# Multidimensional symptom management in palliative care: exploring ways to support generalist clinicians across care settings

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# CHAPTER

# 1

## General introduction and thesis outline

## 1.1 PALLIATIVE CARE APPROACH

“Palliative care is care improving the quality of life of patients and their families, who are facing a life-threatening condition or frailty, through prevention and relief of suffering by means of early identification and careful assessment, and treatment of problems of a physical, psychological, social, and spiritual nature. Over the course of the illness or frailty, palliative care aims to preserve autonomy, access to information and the opportunity to make choices.” This modified version of the 2002 World Health Organization (WHO) definition of palliative care (1) is used in the Netherlands Quality Framework for Palliative Care, that was published in 2017 (2,3). The Netherlands Quality Framework was drafted by a representative body of patients, friends and family, healthcare professionals and health insurers and aimed to answer the following key question: “What do we [...] agree that the criteria for quality of palliative care in the Netherlands should be?”. The framework is intended to support healthcare professionals (caregivers, nurses, general practitioners, and hospital medical specialists) in developing and implementing palliative care, enabling them to provide high quality, safe and effective care for all palliative-stage patients, at the right time and in the right place (2). It is important to note that palliative care is not the opposite and is not separated from usual patient care, but rather a care approach that should be integrated in the care for all patients with a life-threatening illness (4).

The necessity of palliative care is underlined by the number of patients who need it. In the Netherlands, 150.000 people died in 2017 and the death of 105.766 people (70%) was preceded by an illness trajectory. These patients likely needed palliative care at some point in their illness trajectory (5). The need for palliative care will only increase, as it is expected that by 2055, 209.000 patients will die yearly (6), and 70.3-75.4 percent of these deaths will be proceeded by an illness trajectory (7).

## 1.2 ORGANIZATION OF PALLIATIVE CARE

In the Netherlands, palliative care is usually organized according to the generalist-plus-specialist palliative care model (8-11). Within this model, all clinicians (both nurses and physicians) are expected to provide basic palliative care. Generalist palliative care consists of managing physical and psychological problems and having conversations about prognosis, treatment goals and life-sustaining treatments. Clinicians who are specialized in palliative care can support generalist clinicians to provide care for patients with more complex care needs, such as refractory symptoms or difficult psychosocial and spiritual problems (9, 10). In the Netherlands, palliative care is not an official medical (sub)specialty, contrary to for example the United States (US) and a minority of European countries (12). In general, clinicians are considered specialists in palliative care if they completed one of three dedicated palliative care training programs for nurses or doctors, and/or are a member of palliative care consultation service. All other doctors and nurses are considered generalists in palliative care. Dutch palliative care specialists usually support generalist clinicians through consultation, and generalist clinicians thus remain in charge of the majority of palliative care delivery.

## 1.3 CORE PRINCIPLES OF PALLIATIVE CARE

From the Netherlands Quality Framework's definition, three core principles of the palliative care approach can be derived. First, patients who might benefit from a palliative care approach should be identified in a timely manner. This enables clinicians, patients, and their caregivers to start talking and thinking about the meaning of the last stage of life in time. It has proven difficult for generalist clinicians to identify patients who may benefit from integrating a palliative approach in their care because it requires a different mindset than in usual health care delivery, where determining the type of required care is mostly diagnosis driven. Identifying the need to integrate a palliative care approach is indicated by the needs of a patient with any life-threatening illness, regardless of their diagnosis. Types of illnesses that may require palliative care integration at some point in the disease trajectory include advanced cancer, heart failure, severe chronic lung diseases, end-stage renal disease, neurological diseases, dementia, and frailty of old age (13, 14).

A second core principle of a palliative care approach is a combination of preserving a patient's autonomy, warranting them and their caregivers' access to information and giving patients and their caregivers the opportunity to make choices. It should be established clearly what patients and their caregivers consider beneficial for their quality of life. As such, empowering patients and their caregivers is important. Patient empowerment is defined by the WHO as 'a process through which people gain greater control over decisions and actions affecting their health'. As a result of empowerment, patients should be equipped to participate in informed, shared decision making, which is a guiding principle in palliative care (15).

A third core principle is that palliative care should help patients to achieve or maintain their optimal quality of live, by relieving suffering through adequate management of potential physical symptoms and non-physical problems. This is important because most patients with a life-threatening illness experience multiple physical symptoms simultaneously. Such symptoms may be a result of the disease itself, comorbidities, or associated treatments. The number of symptoms and symptom severity change over time, and especially increase in the last months of life (16, 17). In addition, patients may experience psychological, social, and spiritual problems, such as depression, worries about the future of their family or friends and fear of the unknown. Experiencing physical symptoms and psychological, social, and spiritual problems have all been shown to negatively impact well-being (18-22).

## 1.4 MULTIDIMENSIONAL PALLIATIVE CARE

Relieving suffering requires adequate management of current and future physical symptoms and non-physical problems. In the last months before their death, regardless of the type of advanced life-threatening illness, patients usually experience multiple physical symptoms simultaneously (17, 21, 23) and they often also experience psychological, social, and spiritual problems (23). The needs of patients and their caregivers in all four domains are likely to vary over time, according to their type of life-threatening illness and concurrent typical illness trajectory. Three different illness trajectories have been described for patients with different types of underlying illnesses. When looking at the physical domain, these comprise: 1) steady progression of disease and usually a distinct terminal phase (mostly cancer); 2) gradual decline, punctuated by episodes of acute deterioration and some recovery, with more sudden, seemingly unexpected death (mostly organ failure); 3) prolonged gradual decline (frailty or dementia) (24, 25). In figure 1 the variations during the course of disease within the other three domains are described (figure 1).

It is key that potential problems in all these four dimensions are considered when trying to relieve symptom burden. In this thesis, multidimensional symptom management is defined as the simultaneous assessment, treatment and reassessment of multiple symptoms while considering physical, psychosocial, and spiritual aspects. In a broadly adopted symptom management framework, symptoms have been defined as ‘subjective experiences reflecting changes in a person’s biopsychosocial function, sensation, or cognition’ (26). This definition indicates that whether a patient experiences a symptom and the intensity of this experience  are also influenced by non-physical factors. This is illustrated in detail in the total pain model, which was first introduced by Cicely Saunders (figure 2) (27, 28). The experience of pain is not only caused by ‘actual or potential tissue damage’ (29) but is also affected by psychological, social, and spiritual factors (27, 29). Vice versa, physical symptoms can cause or increase non-physical problems, such as feelings of hopelessness, isolation, and fear of suffering (30, 31). Due these interactions, clinicians and patients need to consider both physical symptoms and non-physical problems if they want to optimally relieve symptom burden.

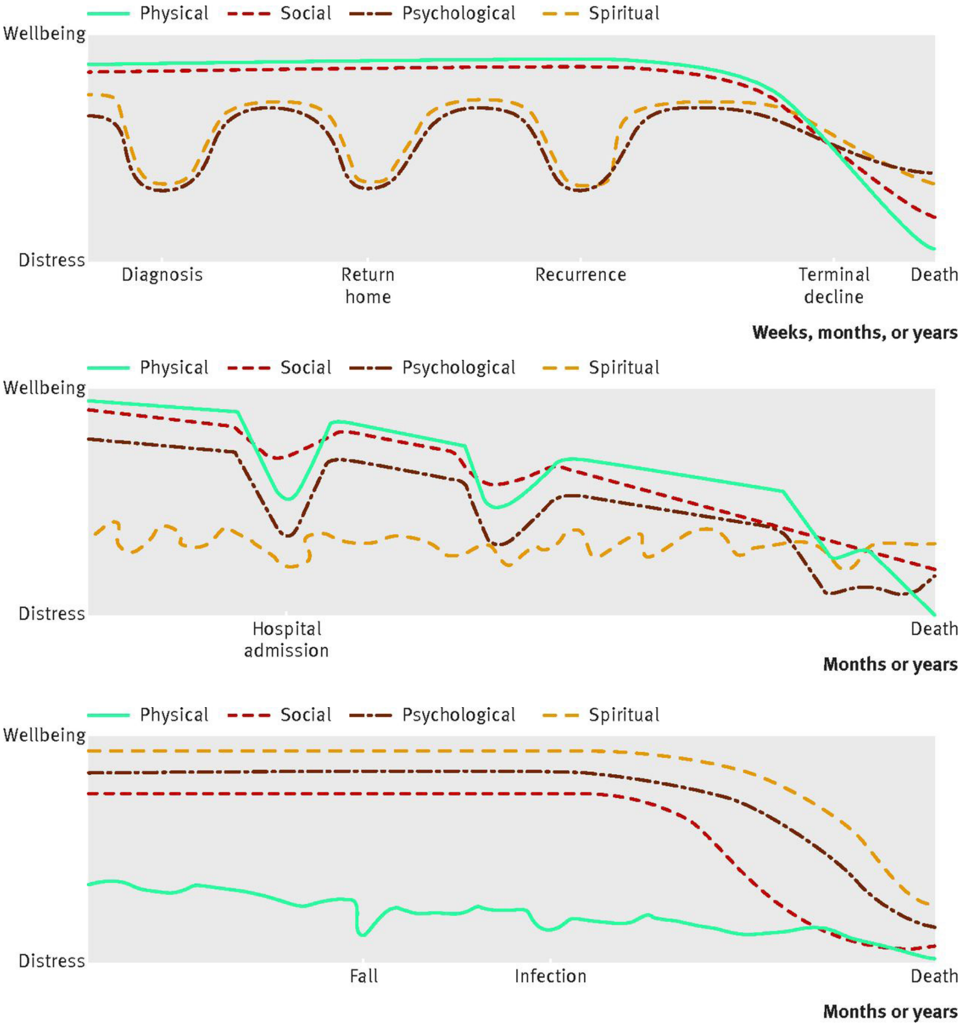

**Figure 1.** Variations in the course of physical, social, psychological, and spiritual needs of patients and their caregivers according to their type of life-threatening illness (25). Conditions such as cancer causing rapid functional decline (top); intermittent decline, typically organ failure or multimorbidity (middle); gradual decline, typically frailty or cognitive decline (bottom).

Despite widespread consensus on the importance of multidimensional symptom management, the concept is difficult to integrate into daily practice, even in specialized palliative care settings like hospices (32). Several aspects of current clinical practice seem problematic for the integration of multidimensional symptom management. First, during regular history-taking, patients spontaneously mention a median of one symptom (range 0-5) only, whereas systematic symptom assessment yields a median of 10 symptoms (range 0-25) (33). Second, research has shown that nurses and physicians who are not specialized in palliative care find it difficult to address and discuss the non-physical dimensions of palliative care (34, 35). Third, current palliative care symptom management guidelines usually only consider separate symptoms, but do not consider a comprehensive treatment approach for simultaneously occurring symptoms (36, 37). All factors likely cause the focus of symptom management to be on one or a few physical symptoms. Not addressing and treating simultaneously occurring physical symptoms causes symptoms to remain unrelieved, which negatively impacts quality of life and functioning (38). Insufficiently considering potential problems in the non-physical domains also negatively impacts quality of life (30). It is therefore important to support clinicians with integrating multidimensional symptom management in their daily practice.

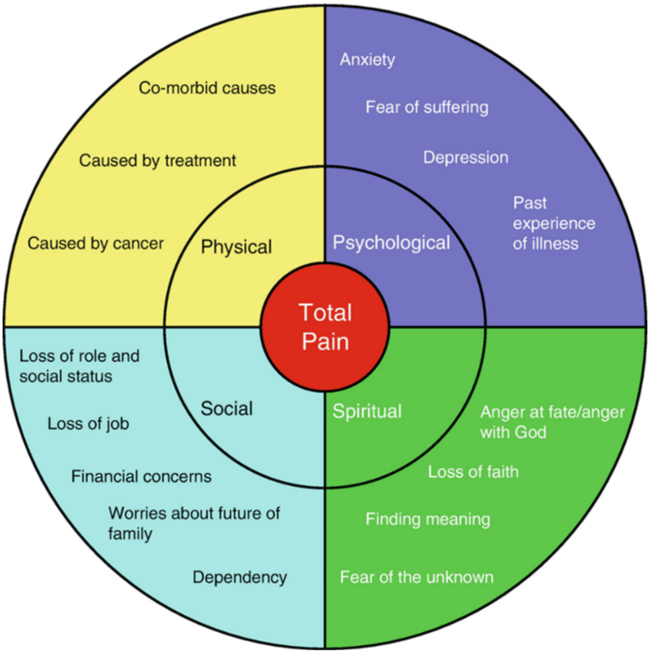

**Figure 2.** ‘Total pain‘ model (28).

## 1.5 PALLIATIVE CARE CONSULTATION TEAMS

As of 2017, hospital-based palliative care consultation teams (PCCTs) are available in all Dutch hospitals (39). The aims of these hospital-based PCCTs are twofold: 1) to support generalist clinicians in delivering palliative care, and 2) to directly support patients and their caregivers. For these purposes, their work involves both nonclinical and clinical activities. Nonclinical activities constitute education of generalist clinicians, palliative care research, implementing quality improvement measures and development of institutional palliative care guidelines and policies (8, 40). Also, PCCT members can advise generalist clinicians on patient care, and can directly support patients and their caregivers. The clinical work of PCCTs has shown to improve patient outcomes. It is associated with a better quality of life, improved symptom control, higher patient satisfaction, less time spent in the hospital, more patients dying in their preferred place, and improved quality of dying in the hospital (41-47). Based on these positive effects, involving palliative care specialists in every patient with a life-threatening illness could be advocated. However, the number of patients in need of palliative care grossly exceeds specialist care team capacity (9,10). It is therefore paramount that generalist clinicians and PCCT members effectively work together in providing optimal care for patients with palliative care needs. Whether PCCT involvement is required depends on two factors. First, it depends on the level of complexity of the patient’s care needs, which can vary at different points in the patient’s illness trajectory (figure 3). Second, whether and how much PCCT involvement is required depends on the level of palliative care knowledge and skills of the attending individual generalist clinician or generalist care team.

It is important to note that palliative care consultations usually take place at the initiative of generalist clinicians. This means that the generalist must be able to identify which patients have palliative care needs and must recognize when PCCT involvement is required. Insufficient palliative care knowledge and skills of generalist clinicians hinder adequate consultation of specialist palliative care services (48). The Netherlands Comprehensive Cancer Organization (IKNL) periodically evaluates the state and activities of Dutch hospital PCCTs through a national survey. In the most recent evaluation in 2020, PCCTs did 13.044 consultations for inpatients in 46 hospitals with a combined total of 1.080.368 hospital admissions (49). This means that a PCCT was involved in the care of 1.3% of inpatients compared to 0.9% in 2017 (50). This implies a rise, however, it is little compared to 4.8% in the US in 2015 and 5.6% in 2018 (51, 52). Initiatives to improve the integration of these services have been undertaken and are still ongoing. For example, clear criteria for referral to or consultation of such services have been developed for generalist clinicians, based on international consensus (53, 54). In addition, hospital-based palliative care consultation teams usually developed local, institutional palliative care guidelines, in line with recommendations of international palliative care organizations (8).

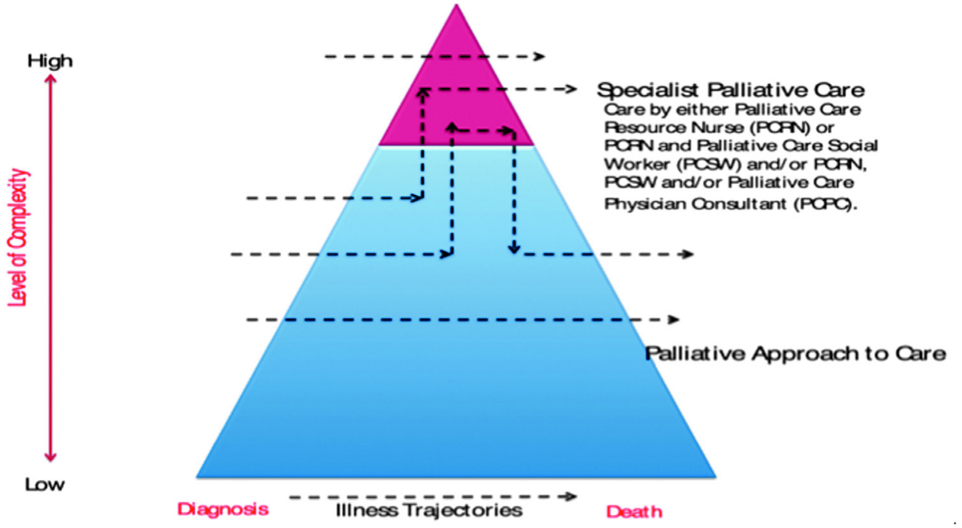

**Figure 3.** Interaction of specialist palliative care teams with generalist clinicians based on levels of care complexity (Adapted from LEAP Core, Pallium Canada) (8).

## 1.6 PALLIATIVE CARE AWARENESS AND SKILLS OF GENERALIST CLINICIANS

Although attention for palliative care has increased over the last decade, there are still misconceptions that hamper good quality care for every patient and caregiver.

These misconceptions include that 1) palliative care is only for patients with cancer, 2) it equals care in the terminal phase (13, 55-57) and 3) palliative care approach cannot be integrated with disease-modifying treatment, such as targeted therapy in case of cancer (55, 58-60). Most of these misconceptions likely stem from the old concept of palliative care, wherein palliative care started when all disease-modifying treatments were no longer an option (figure 4). The new palliative care model promotes integrated palliative care, wherein palliative care is provided alongside treatment with curative or disease-modifying intent (61).

There is one Dutch study that evaluated the self-perceived confidence of final-year medical students to deliver palliative care and found that the majority felt unprepared (62). When looking at generalist clinicians' self-reported attitudes towards palliative care provision in other western countries, generalist doctors at all training levels and across medical fields often feel unprepared. Doctors in the first years after graduation have reported feeling 'thrown in at the deep end' and feeling unprepared and unsupported in providing palliative care (63). Moreover, medical specialists in the oncology field, such as medical oncologists, radiation oncologists and oncological surgeons, have generally reported feeling insecure about their palliative care knowledge and skills and rate their palliative care education as insufficient (64-67). In addition, a considerate number of general practitioners (GPs), who usually play a key role in providing palliative care, seem to feel unprepared: a quarter of 516 surveyed UK GPs rated their palliative care training as absent or inadequate (68), and a quarter of 573 surveyed Danish GPs (69) and 31% of 56 surveyed Australian GPs reported they lack confidence in providing palliative care (70). For nurses in western countries, it appears to differ per medical field how they perceive their own ability to deliver palliative care. The majority of oncology nurses generally feels prepared (71). However, nurses that care for non-cancer patients, like a great majority of nephrology nurses, report that they feel unprepared and need palliative care education (72).

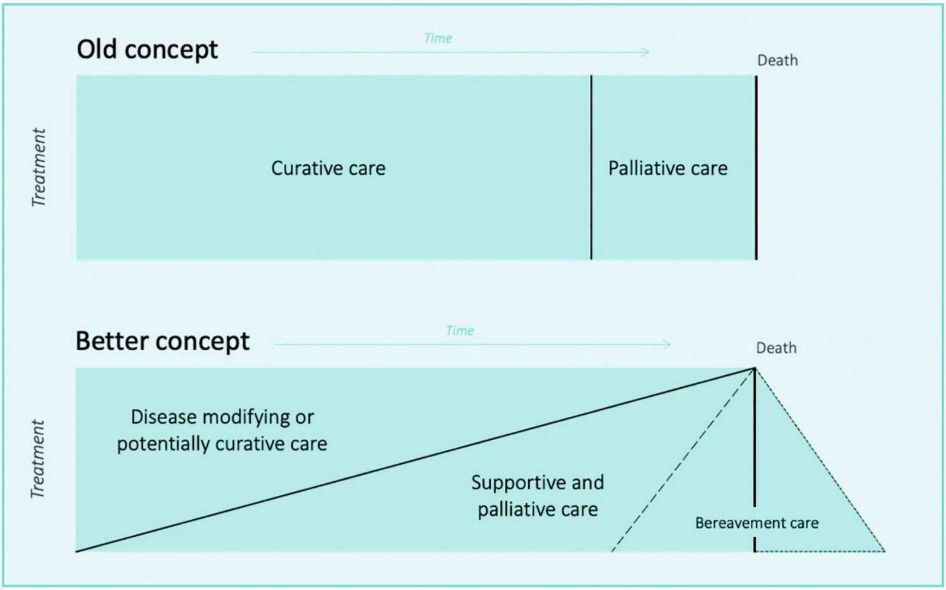

**Figure 4**. Old and new concept of palliative care (24)

Until recently, a very limited amount of palliative care education and training was integrated in the Dutch basic medical curricula and postgraduate training programs (73, 74). Palliative care education has been formally integrated in the basic medical curriculum for doctors as of 2020 (75) and in the masters’ curricula for advanced nursing practitioners and physician assistants as of 2023. Efforts are currently made to also formally integrate palliative care education in the basic curricula of carers, nurses and in postgraduate training programs for medical specialists in a national project that aims to optimize palliative care education (Optimaliseren Onderwijs Palliatieve Zorg (O2PZ)). A specific difficulty with preparing generalist clinicians for delivering palliative care, is that the skills required are often not aligned with the general 'cure' approach of health care and the society, as described in a 2015 Dutch evaluation of appropriate care in the last phase of life (76). For example, 'doing something' instead of refraining from treatment is the standard for clinicians, likely because they are trained to cure patients. Therefore, not starting treatment or starting treatment with other than a curative intent may feel as a failure. In addition, 'giving up' is generally not an option in most societies and both clinicians and patients are not used to talking about death and dying. Talking about refraining from treatment also takes more time than starting active treatment. These mechanisms stand in the way of discussing and documenting end-of-life preferences. Moreover, life-prolonging treatments are overrepresented in guidelines as they are usually not tailored to the elderly or patients with multiple illnesses. Recommended treatments are therefore mostly not targeted at improving or maintaining quality of life. Lastly, in the current reimbursement system, healthcare institutions and healthcare professionals are often paid per treatment procedure, which create an incentive for starting active treatment (76).

## 1.7 SUPPORTING GENERALIST CLINICIANS IN IMPROVING THEIR PALLIATIVE CARE KNOWLEDGE AND SKILLS

### 1.7.1 Improving basic palliative care skills

In addition to the establishment of specialist palliative care services, many other efforts have been made over the last decades in the Netherlands to support generalist clinicians in delivering palliative care. As aforementioned, structural palliative care education has improved over the years, in line with international developments (77-79). Another point of focus has been the implementation of tools to help generalist clinicians to identify patients who might benefit from a palliative care approach. In the Netherlands, the one-year surprise question is considered the gold standard tool for this (2). Hence, if the clinician answers "No"  to the question "Would I be surprised if this patient died within the next twelve months?" identifies patients who will likely benefit from a palliative care approach (80, 81).

### 1.7.2 Symptom assessment

Several solutions have been suggested for addressing symptom burden more comprehensively and multidimensionally. Most notably, symptom assessment scales have shown to improve the assessment of total symptom burden (33, 82). Many multidimensional assessment tools for palliative care have been described (83) and several of these symptom assessment scales are widely used in palliative care research and clinical practice, such as the Edmonton Symptom Assessment System (ESAS). The ESAS systematically measures symptom severity of ten prevalent physical and psychological symptoms by using a numeric rating scale (NRS) from 0 (no complaints) to 10 (worst imaginable or intolerable) (82). The validated Dutch adaptation of the ESAS is the Utrecht Symptom Diary (USD) (84). The USD measures symptom presence and intensity of 12 listed symptoms and contains an additional question regarding which symptom(s) bothers the patient the most and is their priority for support.

In addition to symptom assessment scales, efforts have been made to identify which symptoms frequently occur simultaneously in patients with advanced life-threatening illnesses, so called symptom clusters (85). Symptom cluster research has advanced symptom science in research through identification of common etiologies of symptom clusters and the impact of symptom clusters on patient outcomes, such as functioning and quality of life (86).

Efforts to improve adequate treatment of a patient’s physical symptoms and non-physical problems have also been made, mostly by developing national palliative care symptom management guidelines (37) in line with developments in other countries (87). The Dutch national guidelines are provided per individual symptom. For each symptom, recommendations are provided on history taking, physical examination, and pharmacological and non-pharmacological interventions (37). The lack of comprehensive treatment strategies for simultaneously occurring physical symptoms and problems in the non-physical dimensions is problematic, given the relatedness of physical symptoms and non-physical problems (27-31).

### 1.7.3 Difficulties with supporting generalist clinicians

There are difficulties with the integration of symptom assessment scales, results of symptom cluster research and symptom management guidelines. First, wide implementation of symptom assessment scales is lacking in both specialist and generalist palliative care settings. Barriers for implementation include time constraints and negative perceptions among clinicians about the usefulness of such scales (88). Also, scores on symptom assessment scales are often not acted upon even in institutions where symptom assessment scales are routinely integrated in patient care (82). Second, many symptom cluster studies have been performed but their results have not convincingly affected clinical practice. This may be because there is no gold standard for identifying symptom clusters in practice and subsequent recommendations for interventions for symptom clusters are still lacking (36, 86). This may be because identified symptom clusters differ greatly between studies and cluster research has until now mostly been conducted in specific subgroups of patients with a life-threatening illness (85). Third, medical guideline implementation in the daily practice of clinicians has proven difficult

(89, 90). Evaluations of barriers for using palliative care guidelines have not identified specific problems, but mainly relate to the difficulties of implementing medical guidelines in general (91). Domains with barriers to guideline implementation include the cognitive domain, negative attitudes, and social and organizational domains. Examples of specific barriers are clinicians who believe that the evidence base for guidelines is insufficient, and that using the guideline costs too much time, and leads to a heavy workload (90).

## 1.8 SETTING OF THE RESEARCH PRESENTED IN THIS THESIS

The studies presented in chapter 3 to 6 of this thesis are part of the multicenter MuSt-PC project (a Multidimensional Strategy for Palliative Care; 2017-2021; NCT0366516). This national project is a collaboration between the seven Dutch Centers of Expertise in Palliative care and IKNL and is funded by ZonMw and Dutch Cancer Society (KWF Kankerbestrijding) for the period 2018-2024. The project intends to develop, evaluate, and implement a clinical decision support system (CDSS)-like tool to support generalist clinicians to improve symptom management in palliative care. CDSSs are a promising solution for improving the integration of symptom assessment scales and the implementation of medical guidelines. CDSSs provide clinicians with patient-specific recommendations to support their clinical decision-making. Such systems use individual patient data as input and intelligently filter information from an underlying medical knowledge base (92). There is convincing evidence that CDSSs improve clinician performance, which is reflected in increased guideline adherence (93, 94), and patient benefits. CDSSs may reduce mortality and adverse events and they aid patient decision-support (94, 95). Diagnosis-specific and symptom-specific CDSSs are available in palliative care (96, 97). However, a tool that combines a patient-reported symptom assessment score with guideline-based symptom management recommendations regardless of patients' underlying illness, has not yet been developed (98). Research has shown that introducing tools that support clinical decisions in daily practice is not without obstacles, including reluctant end-user attitudes and negative impact on clinical workflow (92, 94).

## 1.9 AIMS AND THESIS OUTLINE

The aims of this thesis were to explore how generalist clinicians can be supported by a PCCT in providing palliative care and how they can be supported with multidimensional symptom management in particular. Both are in line with the aim of the Netherlands Quality Framework for Palliative care to enable healthcare professionals to provide high quality, safe and effective care for all palliative-stage patients (2).
Research questions were the following:

1. What do generalist clinicians perceive as barriers to palliative care and as educational needs?
2. What is their awareness and use of available palliative care support options?
3. What are barriers and facilitators to multidimensional symptom management in generalist palliative care?
4. Which symptoms frequently occur simultaneously in patients with palliative care needs?
5. Is using a clinical decision support system for multidimensional symptom management in generalist palliative care acceptable and feasible?

**Chapter 2** describes the combined results of a survey and retrospective cohort study. Generalist clinicians working at Leiden University Medical Center (LUMC) were surveyed in 2012 and 2016. With the survey we aimed to 1) identify what generalist clinicians perceive as palliative care barriers and educational needs and 2) to evaluate their awareness of available palliative care support options. The retrospective cohort study aimed to evaluate referral patterns of generalist clinicians to the LUMC specialist palliative care team, to identify how the PCCT as a specialist support option is utilized by generalist clinicians. In **chapter 3,** barriers and facilitators to multidimensional symptom management are evaluated in a focus group study with various stakeholders (patient representatives, generalist nurses and physicians, palliative care specialists). **Chapter 4** covers a large cross-sectional survey study among patients with palliative care needs. The study aimed to determine the prevalence of simultaneously occurring symptoms. **Chapter 5** presents the results of a secondary analysis of the cross-sectional survey data collected in the study of chapter 4. We evaluated if it is feasible to predict co-occurring symptoms based on the symptoms that a patient spontaneously mentions using a Bayesian Network. The predictions could help generalist clinicians to prioritize which symptoms to assess. **Chapter 6** describes the results of a focus group study among the same stakeholders as chapter 3. It evaluates the acceptability of a clinical decision support system that combines a patient-reported symptom assessment scale with guideline-based recommendations for multidimensional symptom management.

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