with appropriate codes in order to outline the core concepts of the interviews. Second, a comparison between interviews was conducted, combining the codes in clusters, in order to define the concepts and identify similarities and differences between interviews\(^9\). The two researchers discussed their codings until consensus was reached. Regular contact (face-to-face, by Skype and by email) was used during the analysis to refine codes and to group the codes into unique categories. When no consensus could be reached, a third researcher was consulted (YE). Themes and categories were regularly fed back and discussed with two other authors (MVD and YE).

Ethical considerations

The Medical Ethics Committee of the district Arnhem-Nijmegen has declared that this study doesn’t fall within the remit of the Medical Research Involving Human Subjects Act (WMO) (registration number 2012/075). This means that this study can be carried out without an approval by an accredited medical ethics committee.
Results

Thirteen nursing homes in six European countries (France, Germany, Italy, Norway, Poland and the Netherlands) participated in the vignette study. In all nursing homes, the staff were responsible for the provision of palliative care. In Germany, Poland and one Dutch nursing home, staff had 24/7 accessibility to specialist services, whereas in the other nursing homes this fluctuated between working hours only to none at all. In one German, the Italian and Dutch nursing homes, an end-of-life care pathway was commonly used for the last three days of life of a person in need of palliative care.

In total, 84 professionals took part in the multidisciplinary team discussions (Table 2). Professionals in nine nursing homes considered Mrs. White in need of palliative care (Table 3). In four nursing homes, professionals stated that Mrs. White was not in need of palliative care. The multidisciplinary team reached consensus on their view when to consider Mrs. White in need of palliative care in ten nursing homes. The opinions of the multidisciplinary teams varied so much in the remaining three nursing homes, that they were not able to reach consensus during the discussion of the vignette.

The reasons why the multidisciplinary teams did or did not consider Mrs. White in need of palliative care varied and could be grouped into three categories representing different attitudes of staff members on the entry point for palliative care: (1) palliative care starts early in the disease trajectory, (2) palliative care starts when signs and symptoms of advanced dementia are present, and (3) palliative care starts when curative treatment for co-morbidities is no longer possible.

| Table 2: Participating professionals per nursing home |
|-----------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|-------|
|                | DE-1 | DE-2 | FR-1 | FR-2 | IT-1 | IT-2 | IT-3 | NO-1 | NO-2 | NL-1 | NL-2 | PL-1 | PL-2 |
| Physician       | -    | -    | 1    | 1    | 1    | 1    | -    | -    | -    | 1    | 1    | -    | -    | -    | -    |
| Nurse           | 3    | 2    | 1    | 1    | 1    | 1    | 1    | 6    | 3    | 5    | 2    | 3    | -    | -    | -    | -    |
| Healthcare assistant | 4  | 2    | 1    | 3    | 1    | 1    | -    | 3    | 1    | 3    | -    | -    | -    | -    | -    | -    |
| Psychologist    | -    | -    | -    | -    | 1    | 2    | -    | -    | -    | -    | -    | -    | 1    | 1    | -    | -    |
| Social worker   | -    | -    | -    | -    | -    | -    | -    | -    | -    | -    | 1    | -    | -    | -    | -    | -    |
| Other           | -    | -    | 2    | 5    | 3    | 2    | 4    | -    | -    | 1    | -    | 1    | 3    | -    | -    | -    |
| Total           | 7    | 4    | 11   | 7    | 7    | 6    | 5    | 7    | 6    | 5    | 6    | 8    | -    | -    | -    | -    |

DE: Germany, FR: France, IT: Italy, NO: Norway, PL: Poland, NL: the Netherlands

Palliative care should start early in the disease trajectory

Professionals in a German nursing home (DE-2) unambiguously agreed that Mrs. White was a person in need of palliative care from the day she moved in. A similar answer came from an Italian nursing home (IT-2), whereby some professionals stated that dementia is a terminal disease and consequently all their residents, including Mrs. White, should be treated as people in need of palliative care. In
the Netherlands, the vignette generated a debate between professionals in a nursing home (NL-1): participating healthcare assistants first had the impression that palliative care only involved the last three days of life. Two nurses, however, persuaded the healthcare assistants that they should consider people like Mrs. White, with a diagnosis of dementia, as in need of palliative care. In the end, the multidisciplinary team agreed that Mrs. White was in need of palliative care. Similarly, some professionals of a Norwegian (NO-2) and of a Polish (PL-2) nursing home argued that people with early-stage dementia should be considered in need of palliative care.

**Palliative care should start when clinical symptoms of advanced dementia are present**

A German nursing home (DE-1) used a self-developed assessment tool to identify palliative care needs and symptoms of their own residents. For that reason, the members of this team agreed that if Mrs. White would meet the criteria of this assessment tool, they would consider her in need of palliative care. Similarly, staff in an Italian nursing home (IT-1) unanimously considered Mrs. White in need of palliative care if she suffered from serious communication deficits, physical disorders, pain and severe agitation. Yet, in a second Italian nursing home (IT-2), staff were not able to reach consensus whether to consider Mrs. White in need of palliative care. Some professionals did mention that palliative care is exclusively applicable for people with advanced dementia. In a third Italian nursing home (IT-3), team members agreed that a person with advanced dementia would be considered in need of palliative care. However, they considered that Mrs. White, as depicted in the vignette, did not show symptoms of advanced dementia. An analogous concept was expressed by professionals in two French nursing homes (FR-1 and FR-2). They unanimously agreed that Mrs. White was not in an advanced stage of dementia and therefore not in need of palliative care. Professionals in a Norwegian nursing home (NO-1) also shared this opinion. However, in another Norwegian nursing home (NO-2), staff were not able to reach consensus. Some stated that palliative care is applicable for people with dementia with a short life expectancy. Lastly, Polish professionals (PL-1 and PL-2) referred to the time point in the disease trajectory in which dementia symptoms seriously hamper a person’s autonomy and demand intensive medical and nursing care.

**Palliative care should start when curative treatment for comorbidities has no longer a beneficial effect**

Professionals from a Dutch nursing home (NL-2) agreed that at the time Mrs. White is experiencing physical diseases and the doctors decide not to treat these anymore, she should be considered in need of palliative care. In a Norwegian nursing home (NO-2) professionals did not reach consensus, and only some of them considered Mrs. White in need of palliative care when she would no longer benefit from medical or surgical treatment.
<table>
<thead>
<tr>
<th></th>
<th>DE-1</th>
<th>DE-2</th>
<th>FR-1</th>
<th>FR-2</th>
<th>IT-1</th>
<th>IT-2</th>
<th>IT-3</th>
<th>NO-1</th>
<th>NO-2*</th>
<th>NL-1</th>
<th>NL-2</th>
<th>PL-1</th>
<th>PL-2*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you consider the person in the case vignette to be in need of palliative care?</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>When she is in the early stage of dementia</td>
<td>-</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>+</td>
<td>-</td>
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<td>+</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>When she has signs and symptoms of advanced dementia</td>
<td>+</td>
<td>-</td>
<td>+</td>
<td>+</td>
<td>+</td>
<td>+</td>
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<td>+</td>
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<td>+</td>
</tr>
<tr>
<td>When she has no more beneficial effect of curative treatment for co-morbidities</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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</tr>
</tbody>
</table>

DE: Germany, FR: France, IT: Italy, NO: Norway, PL: Poland, NL: The Netherlands
* Services where there was no consensus between professionals
Discussion

This study highlights the challenges faced by professionals working in long-term care settings with people with advanced dementia in defining the time point when palliative care should start. With the help of a case-vignette, we identified three time points in the disease trajectory of a person with dementia that teams of nursing home professionals considered as the moment to start palliative care: (1) from the early stages of dementia, (2) when signs and symptoms of advanced dementia are present, and (3) from the time point that curative treatment for co-morbidities is futile. Discrepancies were found not only between European countries, but also between staff members working in the same LTC setting. In some nursing homes, for example, professionals disagreed about the time point a person with dementia is in need of palliative care. Also between countries, different time points when a person becomes eligible for palliative care were mentioned.

However, most professionals described that palliative care should be provided when a person with dementia shows symptoms indicating the advanced stage of dementia is approaching the end-of-life phase, such as swallowing disorders, pain, or when the body does not respond to food or liquids anymore.

Birch et al. described that professionals often find it difficult to recognise unmet palliative care needs of people with dementia because the progression of dementia differs in each person. The progression towards the advanced stages of dementia, for example, remains unpredictable. Prognostic indicators to identify end-stage dementia may increase the availability of palliative care options for people with dementia and their families, but they are often used too late and seem unreliable to predict a person’s death. Some of the professional teams in our study responded that the early stages of dementia can be considered as the time point palliative care starts. Black et al. described that recognising the needs and preferences of people with dementia early in the disease trajectory facilitates the involvement in the decision-making process and advance care planning.

Professionals in two nursing homes considered the time point that curative treatment for co-morbidities is futile and does not improve the person’s quality of life as the starting point for palliative care. However, similarly to using prognostic indicators, considering the time point when co-morbidities cannot be treated might be too late in the disease trajectory to provide proactive palliative care as the cognitive abilities of a person with dementia have declined too much so that the person is no longer able to participate in the decision making process and advance care planning.

Before group discussion, some professionals even considered the last days of life as the starting point for palliative care, meaning when the patient is about to die. Although we only reported about the final considerations of the professionals, it is important to note that this could potentially be a fourth time-point.
Differences between countries in identifying the time point of the palliative phase were expected, because of different cultures and national regulations for palliative care\(^23\). However, even within countries, different opinions about the time point of the palliative phase were identified. Thereby, there appeared to be differences in definition about palliative care between services. Although important consensus statement reports such as the EAPC’s White Paper, defining optimal palliative care in older people with dementia\(^12\), have been developed and disseminated, they are not sufficient to overcome these barriers. Access to palliative care therefore depends on the perceptions of palliative care professionals about when palliative care becomes appropriate for people with dementia. There is a need for further research into the differences palliative care makes to quality of life and end of life care for people with dementia, and the perceptions of palliative care professionals about the value of engaging in the care of people with dementia. Knowledge about and experience in palliative care of professionals working in dementia care therefore need to be improved\(^24\). Teaching professionals to lead their caregiving by needs probably might be the most important step in providing timely palliative care in each phase of the disease. Reaching consensus about the definition of palliative care and subsequently about the time point of the palliative phase is therefore necessary\(^25\).

This study can contribute to the ongoing discussion on this topic by showing that there are three time points when nursing home professionals consider a person with dementia in need of palliative care: early in the disease trajectory, advanced dementia or when curative treatment for co-morbidities has no more beneficial effect. Even within services, it appeared that sometimes there were different opinions regarding the starting point of the palliative phase. Future attempts to define the optimal time point of the palliative phase in dementia should acknowledge these differences.

**Strengths and limitations**

This study contributes to our knowledge about the challenges that professionals working in LTC settings experience during their daily work with people suffering from dementia, particularly regarding their palliative care needs. Besides, it is the first study in which we get insights in how professionals that work with people with dementia on a daily basis define the starting point of palliative care. This is an important addition to the theoretical studies on this topic\(^12,26\). However, some limitations have to be taken into account. Participants did not receive a definition of palliative care prior to their discussion about the starting point of palliative care as it was the aim of this study to allow them to share their own definitions and clinical perceptions about palliative care. Their opinions may have therefore been influenced by the type of palliative care intervention available in their service. If we would have provided the WHO definition of palliative care, their own meaning would probably have been influenced by this.
Second, as answers provided by the participants were anonymised, it was not possible to identify differences in the personal perspectives of the healthcare professionals. If these would have been reported, the anonymity of the participants would have been at stake because of the few services and professionals involved.

Third, although data was collected in nursing homes in six European countries, the data may not be representative for all services at the regional or national healthcare system in the respective countries. This study was too small to grasp such differences. Further multicenter and multinational studies have to be conducted to analyse regional or national differences regarding the starting point of the palliative phase.

Fourth, it was the aim of this study to explore when professionals in long-term care settings consider a person with dementia in need of palliative care and not to reach consensus about the time point that the palliative phase starts in people with dementia. Future research can therefore use the three time points identified in this paper, to further explore the possibilities of reaching consensus about the time point of the palliative phase in people with dementia within and between services.

**Conclusion**

The findings from this study show that professionals across Europe have different opinions regarding the time point when to consider a person with dementia in need of palliative care. The range of opinions described in this study lead to the recommendation that multiple methods for information and education of staff members should be pursued to improve palliative care policy and service delivery for people with dementia.
References

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Identification of the palliative phase in people with dementia.


General discussion
In the previous chapters, I presented the results of the EU funded 7th Framework IMPACT (IMplementation of quality indicators for PAlliative Care sTudy) project, which aimed to develop and introduce quality indicators in order to assess and improve the organisation of palliative care for patients with cancer or dementia. In the first chapter, a description of the problem and subsequently the research questions were presented. Chapter 2 provided a more detailed description of the entire IMPACT project. In this final chapter, the main findings of the studies carried out in chapter 3 to 7 are presented and discussed in the light of relevant and recent literature. Subsequently, the most relevant methodological issues and the implications of the results are discussed. Finally, a number of recommendations for practice, policy and future research are given.

Summary and interpretation of main findings

Quality indicators to assess and improve the organisation of palliative care were developed

Getting insights in the quality of care provided is an essential first step of improving the organisation of palliative care. However, there are few science-based quality criteria regarding the organisation of palliative care.

In chapter 3, I described how we developed a set of quality indicators resulting from a five-round modified RAND Delphi-procedure with an international panel of professionals and researchers active in the fields of palliative cancer and dementia care. The final set consists of 23 quality indicators that described the accessibility of the palliative care service, its infrastructure, the use of symptom assessment tools, management of personnel, documentation of clinical data, quality of care and education. These identified domains are in line with the recommendations how to improve the organisation of palliative care as stipulated by the Council of Europe. In contrast to quality indicators for palliative care developed in the past, these quality indicators have been developed within an international context. Moreover, compared to other quality indicators on the organisation of palliative care, our quality indicators focus on both cancer and dementia care, thereby making the step to broaden palliative care to other diseases than cancer. In our Delphi-procedure, we explicitly included healthcare professionals working in dementia care to rate the usefulness of the quality indicators. But panellists in our study agreed not to formulate disease-specific quality indicators as it was the aim of our set to focus on the organisation of services and not on the care provision itself. I believe that our set of quality indicators therefore is unique: it can be used in different countries, and in services for patients with cancer and in those for patients with dementia. However, because our set of quality indicators is generically applicable in different services and for different diseases, it is possible that country or setting-specific quality indicators are missing in this international set. If appropriate, each country can add them.

The quality indicators we developed can identify potential areas for improvement. They can be used by healthcare professionals as mirror information to improve
the organisation of palliative care in their service. As such, our quality indicators can be called ‘internal quality indicators’. Because they were developed for this specific purpose, they are not meant to be used for external purposes, such as accreditation or certification. Further validation, reliability of repeated measurement, inter-rater reliability, case mix adjustment and discriminatory capacity should be further defined. Within the IMPACT project, our quality indicators have been tested in a pre-post test intervention study. These results have yet to be published and are beyond the scope of this thesis.

**Strategies to improve the organisation of palliative care were identified**

Different strategies to change the organisation of care exist. Yet, few studies investigated the use of such strategies specifically for the organisation of palliative care.

In chapter 4, I described the results of an integrative review in which we found 68 studies that met our inclusion criteria: they described specific strategies to improve the organisation of palliative care. These studies included educational strategies, process mapping, feedback, multidisciplinary meetings and multi-faceted interventions. Most studies reported positive results regarding the implementation of quality improvement activities for the organisation of palliative care using any of the identified strategies. Even interventions like audit and feedback, that was found to be hardly effective in a Cochrane review, showed positive results in our review. The same accounts for continuing education meetings, printed educational methods, educational outreach, reminders, and for example inter-professional collaboration. These positive results are also not in line with an overview of Grol and Grimshaw, in which they included 54 reviews about the effectiveness of different interventions to change clinical practice. Most interventions they studied, including educational activities, feedback and multiprofessional collaboration had mixed effects. They also found that combined interventions were more effective than single interventions. The positive results identified in our review might be caused by the fact that participants in a quality improvement project perform better as a result of knowing that they are a study object (Hawthorne effect), because effects were often measured directly after the intervention or because only a few studies were randomised controlled (RCT) or blinded studies. Aoun et al. described that RCTs comprise only about 6% of all studies conducted in palliative care. RCTs require significant time and funding, expert research guidance, and particularly in palliative care populations they are scarce because of recruitment restrictions, high attrition, (selection) bias, lack of blinding, confounding, and small sample sizes. Nonetheless, there is a need for high-quality evidence in palliative care.

By reviewing existing literature on this topic, a description of the existing strategies both revealed the weakness of the evidence as well as the potential of several strategies. Moreover, although we identified a wide range of strategies, it is possible that we have missed potentially interesting publications, as there are no
uniform search strategies to identify improvement strategies for the organisation of care, even though there are initiatives such as the Cochrane Effective Practice and Organisation of Care (EPOC)\textsuperscript{21}, or the Expert Recommendations for Implementing Change (EIRC)\textsuperscript{22}.

**An overview of barriers and facilitators of strategies to improve the organisation of palliative care was developed**

To implement changes in the organisation of palliative care, it is important to know which potential factors facilitate or hinder the intervention. However, an overview of such barriers and facilitators for the organisation of palliative care was lacking. In chapter 5, I described barriers and facilitators of strategies to improve the organisation of palliative care, as mentioned in 40 individual and 10 focus group interviews with professionals involved in palliative care in five European countries (England, Germany, Italy, Norway and the Netherlands). These barriers and facilitators were categorised into five themes: the innovation itself, the individual professional level, group dynamics, the organisational context, and the local political-economic context. These themes are in line with those described in other studies, in other areas of healthcare like the organisational culture, structural characteristics, implementation climate and readiness\textsuperscript{23}. Lennox et al. studied challenges of implementing a COPD care bundle. The barriers they identified were: lack of time, shortage of staff and lack of staff engagement and their facilitators were related to improve engagement of staff, education and financial incentives\textsuperscript{24}. Our barriers and facilitators are also comparable to those identified regarding the provision of palliative care itself, such as time constraints\textsuperscript{25}, lack of funding\textsuperscript{25,26}, and lack of professional awareness\textsuperscript{26}.

In our study in five European countries, we found similarities between the organisation of care in different services and countries, despite national and international differences in culture, healthcare system and organisation of palliative care. For example, in all type of settings and in all countries professionals indicated that financial resources and a positive attitude to change are of the highest importance. This suggests that sufficient funding and the motivation of staff are a prerequisite to change. Thereby, facilitators that were mentioned as a barrier when absent (e.g. attractiveness of improvement strategies) can also be considered as an essential requirement to change. Our barriers and facilitators should therefore be considered when implementing quality improvement initiatives into the organisation of palliative care. However, an additional assessment of national barriers and facilitators remains a necessity, irrespective of the findings from our international study, as was also stipulated by Grol\textsuperscript{27}.

**Strategies to implement the results of research into daily clinical palliative care were defined**

When a research project has been finished, it is important to implement its results into daily clinical practice. However, this step is often insufficiently explored,
leaving many research results unused.

In chapter 6, I presented recommendations on how to implement the results of research projects into daily clinical practice. Key opinion leaders participating in two parallel nominal group sessions identified and prioritised a set of potential strategies, which could be categorised into five common themes: dissemination of the results, unique selling points, educational activities, involvement of stakeholders and consequences of implementation. Our findings are in line with previous studies\textsuperscript{11,18,28-30}, but add the prioritising by the participants of strategies to influence the implementation of quality improvement activities in palliative care. Thereby, these strategies are still not used in a structured way. But when applied in other projects, they often resulted in promising effects. In the USA, for example, the use of financial consequences has resulted in a reduction of the hospital acquired infection rate\textsuperscript{31}.

Although the panellists in our study made a congruent description of strategies similar to what is known from the literature, they did not consider de-implementation and mandating of quality improvement activities. Yet, these aspects are considered essential to improve daily clinical practice\textsuperscript{32,33}. The recommendations that resulted from the nominal group sessions should therefore not be considered as standalone and ready-to-use strategies; they need to be tailored to the specific situation. Implementation of our recommendations should therefore always be guided by a stepwise implementation approach.

**The identification of the starting point of palliative care in people with dementia remains unclear**

Palliative care was originally developed as care for patients with cancer. During the last decade, palliative care is increasingly provided to patients with other types of diseases, such as dementia. The question is, however, when these patients are eligible for palliative care.

In chapter 7, we found that healthcare professionals caring for people with dementia in long-term care facilities described three time-points when they consider a person with dementia in need of palliative care: 1) at an early stage of dementia, 2) when signs and symptoms of advanced dementia are present, or 3) as soon as curative treatment for co-morbidities is futile.

The first time-point (considering the early stage of dementia as the starting point for palliative care) is comparable with the recommendation of the European Association on Palliative Care (EAPC) to consider the diagnosis of dementia as the starting point for palliative care\textsuperscript{34}. Healthcare professionals often find it difficult to recognise unmet palliative care needs of people with dementia\textsuperscript{35}, and late identification of the palliative phase may results in problematic communication with the person with dementia\textsuperscript{36}. Identifying needs and preferences early in the disease trajectory should therefore facilitate the involvement in the decision-making process and advance care planning\textsuperscript{37}.  

\textsuperscript{11,18,28-30}
However, in our study, most professionals considered the second time-point (when a person with dementia shows symptoms indicating the advanced stage of dementia) as the starting point for palliative care. This is in contrast with the recommendation of the EAPC to consider the diagnosis of dementia as the starting point of palliative care. Birch, for example, explains that because of the unpredictability of the disease trajectory of dementia, the length of the remaining life of a person with dementia is not clear. Raymond et al. described that family members felt frustrated when they had to discuss end-of-life care as it was difficult to accurately anticipate the end of life for a person with dementia. The person with dementia and his or her family first have to learn how to live with the disease and its consequences, once a diagnosis of dementia has been made. Palliative care should therefore not ‘take over’ usual care for persons with dementia, but should remain an additional service. Pacala described this by comparing palliative and geriatric care and stated that these two fields “spend far too much time highlighting the marginal differences between the two disciplines in an effort to justify their own existence”. But palliative care does not usurp geriatric care, nor does palliative care usurp dementia care. Instead, palliative care should identify mutual strengths and recognise the differences with other types of care in order to bring the provision of palliative care to a higher quality level, irrespective of setting or disease.

The third time-point mentioned (when curative treatment for co-morbidity becomes futile), might be too late in the disease trajectory to provide proactive palliative care as the cognitive abilities of a person with dementia have declined too much so that the person is no longer able to participate in the decision making process and advance care planning. Raymond et al. described that professionals have a lack of knowledge about palliative care, especially those providing dementia care. Education and training in palliative care for patients with dementia needs to be developed and implemented.

Because we collected our data using a case-vignette in a limited number of settings and countries, (France, Germany, Italy, Norway, Poland and the Netherlands), generalizability to other countries or settings is restricted; further research is therefore necessary. Yet, our study showed that professionals have varying opinions when to consider a person with dementia in need of palliative care, not only between countries, but also within countries and between staff members of the same long-term care facility. Secondly, it showed that professionals often have a lack of understanding what palliative care actually is about. Our findings can therefore contribute to the changing paradigm on this topic.

Main discussion and conclusions
This thesis has resulted in 1) a set of quality indicators to assess and improve the organisation of palliative care, 2) an overview of strategies to improve the organisation of palliative care, 3) a description of barriers and facilitators regarding
improvement strategies, 4) an overview of strategies to implement changes into daily clinical practice and 5) a critical assessment whether the above described strategies can also be used in palliative dementia care by identifying the time-points when professionals working in long-term care facilities consider a person with dementia in need of palliative care.

All these findings are related to the first four steps described in Grol’s stepwise Implementation of Change Model\textsuperscript{27}. When a thorough analysis of the actual performance, identification of barriers and facilitators and specific improvement strategies are not considered when improving the quality of care, failure of the implementation is imminent. Despite this potential risk for failure, there is still a lack of attention regarding implementation science, resulting in a lot of scientific efforts being wasted\textsuperscript{41}. Also in palliative care, a lot of newly found evidence is not implemented. Hanchanale and Jordan\textsuperscript{42}, for example, reported that only 43\% of abstracts presented at an international palliative care conference in 2005 eventually made it to peer-reviewed publication. But even when research is published, the impact of the scientific evidence that is presented remains limited. Greenhalgh et al.\textsuperscript{43}, documented five downsides for evidence based medicine: statistically significant benefits may be marginal in clinical practice; inflexible rules and technology driven prompts produce care that is management driven rather than patient-centered; evidence-based guidelines often map poorly to complex multimorbidity; the evidence base is biased by organisations, like pharmaceutical companies, that have a special interest in specific results; and the volume of evidence has become unmanageable. Adequate use of a stepwise implementation model is therefore important to ensure that optimal and tailored strategies are being introduced into daily clinical practice.

The results presented in this thesis can be used to assess and hence change the organisation of palliative cancer and dementia care. We thereby recommend to apply Grol’s Implementation of Change Model to improve the organisation of palliative cancer and dementia. However, where Grol only mentions the “integration of changes into routine care”, we propose to explicitly add to Grol’s Implementation of Change Model, the identification of specific strategies to ensure implementation of new scientific evidence into clinical practice. This facilitates researchers to think about how to ensure wider implementation of their results more early in a research project and allows the translation of research results to other areas of healthcare.

**Implications for practice, policy and research**

The findings described in this thesis allowed to make the following recommendations (table 1): 

**Recommendations for practice**

We developed a set of quality indicators that can be used to assess and subsequently
identify areas for improving the organisation of services providing palliative care. While explicit measurement constitutes an important first step for improving the quality of the organisation of palliative care, measurement alone is not enough. Other critical steps are also necessary, such as feeding back the results; identifying and specifying improvement objectives; identification of potential barriers and facilitators; identifying and implementing effective strategies; and measuring the impact of the implemented strategies. For which this study provided the tools for. Besides using our set of quality indicators, services should understand that specific tools must be used that can guide quality improvement objectives. For example, the online application developed by the IMPACT project (http://impactpalliativecare-assessment.eu), that assesses and hence guides services in their quality improvement process.

Secondly, this thesis showed that sub-optimal palliative care is provided across Europe. Although there are different initiatives that aim to improve the identification of those patients that may profit of palliative care (e.g. the surprise question), there is a need to further improve the knowledge and provision of palliative care. I encourage the model presented by Quill and Abernetly, in which they distinguish two levels of palliative care: “primary palliative care (skills that all clinicians should have) and specialist palliative care (skills for managing more complex and difficult cases). In the Netherlands, the use of palliative care consultation teams is a good example of how generalist and specialist services can work together in the provision of palliative care. A potential solution in the Netherlands may be the recently published ‘Care pathway for palliative care 1.0’, which provides recommendations about the provision of palliative care for all healthcare professionals. But without the inclusion of palliative care in the curricula of nursing and medical training, improving (the organisation of) palliative care will remain difficult. I therefore recommend that palliative care becomes an integral part of the core curricula of the medical education for at least physicians and nurses.

Recommendations for policy
The studies conducted in this thesis have shown that there is a vast amount of literature available on quality indicators specifically for palliative care. Few quality indicators, however, are actually being used in daily practice. Therefore, we call upon national and international policy makers to enforce the use of our set of quality indicators. In the Netherlands, for example, the Netherlands Organisation for Health Research and Development obliged the use of quality indicators developed by Pasman et al. in all new palliative care research projects. Our set of quality indicators could be adopted by the scientific organisations, like Palliactief in the Netherlands, as a tool to stimulate internal quality improvement projects of settings that provide palliative care. This also stipulates my second point, as I would like to highlight the importance of mandating quality improvement activities: without full support of scientific professional organisations, implementation of quality improvement activities into daily clinical practice will be hampered.
Thirdly, national and international policies should be developed that stimulate the implementation of high quality palliative care. The recommendations stipulated in the ‘2014 European Declaration on Palliative Care’, which resulted from a joined conference of the IMPACT and EURO-IMPACT consortia, may be of particular use for decision makers at regional, national and international level (appendix 1).

Recommendations for future research
The findings reported in this thesis evoke several new questions. First of all, the quality indicators presented in this thesis are meant for internal purposes: as a tool for professionals in order to assess whether their service meets a basic quality level and hence initiate improvement projects. Although the results can be used to compare services, they cannot be used for a quality rating. Additional research is necessary to identify whether and how the current set of quality indicators can also be used for external purposes.

Second, we showed that a large variety of strategies are being used to implement quality improvements to the organisation of palliative care. However, only few studies used a randomised controlled design. In order to prevent further sub-optimal research designs and unnecessary duplication of studies and facilitate comparison of studies, I recommend that more randomised controlled trials should be started, or that high quality alternative designs will be developed.

Third, I recommend that researchers identify strategies to translate their results into daily practice more early in their research project in order to prevent wasting of all their efforts.

Fourth, improving palliative care for persons with dementia is only possible when all professionals caring for them have a basic knowledge about palliative care. Therefore, it is important to further explore what palliative care adds to the care of persons with dementia and subsequently when the palliative phase starts in persons with dementia.
Table 1: Recommendations following the results presented in this thesis

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Field</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Practice</td>
</tr>
<tr>
<td>Use a stepwise implementation model to assess, initiate and guide quality improvements in daily clinical practice</td>
<td></td>
</tr>
<tr>
<td>1.2</td>
<td>Practice</td>
</tr>
<tr>
<td>Encourage the distinction between primary palliative care and specialist palliative care</td>
<td></td>
</tr>
<tr>
<td>1.3</td>
<td>Practice</td>
</tr>
<tr>
<td>Promote the knowledge and experience of healthcare professionals by ensuring that palliative care becomes an integral part of the core curricula of the medical education for at least physicians and nurses</td>
<td></td>
</tr>
<tr>
<td>2.1</td>
<td>Policy</td>
</tr>
<tr>
<td>Enforce the use of our quality indicators to assess the level of quality of the organisation of palliative care provided by services</td>
<td></td>
</tr>
<tr>
<td>2.2</td>
<td>Policy</td>
</tr>
<tr>
<td>Mandate quality improvements by scientific professional organisations</td>
<td></td>
</tr>
<tr>
<td>2.3</td>
<td>Policy</td>
</tr>
<tr>
<td>Develop national and international policies that stimulate the implementation of high quality palliative care</td>
<td></td>
</tr>
<tr>
<td>3.1</td>
<td>Research</td>
</tr>
<tr>
<td>Explore the possibility to use our quality indicators for external purposes (e.g. as a quality rating)</td>
<td></td>
</tr>
<tr>
<td>3.2</td>
<td>Research</td>
</tr>
<tr>
<td>Facilitate the comparison of studies regarding strategies to improve the organisation of palliative care by conducting more randomised controlled trials or other high quality alternatives</td>
<td></td>
</tr>
<tr>
<td>3.3</td>
<td>Research</td>
</tr>
<tr>
<td>Identify strategies to translate new evidence into daily clinical practice more early in research projects</td>
<td></td>
</tr>
<tr>
<td>3.4</td>
<td>Research</td>
</tr>
<tr>
<td>Explore what palliative care adds to the care of people with dementia and subsequently when the palliative phase starts in people with dementia</td>
<td></td>
</tr>
</tbody>
</table>
References


48. CBO. Zorgmodule Palliatieve Zorg 1.0. 2013.
Appendix 1

2014 European Declaration on Palliative Care

“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 treatment of other problems, physical, psychosocial and spiritual” [World Health Organisation, 2002].

Palliative care is required from early in the disease course, can be delivered alongside potentially curative treatment, and continues to include end-of-life or terminal care.

Calling upon policy and decision makers at regional, national and international level to:

1. Recognise that the delivery of and access to high quality palliative care is a public health priority which requires a public health approach.

2. Develop or redraft national and international healthcare policies, such as policies on healthy ageing, long-term care and dementia, to include palliative care as an essential component.

3. Develop or redraft palliative care-specific policies to include referral criteria that allow patients and their family timely access to palliative care consistent with their level of need, regardless of diagnosis, age, prognosis, estimated life expectancy or care setting.

4. Develop or redraft policies to include mechanisms to ensure access to specialist multidisciplinary palliative care services or teams in all healthcare settings.

5. Promote a paradigm shift in health and social care towards basic palliative care skills for all healthcare professionals, to empower them to deliver patient-centred family-focused care for all people with a life-limiting illness, based on personalised or tailored care plans, with attention to all needs of the patient and his or her family.

6. Support inter-professional and multi-disciplinary collaboration as a cornerstone of high-quality care and education in palliative care.

7. Invest in curriculum development and education in palliative care across all disciplines of health and social care at undergraduate and post-graduate level, and establish palliative care as a specialty.
8. Promote public awareness through community level approaches: education of the public and training of family carers and volunteers.

9. Increase funding opportunities for national and international research in palliative care.

10. Establish continuous mechanisms to monitor and improve the quality of and access to palliative care.

Launched in Brussels, October 2014
Summary

In this thesis, a step-by-step approach to find methodologies to improve the organisation of palliative care was taken. Firstly, we identified a set of quality indicators for the evaluation of the organisation of palliative care. Secondly, we identified strategies that can improve palliative care. Thirdly, we identified barriers and facilitators regarding these improvement strategies. Fourthly, we identified strategies to improve the implementation of research results into daily clinical practice. And finally, to explore potential areas for improvement regarding palliative care for people with dementia, we also identified the various time points when healthcare professionals consider people with dementia in need of palliative care.

Chapter 1 and chapter 2 describe the context in which this thesis was written. In chapter 1, I describe that due to the ageing of the population and higher survival rates of people with chronic diseases, there will be an increasing number of patients in need of palliative care. I illustrated what the advantage of palliative care is for patients with cancer and those with dementia. Yet, many patients receive sub-optimal palliative care, despite the large advances in palliative care that have been made over the last decade. To further improve the provision of palliative care, the organisation of palliative care needs to be improved as a base for the provision of optimal palliative care. Chapter 1 concludes with the research objectives and an outline of this thesis.

In chapter 2, a detailed description of the larger EU funded 7th Framework IMPACT (IMplementation of quality indicators for PAlliative Care sTudy) project, of which this thesis was part of, is provided by describing the protocol of the entire project.

Chapter 3 presents the results of a study identifying a set of quality indicators for the evaluation of the organisation of palliative care. An international panel of healthcare professionals and researchers active in the field of palliative cancer and dementia care participated in a five-round modified RAND Delphi-procedure. The Delphi-procedure resulted in 23 useful quality indicators, representing the accessibility of the service, its infrastructure, the use of symptom assessment tools, management of personnel, documentation of clinical data, quality of care and education. This set of quality indicators should be considered for the evaluation of the organisation of palliative care and to subsequently identify potential areas for improvement.

Chapter 4 describes the results of a literature review regarding strategies that were used to improve the organisation of palliative care. An integrative review methodology was used as this allows to summarise empirical and theoretical literature that use diverse methodologies and study designs. After having applied our inclusion criteria to the 2379 initially identified publications, 68 experimental or quasi-experimental studies were included. These studies included educational
strategies (n=14), process mapping (n=1), feedback (n=1), multidisciplinary meetings (n=1) and multi-faceted implementation strategies (n=51). Fifty-three studies reported positive outcomes, 11 studies reported mixed effects and four studies had a limited effect. However, these results should be interpreted carefully as studies might have been subject to the Hawthorne effect, publication bias, and only few of them used prospective, controlled designs. More controlled designs or large prospective studies with improved designs for specific improvement strategies are necessary to compare and identify the most effective strategy to change the organisation of palliative care.

Chapter 5 presents the results of a study on barriers and facilitators regarding strategies to improve the organisation of palliative care. Forty individual and ten focus group interviews were conducted with healthcare professionals involved in the provision of palliative care in five European countries. Barriers and facilitators were inductively grouped into 16 categories and arranged into five themes: innovation, individual professional level, group dynamics, organisational context and local political-economic context. This study demonstrates that although the barriers and facilitators identified differed in scope, context, strength and provenance, they were shared by professionals from different European countries. Taking these barriers and facilitators into account can therefore be seen as a prerequisite to change.

Chapter 6 describes the results of a study identifying strategies to implement improvement activities into daily palliative care practice, when new evidence has been generated. A nominal group technique was used with members of the IMPACT consortium, being international researchers and clinicians in cancer care, dementia care and palliative care. Twenty experts participated in one of two parallel nominal group sessions. The nominal group approach allowed the panellists to prioritise strategies towards the implementation of quality improvement activities specifically for the field of palliative care. The process resulted in a list of strategies that were combined into five common themes: dissemination of the results, unique selling points, educational activities, involvement of stakeholders and incentives and sanctions. Although these themes are in line with those previously described, they are not used in a structural way in daily practice yet. The added value of this nominal group study therefore is the prioritising by the experts of strategies to influence the implementation of quality improvement activities in palliative care. It also showed that efforts to ensure future use of scientific findings should be built into research projects in order to prevent waste of resources.

Chapter 7 presents the results of a study on the starting point of the palliative phase of persons with dementia. Thirteen teams of in total 84 professionals working in long-term care facilities in six countries (France, Germany, Italy, Norway, Poland and the Netherlands) received a case-vignette concerning a person with dementia recently admitted to a nursing home. Part of the professionals considered a
person with dementia already in need of palliative care (1) early in the disease trajectory; some (2) when signs and symptoms of advanced dementia are present; and others (3) from the time point that curative treatment of co-morbidities is futile. This study shows that professionals across Europe, but also within a country or even within a service have varying opinions when to consider a person with dementia in need of palliative care and can therefore contribute to the changing paradigm on this topic.

In chapter 8, the final chapter of this thesis, the most important findings described in chapter 3 to 7 are discussed. The results are placed within a theoretical background and compared with other studies. Besides, methodological issues as well as recommendations for practice, policy and future research are described.

It can be concluded that a good organisation of palliative care is a prerequisite for good outcomes. The results presented in this thesis can contribute to improving the organisation of palliative care by (1) using the quality indicators to assess whether the service meets a basic quality level and subsequently identify potential areas for improvement; (2) using the described strategies to improve the organisation of palliative care; (3) using the barriers and facilitators to tailor the improvement strategies to the needs of the service; and (4) using the implementation strategies to ensure dissemination of the evidence based and best practices into daily clinical practice. Regarding the time-points when to consider a person with dementia in need of palliative care, the variety of opinions of professionals across Europe show that further research is necessary to define the provision of palliative care for persons with dementia.

As such, this thesis adds knowledge about implementation science specifically related to the organisation of palliative care by exploring methods to improve the translation of evidence to areas of healthcare where suboptimal palliative care is still being provided.
Samenvatting

In dit proefschrift is een stap-voor-stap benadering toegepast om methoden te identificeren die de organisatie van de palliatieve zorg kunnen verbeteren. Ten eerste hebben we een set van kwaliteitsindicatoren ontwikkeld om de organisatie van de palliatieve zorg te evalueren. Ten tweede hebben we strategieën bestudeerd die de palliatieve zorg kunnen helpen verbeteren. Ten derde zijn belemmerende en bevorderende factoren van deze strategieën geïnventariseerd. Ten vierde hebben we strategieën geïdentificeerd waarmee onderzoekresultaten in de dagelijkse praktijk kunnen worden geïmplementeerd. Tot slot hebben we gekeken naar mogelijke verbeterpunten wat betreft de palliatieve zorg voor mensen met dementie. Daarbij hebben we de verschillende momenten dat zorgverleners mensen met dementie als palliatief patiënt beschouwen in kaart gebracht.

Hoofdstuk 1 en hoofdstuk 2 beschrijven de context waarin dit proefschrift is geschreven. In hoofdstuk 1 heb ik beschreven dat door de toenemende vergrijzing en een groeiend aantal mensen met chronische ziektes, het aantal mensen dat in aanmerking komt voor palliatieve zorg zal toenemen. Ik heb daarbij weergegeven wat de voordelen van palliatieve zorg zijn voor patiënten met kanker en voor mensen met dementie. Echter, er zijn veel patiënten die sub-optimale palliatieve zorg ontvangen. Dit ondanks de vele ontwikkelingen die de palliatieve zorg de laatste jaren heeft doorgemaakt. Om het aanbod van palliatieve zorg verder te kunnen verbeteren, zal ook de organisatie van palliatieve zorg verbeterd moeten worden zodat deze als basis kan fungeren voor het verlenen van optimale palliatieve zorg. Hoofdstuk 1 wordt afgesloten met de doelstellingen en een korte beschrijving van dit proefschrift.

In hoofdstuk 2 wordt een meer uitgebreide beschrijving van het door de Europese Unie gefinancierde 7th Framework IMPACT (IMplementation of quality indicators for PAlliative Care sTudy) project gegeven, waarvan dit proefschrift onderdeel is.

Hoofdstuk 3 presenteert de resultaten van een studie waarin een set van kwaliteitsindicatoren ten behoeve van de evaluatie van de organisatie van de palliatieve zorg is beschreven. Een internationaal panel bestaande uit zorgverleners en onderzoekers die actief zijn in de palliatieve zorg, oncologie of dementie heeft geparticipeerd in vijf rondes van een gemodificeerde RAND Delphi-procedure. Deze Delphi-procedure heeft geresulteerd in 23 kwaliteitsindicatoren die de toegankelijkheid van zorg, de infrastructuur, gebruik van meetinstrumenten, personeelsmanagement, documentatie van klinische data, kwaliteit van zorg en het opleidingsaanbod representeren. Deze set van kwaliteitsindicatoren is ontwikkeld ten behoeve van de evaluatie van de organisatie van palliatieve zorg en kan gebruikt te worden om mogelijkheden voor verbetering te identificeren.

Hoofdstuk 4 beschrijft de resultaten van een literatuurstudie naar strategieën die zijn gebruikt om de organisatie van palliatieve zorg te verbeteren. Een
Samenvatting

‘integrative review’ is gebruikt omdat deze methode het toestaat om empirische en theoretische literatuur die verschillende methodieken en studiedesigns gebruiken, te includeren. Na het toepassen van de in- en exclusiecriteria op de 2379 initieel geïdentificeerde publicaties, konden we 68 experimentele en quasi-experimentele studies includeren. Deze studies beschreven strategieën op het gebied van educatie (n=14), het in kaart brengen van processen (n=1), feedback (n=1), multidisciplinaire overleggen (n=1) en studies met twee of meer implementatiestrategieën (n=51). Driënhalfduizend studies rapporteerden positieve effecten, 11 studies rapporteerden zowel positieve als negatieve effecten en in vier studies werd een minimaal effect beschreven. Deze uitkomsten dienen echter met enige voorzichtigheid geïnterpreteerd te worden, aangezien er een kans bestaat dat deze studies zijn beïnvloed door het Hawthorne effect, publicatiebias alsmede doordat slechts weinig studies gebruik maakten van een prospectief, gecontroleerd ontwerp. Om verbeterstrategieën te kunnen vergelijken en de meest effectieve strategieën voor de organisatie van de palliatieve zorg te kunnen identificeren, is het aan te bevelen dat er meer prospectieve studies met een betere studieopzet komen die zijn gericht op specifieke verbeterstrategieën om de organisatie van palliatieve zorg te veranderen.

Hoofdstuk 5 presenteert de resultaten van een studie naar belemmerende en bevorderende factoren ten aanzien van strategieën ter verbetering van de organisatie van palliatieve zorg. Hiervoor zijn 40 individuele en tien focusgroepten interviews uitgevoerd met zorgverleners in vijf Europese landen, die betrokken zijn bij de palliatieve zorgverlening. Belemmerende en bevorderende factoren zijn inductief gegroepeerd in 16 categorieën en gerangschikt in vijf thema’s: innovatie, individuele zorgverlener, groepsdynamiek, organisatie en lokaal politiek-economische context. Hoewel de belemmerende en bevorderende factoren verschillen in omvang, context, sterkte en herkomst, demonstreert deze studie dat ze wel degelijk gedeeld worden door zorgverleners in verschillende Europese landen. Het in acht nemen van deze bevorderende en belemmerende factoren is daarom een voorwaarde om te kunnen veranderen.

Hoofdstuk 6 beschrijft de resultaten van een studie waarin strategieën zijn geïdentificeerd om verbeteractiviteiten te implementeren in de dagelijkse praktijk op het moment dat nieuwe onderzoeksresultaten zijn gegenereerd. Een nominale groepstechniek is gebruikt bij leden van het IMPACT consortium, bestaande uit internationale onderzoekers en zorgverleners op het gebied van de palliatieve zorg, oncologie en dementie. Twintig experts hebben deelgenomen aan één van twee parallele groepsessenties. De nominale groepstechniek stelde de panelleden in staat om strategieën te prioriteren die specifiek bedoeld zijn voor het implementeren van kwaliteitsverbeterprojecten op het gebied van palliatieve zorg. Deze procedure heeft geresulteerd in een lijst van strategieën die werden gecombineerd in vijf thema’s: disseminatie van de resultaten, unique selling point, activiteiten op het gebied van educatie, betrekken van stakeholders.
Samenvatting

en stimulerende factoren en sancties. Hoewel ze overeenkomen met thema’s die eerder zijn beschreven, worden ze nog niet op een structurele manier toegepast in de dagelijkse praktijk. De toegevoegde waarde van deze studie is daarom de prioritering die de experts hebben gegeven aan de strategieën om de implementatie van kwaliteitsverbeteringen in de palliatieve zorg te beïnvloeden. Tevens toont het aan dat inspanningen om toekomstig gebruik van wetenschappelijke output te faciliteren ingebed moet worden in wetenschappelijke projecten om te voorkomen dat onderzoeksgelden worden verspild.

Hoofdstuk 7 presenteert de resultaten van een studie naar het startpunt van de palliatieve fase bij mensen met dementie. Dertien teams met in totaal 84 zorgverleners werkzaam in instellingen in de langdurige zorg in zes landen (Duitsland, Frankrijk, Italië, Nederland, Noorwegen en Polen) ontvingen een casus over een persoon met dementie die recentelijk was opgenomen in een verpleeghuis. Na het bediscussiëren van deze casus, vond een deel van de zorgverleners dat deze persoon in aanmerking kwam voor palliatieve zorg (1) vroeg in het ziekteproces; sommigen (2) bij symptomen van gevorderde dementie; en anderen (3) wanneer het behandelen van co-morbiditeiten niet langer toereikend is. Deze studie toont aan dat zorgverleners in Europa, maar ook binnen één land en zelfs binnen een instelling een grote variatie aan meningen hebben wanneer mensen met dementie in aanmerking komen voor palliatieve zorg. Hierdoor kan deze studie bijdragen aan het veranderende paradigma over dit onderwerp.

In hoofdstuk 8, het laatste hoofdstuk van dit proefschrift, worden de belangrijkste bevindingen, beschreven in de hoofdstukken 3 tot en met 7 bediscussieerd. De resultaten zijn geplaatst binnen een theoretisch kader en vergeleken met andere studies. Hierbij zijn ook methodologische beperkingen alsmede aanbevelingen voor de praktijk, beleid en toekomstig onderzoek geformuleerd.

Er kan worden geconcludeerd dat een goede organisatie van palliatieve zorg een voorwaarde is voor goede uitkomsten. De resultaten die in dit proefschrift worden gepresenteerd kunnen bijdragen aan het verbeteren van de organisatie van de palliatieve zorg door (1) de kwaliteitsindicatoren te gebruiken om te beoordelen of zorginstellingen voldoen aan een bepaald basisniveau en daaraan gerelateerd kunnen ze gebruikt worden om mogelijkheden voor verbetering te identificeren; (2) de beschreven strategieën te gebruiken om de organisatie van palliatieve zorg te verbeteren; (3) de belemmerende en bevorderende factoren te gebruiken om de verbeterstrategieën aan te passen aan de behoeften van de instelling; en (4) de verbeterstrategieën te gebruiken om verspreiding van wetenschappelijke bewijs en best practices in de dagelijkse praktijk te waarborgen.

Ten aanzien van het moment waarop mensen met dementie in aanmerking komen voor palliatieve zorg, laten de verschillende opvattingen van zorgverleners in Europa zien dat verder onderzoek nodig is om palliatieve zorg voor mensen met dementie verder te definiëren.
Als zodanig draagt dit proefschrift bij aan de kennis over implementatiewetenschappen, specifiek gerelateerd aan de organisatie van palliatieve zorg door het bestuderen van methoden ten aanzien van de vertaling van wetenschappelijk bewijs naar de praktijk, waar sub-optimale palliatieve zorg wordt gegeven, te verbeteren.
Dankwoord

Een promotietraject doe je niet alleen. Door de jaren heen krijg je heel wat hulp en advies, bedoeld en onbedoeld. Het dankwoord van een proefschrift is de uitgelezen plaats om iedereen te bedanken die heeft bijgedragen aan mijn ontwikkeling tot onderzoeker. Ik beperk me daarbij tot hen die een belangrijke bijdrage aan dit proefschrift hebben geleverd. Velen zullen daardoor niet in persoon worden genoemd, maar kunnen zich bij dezen toch vertegenwoordigd voelen.

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Dear IMPACT consortium members, a European project of this kind, can’t be a success without the input of its partners. I would like to thank all of you for your generous support, advice, and feedback you gave me. In particular, I would like to thank:
Dankwoord

Professor Iliffe, dear Steve, I think Nathan is very lucky that he had you as his supervisor. Your expertise, generosity and kindness makes you a great researcher. Thank you for all your support throughout the project.

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Birgit, Elena, Ragni, and Nathan, we were responsible for the majority of the IMPACT work. I enjoyed working with all of you, and I think we were a great team. We really did it! I feel confident that each and every one of you will become a great researcher (if not already)!

Elena, a special word to you, because I still don’t know how you managed to do it, but doing your work for the IMPACT project, following your psychology classes, and managing your own PhD trajectory, respect! We have worked together on several papers (both for your and my thesis), which I have enjoyed very much. It was great to experience some of the Italian lifestyle and I look forward to your defence here in Nijmegen.

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Het gaat te ver om alle medewerkers van IQ healthcare en de afdeling Anesthesiologie, Pijn en Palliatieve Geneeskunde persoonlijk te bedanken. Daarom een greep uit de selectie: Frederike, Angelique en Anita als onderzoekmedewerkers voor het IMPACT project hebben jullie geweldig werk verricht. Ik had nooit zonder jullie gekund! Zowel qua werk als sociaal was het prettig om met jullie te mogen samenwerken. Dank!

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Publication list


**van Riet Paap J**, Vernooij-Dassen M, Dröes RM, Radbruch L, Vissers K, Engels Y. Consensus on quality indicators to assess the organisation of palliative cancer and dementia care applicable across national healthcare systems and selected by international experts. BMC Health Serv Res 2014; 14:396


Curriculum vitae

Jasper van Riet Paap was born in Dalfsen, a small village on the country side of The Netherlands. After primary school, he went to secondary school in Zwolle, a city just 15 kilometres away. He completed his secondary school four years later and continued with the School of Nursing on the lower professional educational level. During his years as a trainee Nurse, he successfully completed two internships at the Lister Hospital in Stevenage (United Kingdom). At the age of 20, he received his diploma in Nursing. Although he was offered a job at the Lister Hospital, Jasper continued his study in The Netherlands: he joined the School of Nursing on the higher professional educational level. During these two-and-a-half years he successfully participated in a half-year internship at a tuberculosis organisation in Windhoek (Namibia). Back home, he received his Bachelor of Nursing. This was soon followed by his first job: he worked as a staff nurse at the neurology department of the Diakonessenhuis in Utrecht. One year later, Jasper resigned in order to start classes for a masters degree. Two years later, he successfully completed the Master of Health Sciences, with a specialisation in International Public Health. Subsequently, Jasper enrolled in a PhD study at the Radboud university medical center in which he studied the use of quality indicators to facilitate improvements in the organisation of palliative care in Europe.