Integrated Palliative Care: Clinical, Organizational, and Health System Perspectives

Jeroen Hasselhaar, Agnes Csikos, Carlos Centeno, and Sheila Payne

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Abstract
This chapter explores current literature and initiatives in the field of integrated palliative care. The chapter starts with an exploration of the concept of integrated palliative care, followed by practice examples across Europe, models from the literature, and examples from guidelines. After this, barriers and opportunities for integrated palliative care are investigated. Finally, proceedings from the World Health Organization are highlighted to picture an international perspective. We conclude that integrated care has often been considered and discussed from the perspective of better integrated healthcare delivery, which is needed and valuable. But efforts for better integration of palliative care should move beyond a better organization of medical care and needs to be rigorously designed from the perspective of the suffering patient in the last phase of life, and their families.

1 Introduction

Increasing numbers of people are living with, and dying from, advanced stages of cancer and chronic diseases. In the Western world, cancer is regarded as a most important disease, and many efforts are taken to improve survival. The burden of dying with cancer is greater in resource-poor regions of the world because more people are diagnosed late, with metastatic disease (Fadhil et al. 2017). Although a lot of research and attention was – and will be – invested in finding better treatments and strategies for these diseases, it is also clear that not every patient can be cured. Therefore, optimal care and efforts to improve the quality of a patient’s remaining life are valuable. This is where palliative care comes to the fore. Although the demand and the need for palliative care are expected to increase in the coming years, many countries still struggle to deliver sufficient care for palliative patients and to ensure that palliative care is given adequate prominence in their health policies, health systems, and healthcare. The ideal is often that a very ill patient dies in a comfortable place, free of pain and other symptoms, surrounded by a caring and loving family. The inconvenient truth is that too many patients still experience hospital transfers in the last phase of life, suffer from pain and distressing symptoms, are surrounded by stressed and overburdened family members, and eventually die at a place that was not their initial preference.

The purpose of this chapter is to explore if and how better integration of palliative care can resolve or at least ameliorate these problems. This chapter therefore starts with an exploration of integrated care based on a published definition and shows some clinical practice examples from a European project to illustrate the topic. Secondly, recent investigations in the field of integrated palliative care will be highlighted, revealing models and topics that may be relevant to better integrate palliative care. Thirdly, the state of the art of palliative care integration in professional guidelines will be explored. Fourthly, policy strategies will be introduced and the mapping of integrated palliative care will be discussed, including barriers and opportunities. Finally, next steps to progress integrated palliative care will be identified and discussed.
2 A Description of Integrated Palliative Care

Integrated care mostly focuses on giving the right care, at the right time, by the right caregiver. When translated into the field of palliative care, this involves questions like: “what is appropriate palliative care at a given moment in the trajectory of a patient with advanced illness?”, “what is the right moment to start or enhance palliative care?”, and “which informal and professional caregivers are involved at what moment and how do they interact?”

In the context of a European Commission-funded project on integrated supportive palliative care (http://www.insup-c.eu), a working definition for integrated palliative care has been agreed that reads as follows:

Integrated palliative care involves bringing together administrative, organisational, clinical and service aspects in order to realise continuity of care between all actors involved in the care network of patients receiving palliative care. It aims to achieve quality of life and a well-supported dying process for the patient and the family in collaboration with all the caregivers, paid and unpaid. (Van der Eerden et al. 2014)

To investigate integration in the context of palliative care, the model proposed by Valentijn et al. (2013), originally developed for primary care, may be helpful. In its essence, the model distinguishes six elements of integration, namely, clinical integration, professional integration, organizational integration, system integration, functional integration, and normative integration. Furthermore, these elements of integration have a role at a microlevel, a mesolevel, and a macrolevel (Table 1).

When considering integrated palliative care, several of these elements resonate. Examples of clinical integration, with a focus on person-centered care, are improving a patient’s quality of life and prevention and relief of suffering. But also the multidimensional investigation of physical, social, and spiritual problems in palliative care reflects an important element of clinical integration. The call for early applicable palliative care could be considered an example of professional integration, where professionals from several disciplines work together in a multidisciplinary team to provide timely palliative care. Organizational integration, referring to organizational relationships to deliver comprehensive services, could emerge in developing a support system to help patients and their families live as actively as possible, by arranging a package of social care, home care, and volunteering. System integration can refer to the financial healthcare structures that support or not support palliative care development, the presence of healthcare plans for

<table>
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<tr>
<th>Table 1</th>
<th>Aspects of integrated care. (Based on Valentijn et al. 2013)</th>
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<tbody>
<tr>
<td>Microlevel</td>
<td>Mesolevel</td>
</tr>
<tr>
<td>Description of integrated care elements</td>
<td>Clinical integration: refers to the coordination of person-focused care in a single process across time, place, and discipline</td>
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Normative integration (all levels): refers to a common frame of reference with shared values, culture, and goals to ensure coherency

Functional integration (all levels): refers to supportive functions and activities (e.g., financial, management, and information) structured around the primary care process
palliative care, but also the financial and medical sources and education available for palliative care at a country and at a regional level. Normative integration of palliative care can be traced back in the WHO definition when it is said that palliative care affirms life and regards dying as a normal process and intends neither to hasten nor postpone death. Finally, functional integration considers supportive functions and activities with a management, financial, and informational background, needed to align the work of care professionals. It is important for any palliative care service to have appropriate management, possibilities for (digital) information sharing, and financial resources to pay staff. As will be seen in the next paragraph, palliative care services sometimes struggle with this.

3 Five Examples of the Organization of Integrated Palliative Care Across Europe

In 2010, the European Association for Palliative Care (EAPC), in its white paper on standards and norms, introduced a graded system of palliative care services (Radbruch and Payne 2010). They make a distinction between a palliative care approach, general palliative care, and specialist palliative care. General palliative care is provided by all kinds of healthcare professionals like, for example, oncologists and geriatric specialists, whose primary focus is not palliative care but who have a profound knowledge and experience with death and dying in their practices. In addition, specialized services like palliative care units, inpatient hospices, or hospice at home teams are available for patients with complex palliative care needs, based on a multidisciplinary team approach. A palliative care approach requires, for example, that basic principles of palliative care are integrated in the education of physicians, nurses, and other related professions. Considering this theoretical model, it is of interest to see how palliative care is organized in practice, in particular what examples of integrated palliative care can be found.

Recently, a European project about integrated palliative care (InsupC) investigated 22 promising initiatives in 5 European countries, namely, the Netherlands, Hungary, Belgium, England, and Germany. The project has been described in a free e-book (Hasselaar and Payne 2016), where the below offered case descriptions can be found in more detail. Initiatives were eligible to be included when:

- The initiative was an established local palliative care collaboration.
- The collaboration contained at least two different organizations.
- A hospital could be part of that collaboration.
- Collaborating healthcare professionals provided direct patient care.
- The collaboration had a multidisciplinary background.
- The collaboration aimed to provide palliative care for one or more target groups (cancer/advanced COPD/chronic heart failure).

Integrated palliative care initiatives selected for participation in the InsupC study mainly involved hospital- or hospice-based services in conjunction with home care services. Although initiatives were selected based on accepting referrals of patients with cancer, COPD, and heart failure, the majority of included initiatives mainly treated patients with cancer. Table 2 and Fig. 1 show the InsupC research design and the inclusion of patients (n=156) and informal caregivers (n=88) within the InsupC project. Semi-structured interviews were performed with patients and with their informal caregivers. In addition, group interviews were held with professional caregivers at each initiative.

From all selected initiatives, five examples were further selected and described (Hasselaar and Payne 2016). Below, short descriptions of these five initiatives in five European countries are given in order to get a better understanding of integrated palliative care but also to see how inspiring initiatives work toward better integration.
In Belgium, a regional home care initiative called “White Yellow Cross” was investigated that has developed a care pathway to enable patients to stay at home until death. When a patient meets predefined palliative care criteria, the pathway becomes activated, nurses consult with the GP, and systematic pain and symptom monitoring is started. Specialist palliative care nurses act as case managers for the palliative patients. Strong relationships have been developed with the general practitioners and local hospitals in order to support patient transfers and to treat patients at home as well as possible. A specialist palliative care team (Pallion) is available when needed. This enables the initiative to offer family care and medical supplies alongside nursing care. Information is exchanged via an electronic system, including pain and symptom monitoring. After a patient has died, evaluation meetings among involved professional caregivers take place. Aftercare is part of the pathway, and once a year a memorial ceremony is organized to remember deceased patients. Improvement opportunities were identified including that palliative care is often limited to terminal care, that there are too few specialized
nurses, and that electronic information exchange with hospitals is virtually nonexistent.

### 3.2 A One-Stop Integrated Palliative Care Facility in Germany

Germany offers an example of a one-stop integrated palliative care facility in Tübingen. The “Tübinger” project started in 1994 as a fundraising project and offers different options for palliative patients, like inpatient care, outpatient care, and palliative care in home settings. It has a specialized unit with ten beds served by a multidisciplinary team also including psychological and social support as well as art and music therapy. There is a specialized palliative home care team (SAPV team) consisting of physicians, a coordinator, and nurses, all trained in palliative care. This SAPV team also collaborates with two other regional hospitals, general practitioners, home care services, other professionals involved in palliative care, and pharmacies. The majority of referrals were initiated by general practitioners or self-referrals. About one third of admissions came from hospital. Upon referral, a first visit takes place, and, if the patient meets the inclusion criteria, a care plan will be developed. Although treatment at earlier stages of disease (early integration) is possible, this is often not compensated by health insurers. Charitable funding is still possible through the initial fundraising group, which enables the initiative to offer extra services, for example, a car for the home care team. In the “Tübinger” project, hospital and home care work closely together to offer palliative care, for example, palliative care professionals are often simultaneously employed. This enables a single point of reference and caregiver continuity for patients and family. Using a cloud-based system, information within the team is easily spread. The fact that the initiative had already existed for 25 years fostered acceptance of coordination and participation in local care networks. In three quarters of patients who preferred to die at home, their wish could be realized. Still, there is a predominance of advanced cancer patients; reimbursement can be cumbersome, in particular, when it comes to early integration; and continuity of care in transfers between hospital and home sometimes remains vulnerable.

### 3.3 Integrated Inpatient and Outpatient Palliative Care in Hungary

In Hungary, there is a general lack of well-trained care personnel in the field of palliative medicine and care. Inpatient hospice services are unevenly distributed across the country and concentrated in a few urban areas. Access to hospices is mostly limited to advanced cancer patients. A promising example of well-integrated palliative care can be found in Pécs, located in the South of Hungary. The clinical center of Pécs is one of the largest healthcare providers in Hungary and part of Pécs University. It hosts academic staff for research and education in palliative care together with a clinical consultation team (started 2013), an outpatient clinic (started 2012), and inpatient beds on the oncology ward (started 2016). There are close connections with the hospice (inpatient and at home; founded in 2004), partly sharing the same employees. Altogether, the palliative care network includes palliative care consultants, general practitioners, nurses, physiotherapy, psychology, and social work. The problems reported were lack of qualified staff, mainly physicians and nurses with many professionals only part-time working in palliative care. Furthermore, there is lack of funding and understanding of services, leading to late and limited use of hospice care. Currently, IT systems for patient documentation are fragmented, hampering transfer of information.

### 3.4 A Network Approach in the Netherlands

The Netherlands has a geographical coverage of regional networks for palliative care established in the early 2000s. The exemplary initiative involves a network connecting advanced cancer care in primary and secondary care in Schiedam (close
to Rotterdam). The initiative started from a regional hospital with the goal to provide continuity of palliative care for patients with cancer, regardless of where they are. As patients often moved between care settings, a network was needed to connect these care settings and to optimize collaboration. Therefore, the oncology unit started weekly multidisciplinary meetings as a part of the regional palliative care network “Nieuwe Waterweg Noord,” covering four medium-sized towns. This network is supported by the comprehensive cancer center in Rotterdam. What makes this initiative exemplary is the way they succeed to create a seamless web of care around a single patient in need of palliative care and his/her family.

The multidisciplinary meetings consist of the hospital staff, a nursing home physician also palliative care consultant, a network coordinator also representing home care and palliative care units, and general practitioners by invitation. Caregivers however stay employed at their own organizations. Collaborations have been built with other care providers like mental healthcare, general practitioners, family care support, home care, volunteers. Every participant can list patients to the meeting and inpatients as well as outpatients can be discussed. Workplans are written after each meeting and spread to involved caregivers. Altogether the initiative succeeds in connecting primary and secondary care within a well-functioning regional network, not at least due to the presence of a coordinating nurse as a linchpin function. The network would benefit from better involvement of general practitioners, for example, in attending the weekly meetings, and better electronic information exchange like video conferencing or transmural electronic patient records. Finally the daily running of the network depends on a few highly committed professionals and is mainly dedicated to advanced cancer patients.

### 3.5 A Hospice Without Walls in England

One final example concerns a hospice at home in a rural area in West Cumbria, in the North of England. This initiative was established in 1987 when there was a need for specialist palliative care, but funds were lacking to establish a hospice building. Alternatively, an approach was chosen where patients were supported at their usual place of care, regardless whether this is their home, a hospital, or a nursing home. This service works alongside the National Health Service (NHS) in a “service level agreement” and delivers services from a town center building. It accepts referrals from patients with all life-limiting diseases, like cancer, COPD, and chronic heart failure. It receives one quarter of its funding from the NHS and the rest through public donations. It offers home nursing, a lymphedema service, family and bereavement support provided by trained volunteers, one-to-one support, and complementary therapies. There is no inpatient unit, but the service collaborates with local community hospitals, nursing homes, social work, and NHS-funded general practitioners and palliative care nurse specialists. There is an important place for volunteers in a variety of roles, from administrative tasks to massage therapy and bereavement support. Collaborations are built via weekly multidisciplinary meetings, one meeting covers current patients receiving care, and one meeting covers patients with complex palliative care needs. Due to the rural area, caregivers work in rather small teams, and emphasis is put on well-developed interprofessional relationships. Improvement opportunities involve an electronic system for information sharing which is planned, funding is uncertain and highly dependent on local donations, due to rural location staff can be difficult to recruit, and there is still a challenge to integrate healthcare and social care.

### 3.6 Patient and Informal Carer Interviews

In the analysis of the InsupC patient and family caregiver interviews, it was considered how relational, informational, and management continuity were considered important aspects of functional integration (Den Herder-van der Eerden et al. 2017). Experiencing close relationships with
their palliative caregivers was considered important in all countries, in particular, that professionals were not only interested in the disease progress but also considered the patient as a person. Although general practitioners were generally considered important actors in the network of the patient, some complaints were made about a lack of GP involvement. For patients in the last phase of life, not only continuity of care but also continuity of carer is important. Retelling their stories to different professional caregivers was therefore considered frustrating and decreased trust. However it appeared that information continuity became very vulnerable when healthcare providers didn’t share and transfer information well. Management continuity became blurred when healthcare professionals worked in a fragmented fashion and lost sight at the patient as a whole person. In the study this was often related to hospital settings or hospital-home transfers. Collaborative team approaches were considered pivotal to facilitate relational, informational, and management continuity.

3.7 Current Challenges

It is of interest to see that across European countries, initiatives increasingly start to pay attention to the integration of their services in the local and national healthcare system. This often results in the building of networks between regional healthcare providers. Palliative care teams frequently exist of professionals of several organizations who work together in a multidisciplinary setting. It also happens that palliative care professionals have a labor contract in several organizations, for example, working as a GP and working in a hospice at home environment or working as a medical specialist in a hospital and in a palliative care consultation team. In particular connections between primary and secondary care are sought after but also are experienced as a challenge. This is partly due to the fact that electronic sharing of information outside the specialized palliative care team is mostly lacking, for example, an electronic patient record that can be shared between professionals from different organizations. Paper documentation and informal communication channels like mobile phones are often used but limit a structural and systematic approach to information exchange and joint action.

An important observation is that integration of palliative care earlier in the disease trajectory and beyond cancer is often not well supported by current healthcare culture and policies and difficult to implement. For example, reimbursement is often directed at terminal care with an expected life expectancy of less than 6 months, patient referrals come in late, advance palliative care planning may therefore be difficult, and services are mostly originating from (and still highly linked to) advanced cancer care.

Despite these challenges, interesting developments are currently ongoing. Inpatient palliative care providers recognize the value of integration and facilitate regional palliative care networks, connecting a diversity of service providers that deliver generalist palliative care. And at the same time, there seems a wider recognition that specialized palliative care should become available where the patient is, including his/her home. The UK hospice at home, for example, although partly born out of a lack of budget to build a hospice, proved to be very supportive in treating patients at home. The Dutch developed a network approach to support this, the Belgians have a primary care pathway, the Germans developed a one-stop shop, and in Hungary they established a hospice at home connected to a hospital consultation team. However, the long-term success of these initiatives requires that collaborations and reimbursement structures in primary care are supportive to palliative care, which is not always the case, for example, when indication and reimbursement for patients are limited to end-of-life care in the last months. Vulnerability exists where initiatives hinge upon the involvement and drive of a few dedicated professional care professionals but may be overcome when federal regulations support the building of teams. In the end, integration also should define roles and make space for generalist as well as specialist palliative care.
4 A Synthesis of Five Models of Palliative Care Integration

In an example of professional integration, the WHO definition states that palliative care “is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.” In previous years, an increasing number of papers have been published showing the positive effects of this “early palliative care integration” with efforts to identify and assess patients earlier in the disease trajectory. In addition, end-of-life care pathways have been developed and investigated together with primary care initiatives. In this section, some recent developments from the literature will be shown.

4.1 Early Integration in a Hospital Setting

One important example of clinical integration in a hospital setting is early integration, which has been increasingly investigated after a landmark RCT study by Temel et al. (2010), showing that newly diagnosed metastatic non-small cell lung cancer patients assigned to an early palliative care visit had a better quality of life and less depressed mood after 12 weeks. In addition they used less aggressive care and reported a longer survival, compared to those receiving normal US oncology treatment. A secondary qualitative analysis of the medical records of 20 patients revealed that key elements of the early ambulatory palliative care visits (compared to standard oncology visits) included addressing of symptoms and coping with relatively more attention to psychosocial care. Furthermore, building of relationships, better illness understanding, and prognostic awareness were important ingredients of these visits (Yoong et al. 2013).

In 2014, Zimmermann et al. published a cluster RCT involving 461 advanced cancer patients with a limited prognosis (6–24 months) in 24 medical oncology clinics, investigating palliative care team involvement at least once a month. Although the primary outcome of quality of life at 3 months did not statistically improve in the intervention group, it did improve at 4 months, which was considered a promising finding. Studies like these (for example Bakitas et al. 2015) will probably be more in-depth discussed in another chapter of this book, but for this chapter it is interesting to consider the possible working mechanism for early integration from the perspective of the so-called CMO approach based on context, mechanism, and outcome (Busetto et al. 2017). Based on the aforementioned literature exploration, it can be illustrated how the CMO approach can apply to early palliative care (Fig. 2).

Early integration in a hospital setting is often achieved by means of outpatient palliative care consultation, directed toward advanced cancer patients. In this setting, promising results have been achieved in terms of better quality of life, less depressed mood, less aggressive care, and in some studies even improved survival. Studies in this field are ongoing, and the results increasingly find their way to practice.

Based on the emerging evidence for the early integration of palliative care in oncology, the American Society of Clinical Oncology (ASCO),

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**Fig. 2** Context, mechanism, and outcome for the early integration of palliative care

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<tr>
<th>Context</th>
<th>Hospital environment, advanced cancer patients</th>
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<tbody>
<tr>
<td>Mechanism</td>
<td>Early integration with palliative (outpatient) care consultation</td>
</tr>
<tr>
<td>Outcome/promising findings</td>
<td>- Better quality of life, after 3-6 months, depending on study - Less depressed mood - Less aggressive care - Improved survival</td>
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</table>
in a recent update (Ferrell et al. 2017:120), formulated as a key recommendation that: “Patients with advanced cancer, inpatients and outpatients, should receive dedicated palliative care services early in the disease course and concurrent with active treatment. Referring patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer caregivers of patients with early or advanced cancer to palliative care services.”

4.2 Integrated End-of-Life Care in Hospitals: The Amber Care Bundle

Amber stands for assessment, management, best practice, engagement, and uncertain recovery. The Amber care bundle is focused on hospital patients whose recovery is uncertain and who are at the risk of dying the next 1–2 months (see www.ambercarebundle.org). It offers a systematic approach to help staff to realize when to start talking with patients and family members about the treatment and the care they prefer when their disease progresses. It combines identification questions, four clinical interventions, and monitoring of patients.

A recent qualitative study among 20 healthcare professionals based at 3 tertiary NHS hospitals in London investigated its potential use in labeling of patients, changing care delivery, and influencing the behavior of involved individuals and teams (Bristowe et al. 2018). Adequate exposure, training, and implementation were considered important preconditions for success. In another study from this group, patients (n = 19) were interviewed, and a survey was performed. It was shown that patients with the Amber care bundle had an effect of increased conversation about prognosis between professionals and patients, although the information received seemed not always easy for patients to understand (Bristowe et al. 2015). A retrospective chart review among 149 patients in 5 hospital wards showed that the Amber care bundle is more often applied in cancer patients and that patients received the Amber care bundle on average 10 days after admission, for a median period of 9 days (Carey et al. 2015). Despite positive initial experiences, more rigorous research is required to establish its efficacy in larger samples (see also Currow and Higginson 2013).

4.3 Integrated End-of-Life Care Pathways

A much debated example of an attempt to integrate palliative care in the last days of life, not limited to cancer patients, is the multidisciplinary care pathway for the dying. Although some positive evaluations have been available (Veerbeek et al. 2008), evidence underlying such pathways has been considered limited (Chan et al. 2016). Recently however, a large cluster randomized trial in acute geriatric wards in ten Flemish hospitals was published. Hospitals were randomly assigned to the CAREful intervention, a “care guide for the last days of life, training, supportive documentation, and an implementation guide” (Beernaert et al. 2017). Positive outcomes were found for nurse-assessed comfort of the dying, but not for family-assessed comfort of the dying or symptom improvement.

This is a promising conclusion in the light that a few years earlier, a well-known care pathway for the dying, namely, the Liverpool Care Pathway (LCP), became heavily criticized. One important conclusion from an independent review in 2013 reads that the Liverpool pathway seemed to work well in settings where it was operated by well-trained, well-resourced, and sensitive clinical teams. But when used without much attention, as a tick box exercise, it runs the risk of not showing enough respect to patients (Neuberger 2013). Due to the political concerns raised, the Liverpool Care Pathway became phased out in England. In other places however where the experiences were more positive, like the Netherlands and Flanders, care pathways for the dying are still being implemented. However, the aforementioned experience shows that care pathways should not
only be studied in an experimental setting but require a well-thought implementation trajectory before large-scale introduction takes place.

4.4 Integrated Palliative Care for Non-cancer Patients

The aforementioned approaches of integrated palliative care focused on a hospital environment, mostly related to cancer. Another approach however was taken by Higginson et al. (2014) who studied the effect of a breathlessness service integrating palliative care, respiratory medicine, physiotherapy, and occupational therapy. In a single blinded randomized trial, the service improved breathlessness mastery (the primary outcome) together with survival after 6 months in the intervention group.

In addition, this group also investigated the integration of palliative care as a complementary service for multiple sclerosis treatment in a randomized phase II trial (Higginson et al. 2009). They found lower mean service costs in the first 12 weeks of follow-up. In a related paper, they also reported an improvement in five key symptoms, although the main outcome measures “palliative outcome scale” (POS) and “the multiple sclerosis impact scale” remained unchanged (Edmonds et al. 2010). The experiments give rise to further thinking about the integration of palliative care and home care.

Bone et al. (2016) developed a model of short-term integrated palliative and supportive care for frail older people in community settings, based on the perspectives of older people, carers, and other stakeholders. Their model is designed for people with nonmalignant conditions living at home. The model involves ongoing general practitioner and community nursing team support and integrated working with specialist palliative care services, for example, visits, holistic assessment, single point of contact for general practitioner, and skilled workers for patient/carers. Potential benefits, according to the respondents, involve improved symptom management, improved carer well-being, and reduced hospital admission. This model however needs more empirical research.

4.5 Gold Standard Framework (GSF) in UK Primary Care

The UK Gold Standard Framework, originally developed to improve palliative care in primary care, became an important driver to integrate palliative care in the community setting as well (Clifford et al. 2016). The GSF is considered a quality improvement program with the aim to enhance proactive care at the end of life. It uses a three-step approach based on early identification, better assessment of clinical and personal needs, and focused planning and coordination. Goals are to improve quality of care, to improve coordination of involved care teams, and to reduce hospitalization. Patients considered to be in the last year of life are identified and registered in a GP-based palliative care register in order to improve care coordination. A survey among 6495 primary care practices in the UK showed that GSF uptake was achieved in about 60% of practices (Hughes et al. 2010).

Notwithstanding this, a primary care audit in 2009 showed that of all dying patients in the investigated 502 primary care practices, only 27% were identified in an end-of-life care register, suggesting a significant space for improvement. However, the identified patients seem to have received better end-of-life care (Omega report 2009). Besides, a finding of limited identification but better outcomes in identified patients was also reflected in a Dutch primary care study (Thoonsen et al. 2015). Lessons learned from the GSF program were formulated as follows (Clifford et al. 2016):

- Although many primary care practices reported using the foundation level of GSF, the uptake was still patchy and variable. A new accreditation program for GSF may stimulate better implementation.
- It is considered important that the GSF does not replace local practices and initiatives. There is no “one size fits all,” and local primary
care practices are stimulated to develop at their own pace, and the overarching framework needs to give opportunities for this.

- Local champions are important together with whole team commitment. Despite busy practices, it is possible to implement the GSF and to improve end-of-life care, not only for cancer patients but also for other target groups like frail elderly people.

The underlying principles of GSF have been adopted in other initiatives like PaTz (Palliatieve Thuiszorg) in the Netherlands. This initiative attracted national attention and is increasingly implemented in home care (van der Plas et al. 2014). In 2016, almost 100 groups were reported all over the Netherlands. Altogether initiatives like the Gold Standard Framework seem a promising way to integrate palliative care in primary care, although the actual percentage of identified palliative patients in GP practices seems still limited.

4.6 Synthesis

Examples I–III (early integration, Amber care bundle, care pathways) mostly address a micro-level where clinical integration is aimed for in a specific setting. The described examples for non-cancer (example IV) however are more related toward the community, connecting a variety of disciplines like physiotherapy and occupational care. The Gold Standard Framework is a program based in primary care but also has the ability to unite key players involved in the care at home, as happens in the Dutch PaTz project. These models (non-cancer models; GSF) move beyond a clinical perspective and also approach integration from an organizational (meso)perspective, even with elements of a macro – program-based – perspective.

Benefits of integrated palliative care have been shown in cancer care, but there is less evidence of initiatives in other conditions (Siouta et al. 2016a). There is increasing evidence of early integration in hospital-based cancer care. However, integration of palliative care across different sites and settings is much less well developed and may vary by country. In the UK, for example, the Liverpool Care Pathway, one of end-of-life care pathways, was heavily criticized for its poor implementation and has now been discontinued (DoH 2013). However there may be beneficial aspects of structured care pathways as were shown in a rigorous evaluation in Flanders in geriatric care (Beernaert et al. 2017). The Amber care bundle has demonstrated initial promising outcomes and is currently the focus of a large clinical trial. There is accumulating clinical trial evidence on the benefits of structured integrated care in palliative care for those with breathlessness and MLS (Higginson et al. 2009, 2014), but not much research has been done in this area. So far, the Gold Standard Framework seems the most widely implemented initiative in primary care and in nursing homes, although its evidence base and application is rather limited to the UK and needs further rigorous research.

To conclude Siouta et al. (2016b) searched the literature to investigate the evidence from empirical models of integrated palliative care. They recommended the following elements for a successful integration of palliative care:

- **Focus of intervention:** The focus of intervention will be placed on symptom treatment, consulting of patients/family and training of the personnel.
- **Setting:** The design of the framework is such that it can be applied to every care setting.
- **Timing of intervention:** The intervention can be initiated throughout the disease trajectory either concurrently or in the end of life.
- **Composition of team:** The framework requires a multidisciplinary team with members that are trained in the delivery of PC. This team can consist of GPs, physician specialists, nurses and specialist nurses, psychologists, social workers, and administrative assistants.
- **Collaboration strategy:** The collaboration strategy, which refers to the ways that the represented disciplines cooperate and assess
emerging issues, should be based on the involvement of the multidisciplinary team and its meetings and the utilization of protocols.

The next section will consider the integration of palliative care within professional guidelines more in-depth.

5 Palliative Care Integration: Lessons Learned from Five Professional Guidelines

Van Beek et al. (2016) investigated the integration of palliative care in 60 cancer guidelines and 14 pathways, originating from 6 languages. Relevant items were categorized using 11 criteria for integrating palliative care in guidelines as proposed by Emanuel et al. (2004). They found that four out of five cancer guidelines advocated a multidimensional assessment and about three out of five mentioned palliative care interventions to reduce suffering and the involvement of a palliative care team. In less than half of the cases, cancer guidelines paid attention to care during the last hours, to advance care planning, to bereavement care, and to (referral) criteria for palliative care involvement. Based on an assessment of five good examples, van Beek et al. made recommendations for integrated care criteria in guidelines (Table 3). However, they also admit that implementation of these criteria in current guidelines can be cumbersome.

Considering the integration of palliative care in guidelines for heart failure (HF) and chronic obstructive pulmonary disease (COPD), a review has been carried out by Siouta et al. (2016a). They investigated European guidelines published between 1995 and 2013 and included 17 guidelines and 2 pathways in their review. Applying the Emmanuel criteria as mentioned above, they concluded that almost all documents addressed suffering reducing interventions, and most (15/19) paid attention to illness prognosis and limitations. About two third of guidelines/pathways mentioned a holistic approach, a palliative care involvement, assessment of the patients’ goals of care, and advance care planning. Only few texts included grief and bereavement. The authors conclude that there is a growing awareness but that many areas still need improvement. Although there is no space to discuss all guidelines related to palliative care in non-cancer, it is worthwhile to mention that palliative care in dementia is also emerging, for example in a recent white paper (van der Steen et al. 2014). The Delphi procedure underlying this white paper mentioned the following domains of importance: person-centered care, communication, and shared decision-making, optimal treatment of symptoms and providing comfort, setting care goals and advance planning, continuity of care, psychosocial and spiritual support, family care and involvement, education of the healthcare team, societal and ethical issues, and prognostication and timely recognition of dying. Quite a few recommendations reflect the abovementioned Emmanuel criteria for integrated palliative care. Despite promising examples on the horizon however, a lot of work still needs to be done to fully integrate palliative care into disease guidelines.

6 Five Policy Strategies and Their Value for Integrated Palliative Care

In this section, some current attempts and proposals to map the development of integrated palliative care will be briefly discussed. One approach clarifies barriers and opportunities for integrated palliative care and will be discussed more in detail because this will demonstrate the current state of the art of integration of palliative care. The section closes with a description of WHO strategies about integrated care.

6.1 Indicators for Integrated Palliative Care

Hui et al. (2015), in collaboration with the European Society for Medical Oncology (ESMO), conducted a Delphi survey to establish indicators for the integration of oncology and palliative care programs in hospitals with more than 100 beds.
<table>
<thead>
<tr>
<th>Criterion</th>
<th>Recommendations based on cancer guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Discussion of illness limitations and prognosis</td>
<td>The guidelines/pathways agree that this can be realized through open and honest communication with patient and family, based on their needs and preferences, and enabling shared decision-making. One pathway also suggests the employment of the surprise question or the Palliative Performance Scale can be used as triggers for initiating such discussions</td>
</tr>
<tr>
<td>2. Recommendations for conducting a whole patient assessment including the patient’s physical, social, psychological, and spiritual issues, their family, and community setting</td>
<td>There is a unanimous consensus on the utilization of a combined physical, psychological, social, and spiritual assessment</td>
</tr>
<tr>
<td>3. Recommendations for when to make these assessments (e.g., at baseline and periodically thereafter)</td>
<td>Assessment should take place early in the disease trajectory. Further, it is recommended that holistic assessment should occur “at any time of day or night” for physical and psychological support and as long as possible for patient’s social participation. Also, its realization should vary depending on changes in the disease or on the appearance of new symptoms and based on application of, e.g., a “distress thermometer”</td>
</tr>
<tr>
<td>4. Recommendations on when palliative care should be integrated</td>
<td>Three strategies are identified: (i) the use of the surprise question, (ii) the evaluation of the patient’s and the family’s needs, and (iii) illness stage – disease-/cancer-related prognostic indicators (e.g., like the indicators mentioned in the Gold Standard Framework)</td>
</tr>
<tr>
<td>5. Assessment of the patient’s goals for care</td>
<td>All the guidelines/pathways agree that this assessment should be based on the continuous communication between the patient and the PC specialists to identify patient goals</td>
</tr>
<tr>
<td>6. Continuous goal adjustment as the illness and the person’s disease progresses</td>
<td>It is suggested that PC specialists regularly consult the patient and adjust goals accordingly</td>
</tr>
<tr>
<td>7. Palliative care interventions to reduce suffering as needed</td>
<td>The guidelines/pathways elaborate on the use of appropriate medication and strategies aimed in reducing both physical and psychological suffering</td>
</tr>
<tr>
<td>8. Advance care planning</td>
<td>Decision-making should be based on patient’s wishes and preferences. One pathway proposes the identification of the ACP via the use of three models (covenant model, contract model, or DNR code)</td>
</tr>
<tr>
<td>9. Recommendation of involving a palliative care team (interdisciplinary team, palliative care consultation, or other palliative care services)</td>
<td>All of the guidelines/pathways strongly recommend the involvement or formation of a multidisciplinary PC team (consisting of physicians, nurses and other health professionals, psychologists, mental health counselors, social workers, spiritual counselors)</td>
</tr>
<tr>
<td>10. Recommendations on care during the last hours of living</td>
<td>The following steps are recommended: identification of the dying phase, communication, support based on patients and family’s needs and wishes, and symptom control</td>
</tr>
<tr>
<td>11. Recommendations on grief and bereavement care</td>
<td>The main proposed strategy involves the immediate and ongoing bereavement, emotional and spiritual support appropriate to the family’s needs and preferences</td>
</tr>
</tbody>
</table>

After 3 rounds, they identified a list of 13 major indicators among which:

- Presence of an inpatient consultation team
- Presence of an outpatient palliative care clinic
- Presence of an interdisciplinary palliative care team
- Place of death consistent with patient preference
- Combined palliative care and oncology educational activities

A reply from Verna et al. (2016) however pointed to the necessity of not only drawing program criteria for big hospitals but also to develop sustainable indicators for integrated – community-based – palliative care, in particular in countries who have less resources for implementation. This is also reflected in the report of a German working group that reported best practice recommendations for the integration of palliative care and oncology (Berendt et al. 2016). After three rounds, high agreement was reached for having an organizationally and spatially independent palliative care unit (> 6 beds), a mobile multi-professional specialized palliative care team, and cooperation with community-based palliative care.

In 2016, Ewert et al. published a taxonomy for integrated palliative care initiatives, based on a consensus meeting with expert, including the following categories:

- Background of disease
- Type of initiative (pathway, model, guideline)
- Sector (inpatient, home care)
- Time frame of intervention (early integration, concurrent, end-of-life care)
- Coordination strategy (network, protocol, team, case manager)
- Primary contact point (palliative care, team, other)

This taxonomy is designed as a tool to identify and describe integrated palliative care, rather than to measure it. It offers insight in the various ways integration of palliative care can take shape but is not restricted to hospital care.

This short investigation shows that indicators to describe palliative care integration have been developed but not widely implemented. More work is needed in this field.

6.2 Barriers and Opportunities for Palliative Care Integration

An investigation from a public health perspective has been performed by Centeno et al. (2017) who used the EAPC Atlas to draft a picture of palliative care integration in Europe. The EAPC Atlas is based on the views of national palliative care associations in Europe about the current state and development of palliative care in their countries. These perspectives are presented in graphics to illustrate palliative care development across Europe and other parts of the world. Drawing from the palliative care Atlas database, it was considered which indicators – through the eyes of European national associations – were barriers and opportunities to the further development of integrated palliative care. The following figure shows the barriers identified (Fig. 3).

It is of interest to see that one third of the identified barriers fall within the policy dimension, about regional regulation and coordination. The integration of palliative care within non-cancer that appeared an important issue in the aforementioned analysis of promising examples is also listed here. Secondly, the most frequently mentioned barriers concerned the lack of basic training in palliative care in courses and curricula, followed by limited options for formal certification or subspecialization within the field of palliative care and medicine. A third group of barriers was related to the integration of palliative care services like human resources, coordination of services, and maturity of the discipline including the availability of multidisciplinary care.

Interestingly (Fig. 4), many of the aforementioned barriers are also considered opportunities, for example, the expansion of basic training for palliative care and the inclusion of palliative care at universities. Expert training and certification
are also considered major opportunities. In the field of policy-making, the regulatory framework has been mentioned by many experts. This refers, for example, to changes in the law favoring palliative care and the development of palliative care strategies and programs. In the context of the previous analysis of inspiring practices, changes in policy strategy like, for example, restricted palliative care reimbursement for advanced cancer may be a solution for better integration toward non-cancer and integration earlier in the disease trajectory. This may also have a positive influence on service development like business plans and resources and the integration of palliative care in professional guidelines which was also discussed earlier in this chapter. Remarkably, research is also mentioned as an opportunity, in particular, by Belgium, Iceland, and the UK. In their study, Centeno et al. (2017) also pointed out that countries with more mature palliative care service availability more often report barriers and opportunities in the area of integrated palliative care, probably related to increasing expectations of palliative care development. Contrary, in countries with less palliative care development, basic palliative care provision seems to be the highest concern.

Fig. 3 Barriers toward integration of palliative care in European countries. Figure developed by the Atlantes group, Navarra, Spain (Prof. Centeno, published with permission). The European palliative care atlas is based on the WHO European region involving 53 countries whose national palliative associations nominated an expert to answer the Atlas questionnaire. In this figure only answers to specific questions about palliative care integration are listed
6.3 Policy Initiatives from the World Health Organization

In 2016, the World Health Organization (2016) launched a new framework on integrated people-centered health services based on a vision that all people have equal access to quality health services in a way that meets their life course needs. According to the WHO, integrated care involves five strategies which can be described as follows:

1. Engaging and empowering people and communities. Patients and families need to be active participants in care that is delivered in an equal and reciprocal relationship, in order to achieve better clinical outcomes. It is also about communities to organize themselves and to make changes in living environments, in particular, toward the underserved, and to provide place and training for informal care.

2. Strengthening governance and accountability. This involves involvement in policy...
formulation and decision-making but also evaluation and societal accountability. Enhancing welfare requires a stewardship role for governments and participatory involvement of communities.

3. Reorienting the model of care. This involves a reorientation toward life course needs of populations. Furthermore, a shift from inpatient care to outpatient and ambulatory care, based on a publicly available primary care to reach the entire population. It calls for multi-professional teams and family- and community-oriented care models where modern technologies and mHealths are embedded.

4. Coordinating services within and across sectors. Services should be organized around the needs and demands of people. This requires integration across health settings. It involves intersectoral alignment and harmonizing of processes and information, not necessarily the merging of institutions. It is centered around care for individuals but also coordination of health programs and providers to bridge administrative, informational, and funding gaps. Finally, it involves multiple sectors like healthcare, social care, labor, and housing.

5. Creating an enabling environment. In order to make transformation happen, the involved stakeholders need to be brought together which requires collaborative leadership where improvements in information and knowledge development, regulatory frameworks, and funding incentives take place.

Although it would be interesting to examine to what extent (inter)national palliative care plans and programs use these five strategies, this chapter can only briefly examine one initiative, namely, the WHO resolution on palliative care.

6.4 The WHO Resolution on Palliative Care

In 2014, the World Health Assembly approved a resolution called “strengthening of palliative care as a component of comprehensive care throughout the life course” aiming to integrate palliative care policies in healthcare systems and healthcare education. Soon after this agreement, a Technical Advisory Group for palliative care was installed. In 2017, an accompanying book was released by the Technical Advisory Group in 2017, emphasizing that palliative care should be implemented as a comprehensive and integral part of the care for patients with advanced and life-limiting diseases. Short- and long-term actions have been formulated, among which the involvement of health ministries at a country level, WHO agencies, policies for resource-poor countries, ethics, the relation toward complex and chronic care, a community perspective, and leadership empowerment (Gómez-Battiste and Connor 2017). WHO demonstration projects for palliative care, among others the Catalan public health program, are described, and the expansion of palliative care to non-cancer patients is stressed.

Altogether, there seems to be a momentum to foster the implementation and integration of palliative care in health systems, where several initiatives could reinforce each other. The book as released by the WHO could guide an implementation program to better integrate palliative care, making use of the five WHO policy strategies for integrated care. This implementation program could be monitored by an indicator set based on already existing platforms for palliative care mapping like the Atlas project including the support of the EAPC (European Association for Palliative Care) and the IAHPC (International Association for Hospice and Palliative Care). Such a supportive joint collaboration could support the further implementation of the WHO palliative care resolution toward better palliative care integration.

7 Summary and Conclusion

This chapter started with a definition of integrated palliative care and a brief exploration of several elements of integrated care in relation to palliative care (clinical, professional, organizational, functional, normative, health system integration). Examples from five European countries were described and discussed. Here, functional integration in terms of relational, informational, and
management continuity appeared to be vulnerable. Furthermore, based on the literature, five models supporting integrated palliative care were discussed mostly at a clinical or a mesolevel, namely, early integration, the Amber care bundle, care pathways for the dying, integration in multiple sclerosis and a breathlessness service, and the Gold Standard Framework in primary care. In previous years, most research and evidence generation about integration has been directed at early integration for hospital-based cancer care. Promising models outside cancer and in community settings could be identified but often need more rigorous investigation and development. Considering the integration of palliative care in professional guidelines, recommendations were summarized based on an analysis of five promising guidelines. Studies investigating a broader analysis of guidelines however showed that full integration still leaves a world to win. Finally a macrolevel policy approach was taken by discussing current initiatives to map integrated palliative care with indicators. In addition, the newly launched integrated care framework of WHO was summarized together with the WHO resolution for palliative care.

Integrated care has often been considered and discussed from the perspective of better integrated healthcare delivery, which is needed and valuable. However, coming at the end of this chapter, it should be acknowledged that real integration goes beyond health service delivery. In the 1960s, Cicely Saunders coined the concept of “total pain” to show that patients cannot be reduced just to their physical problems but that social and life views need to be incorporated as well. Integrated palliative care is in its essence about whole patient care in the last phase of life. The welfare of the patient in this last phase is not only dependent upon the medical services he or she receives but also includes the social environment, the housing, the support, and well-being of family members and informal caregivers. In this respect, it is interesting to refer to the concept of a new public health approach for palliative care, which is based on engaging communities (Sallnow et al. 2016). Efforts for better integration of palliative care should move beyond a better organization of medical care and need to be rigorously designed from the perspective of the suffering patient in the last phase of life. This means that the whole living environment of the patient needs to be taken as a starting point, including family care, social care, place of living, health education and (il)literacy, and healthcare arrangements.

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