

**CHAPTER 1.
INTRODUCTION.**

Chapter 1. General introduction

Palliative care is an approach which improves the quality of life of patients and families who are facing life-threatening illness through the prevention, assessment and treatment of pain and other physical, psychosocial and spiritual problems (Sepulveda et al, 2002).

Modern palliative care

The worldwide development of modern palliative care is deeply rooted in the specialty of oncology. This has fundamentally shaped palliative care, produced some of its major leaders and innovators and provided a population of patients who benefit from the potential of a new approach to the management of advanced disease (Clark 2007). Before the emergence of modern palliative care, academic attention was mainly focused on the potential for a curative treatment for cancer. During the 1950s, new studies provided insight into both social and clinical aspects of care for patients dying from cancer. One study noted that “the fact of palliative treatment is not understood, and hospitals appear to be trying to cure all their patients and failing in a high proportion of cases” (Aitken-Swan & Paterson, 1955 in Clark, 2007).

Dame Cicely Saunders recognised the inadequacy of the care for the dying that was offered in hospitals. In 1967, she and her colleagues opened the world’s first modern hospice in London. At that time, there were only a handful of hospices in the United Kingdom (UK), and these were run by religious foundations. In St Christopher’s Hospice clinical care, teaching, and research were combined with an overall philosophy that a dying person is more than a patient with symptoms to be controlled. Hospice services in the United States (US) developed differently to those in the UK; the US mainly focused on home care (Clark, 2007). Also, in the US there was much less contact with oncology and a much greater focus on non-cancer patients than in the UK. US hospice services grew from a founding organisation in New Haven in 1974 to some 3000 providers by the end of the 20th century (Clark, 2007).

Another important landmark in the emergence of modern palliative care was the 1969 publication of a book entitled ‘On Death and Dying’ by Elisabeth Kübler-Ross, a Swiss – American psychiatrist. Her book on the stages of dying, and how to communicate with patients who were dying, became a worldwide bestseller. She listed a series of emotional stages that people experienced when faced with impending death or the death of someone; denial, anger, bargaining, depression, acceptance.

In the 1970s palliative care hospice teams emerged in hospitals. Hospice ideals and practices also began to be disseminated into the community from the 1970s. Unsurprisingly, the first community teams for palliative care originated in the US and UK. In 1969 Dame Cicely pioneered the first hospice home care team, which took the St Christopher’s model of care and philosophy out into the patient’s home. A team of senior nurses visited

patients and consulted with them and their relatives to assess and advise: 'The nursing team is essentially advisory and no direct nursing or medical care is provided in the home by it, i.e. it does not replace existing services' (Parkes, 1980). The team was supported by a physician, a psychiatrist and the services at St Christopher's Hospice.

In the UK there are two large organisations that boosted the knowledge of palliative care nursing, and still provide palliative nursing care in the community: Marie Curie Cancer Care and MacMillan Cancer Support. The first (Marie Curie) provided nursing care to palliative care patients, whilst the second (MacMillan) aimed to provide specialist palliative support alongside GPs and home-care nurses. The Marie Curie Memorial Foundation 'has been concerned about the shortage of full-time professional nursing care (particularly at night) for those patients who are being nursed at home: a need also exists for those who have some nursing experience, and for 'sitters-in' so that relatives can obtain the necessary rest and relaxation from their responsibilities' (The Marie Curie Memorial Foundation, 1985). From this concern the Foundation's own domiciliary nursing service evolved and saw the Day and Night Nursing Service (1958), employing their own Marie Curie nurses. In 1975 the first Macmillan nurses worked to improve (palliative) care of people with cancer and their families, alongside NHS services (Ten Have & Janssens, 2001).

As a result of the growing interest in palliative care, conferences were organised and palliative care associations were formed. The first International Congress on the Care of the Terminally Ill was held in Montreal, Quebec, Canada in 1976. The European Association for Palliative Care was formed in Milan, Italy, in 1988. The WHO, the directing and coordinating authority for health within the United Nations system, first formally defined the term palliative care in 1989 (the definition at beginning of this chapter is an updated definition from 2002).

Palliative care in the Netherlands

Dutch pioneers in palliative care were inspired by the work of Dame Cicely Saunders and Elisabeth Kübler-Ross. Pioneers were mainly nurses, some physicians, and representatives from Christian healthcare organisations and patient associations (Bruntink, 2002). The first hospice in the Netherlands was founded by Pieter Sluis, at that time a general practitioner (GP) in Nieuwkoop. He started a 'low care' hospice ('bijna-thuis-huis') in 1988, together with dozens of volunteers. Nursing and medical care was provided by home-care nurses and the patients' GP (no professional staff are employed by low care hospices). The first high care hospices, with their own medical and nursing staff, were the Johannes Hospitium in Vleuten and hospice Kuria in Amsterdam (1992), and hospice Rozenheuvel (1994) in Rozendaal (Gelderland). Because of the availability of their own medical and nursing staff, high care hospices generally can provide more medical care than low care hospices. Also in the nineties, the first palliative care units were set up in nursing homes and care homes. Nursing home Antonius IJsselmonde in Rotterdam was

the first to open a palliative care unit in 1993 (Palliactief, 2015).

Since the mid 1990s the development of palliative care has been supported by the government. Palliative care is considered to be a part of regular care (Ministerie van VWS, 2007). Generalist care providers, for instance GPs and home care nurses, as well as institutions such as nursing homes and hospitals, should be able to provide good quality palliative care. These can then be supported by specialist palliative care providers when needed. The policy is to strengthen the knowledge of generalist care providers and support them in palliative care provision. Palliative care is part of the educational programme for GPs and home-care nurses, and there is a wide range of short courses available on palliative care (IKNL, 2014). In 1998, a national palliative care program was launched by the Dutch government to stimulate, amongst other things, the development of local palliative care consultation teams. The first palliative care consultation team was established in 1997 (Kuin et al, 2004), and now they are available all through the Netherlands working under the auspices of IKNL (Integraal Kankercentrum Nederland, a national organisation). Nurses play a central role in the consultation teams (Schrijnemaekers et al, 2005). Most consultations are given by telephone. In some teams, however, consultants can visit the patient (bedside consultation). In bedside consultations a higher number of problems and a wider range of domains (e.g., psychological, spiritual, daily functioning, and support for informal caregivers) are addressed, compared with telephone consultations (Schrijnemaekers et al, 2005).

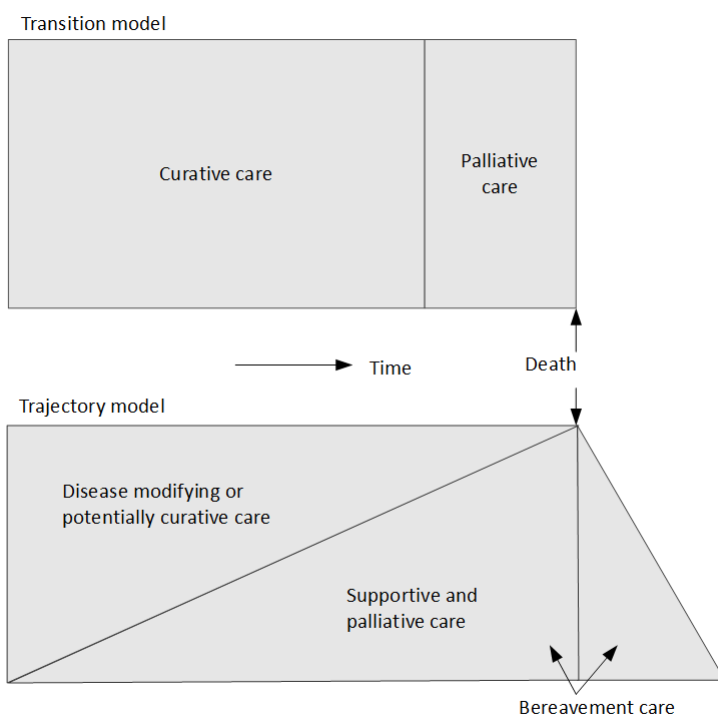
In 2001 palliative care networks were established. The networks operate at a local level in order to connect services and match supply and demand of palliative care services. Currently there are 66 palliative care networks (Netwerken Palliatieve Zorg, 2014). On August 1, 2011 the foundation Fibula was founded to unite the networks.

In 2007, the government launched a new program for palliative care (Ministerie van VWS, 2007). The starting points for this, in line with previous policy, were the definition of palliative care by the WHO and the notion that palliative care should be part of regular care. A new principle was also introduced; the trajectory model of care (Lynn & Adamson, 2003). Until this point, the emphasis was on care in the terminal stages of illness. This philosophy suggested that the shift from curative care to palliative care should be more gradual, and that palliative care should be provided earlier in the disease trajectory alongside curative care (see Figure 1). For this shift to take place, reinforcement of primary palliative care was considered pivotal - so that primary care providers are able to recognise palliative care needs. Most people prefer to die at home (Gomes et al, 2013b), so high quality community-based palliative care is important in enabling patients' palliative care wishes and needs to be met.

A further important impulse was the program for improvement by means of 'Goede Voorbeelden' (Exemplary projects) that started in 2012, which was specifically targeted at the implementation of best practices in palliative care (ZonMw, 2011). The national 'Care module' (Spreeuwenberg et al, 2013) also offers generic information on palliative

care for patients with chronic life-threatening conditions, and provides a framework to improve and guard the quality of palliative care. In 2015 a new National Palliative Care Program started, with the aim to provide the best possible palliative care to patients and informal carers in a multidisciplinary team of informal carers, volunteers, and professionals, integrated into regular care (van Rijn, 2013).

Figure 1. Above the old “Transition” model of care and below the new “Trajectory” model of care as stipulated by Lynn and Adamson



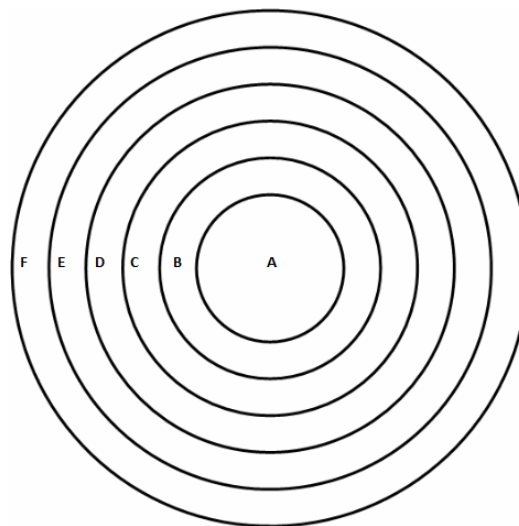
Case management

Case management has its roots in social work. Two basic kinds of service coordination, precursors for modern day case management, can be identified in the second half of the 19th century: Settlement houses and Charity Organisation Societies (Weil & Karls, 1985). The desire of both was to assist the poor but also to safeguard the public coffers. The settlement houses documented problems on the level of family, immigrant group, social and neighbourhood. Their focus was on advocacy and organization of services. The Charity Organisation Societies concentrated on efficiency. They kept records on needy

families, and these records were cross-checked to assure that a family did not receive two food baskets from different organisations.

In a National Conference on Charities and Correction in 1901, a proliferation of services and duplications of effort caused by a lack of communication and coordination among the human services agencies of the time was observed (Weil & Karls, 1985). As a result of this observation, professional standards and methods for systematic collection of information were developed, importance of trained staff and volunteers was stressed, working relationships with members of other disciplines was encouraged, and a need to understand the objectives, methods and services of other agencies was stressed. Case conferences were organised to bring multidisciplinary specialists together to discuss and plan for clients. The proposed model for the 'forces with which the charity worker may cooperate' (Figure 2) can still be applied in modern day case management.

Figure 2. Model of case coordination, dated 1901



A: Family Forces: capacity of each member for affection, training, endeavor, social development

B: Personal Forces: kindred, friends

C: Neighborhood forces: neighbors, landlords, former and present employers, clergymen, fellow church members, doctors, trade-unions, social clubs, libraries, educational clubs, savings banks, building and loan associations

D: Civic forces: school teachers, police, probation officers, factory inspectors, postmen, parks

E: Private charitable forces: charity organization society, church or denomination to which family belongs, national / special / general relief societies, charitable employment agencies, children's aid society, society for protection of children

F: Public Relief force: almshouses, outdoor poor department, public hospitals

These values and ideas spread. In the mid 1920s the newly formed child guidance clinics were experimenting with a team model of service delivery and case coordination - a client-centred form of case management. After World War II, Los Angeles pioneered

multiservice centres to assist veterans to return home. Other services, particularly for the handicapped and for families with 'deviant behaviour' such as child abuse or juvenile delinquency, developed during the 1950s and 1960s. In the wake of deinstitutionalisation (the transfer of mentally ill persons from institutions into community settings), case management in mental health services was developed. For the elderly, case management came into use in the 1970s.

Services typically display an array of case management models. What all of these seem to have in common is that case management is developed in reaction to the growth in size and structure of the health and social services system. The complexity of individual needs coupled with the complexity of services invoke the need for case management. Case management would not exist if human problems were singular or simple, if they could be resolved with a single intervention, and if the needed interventions were readily available and inexpensive (Weil & Karls, 1985). Case management can be defined (Mahler et al, 2013) as a systematic approach to support patients and informal carers, for whom the complexity of social environment or care transcends the possibilities of regular care provision, and in situations where the patient and informal carer can not manage care themselves. The needs of the patient and informal carer should be central to support provided by the case managers.

Case managers in palliative care

With the introduction of specialised palliative care nurses, working in the community alongside GPs and home-care nurses to ensure that patients received the care they needed and wanted, a form of case management in primary palliative care was introduced. Case managers in palliative care are difficult to identify in literature. Firstly, the names of case management vary: care management, care coordination, and managed care being some of the most common in the nursing field. Even when something is called case management, it does not always adhere to the definition of case management used in this thesis. When looking at the hospice home team of St Christopher's and the MacMillan nurses mentioned above, they seem to have the same tasks and provide support similar to that of the case managers in our study. Although they are not referred to in the literature as case managers, we regard the nurses from St Christopher's home team and MacMillan nurses as case managers.

Secondly, not all case managers providing support at the end of a patient's life explicitly focus on palliative care needs. For instance, a case management program for patients aged 75 years or more with severe functional disability and excessive hospital use, never stated that the aim of support was provision of palliative care in the two articles describing the cost of care in the last year of the patient's life (Long & Marshall, 1999; Long & Marshall, 2000). These were retrospective studies, using hindsight knowledge that it was the last year of the patients' life (of 317 patients that received case management, 77 died in the two years of the study). Therefore, we do not consider this to be a palliative

care case management program.

Studies from the US (Engelhardt et al, 2006; Brumley et al, 2003; Aiken et al, 2006; Seow et al, 2008; Krakauer et al, 2009; Head et al, 2010) show positive results for case managers in palliative care. Patients and informal carers supported by case managers are satisfied with care, have less hospital admissions and/or less emergency department visits, make use of hospice care more often and patients develop and revise advance directives more often. The case management programs are mainly implemented at Managed Care Organizations¹. Patients can enter the program when they have a life threatening disease, sometimes with additional criteria such as a maximum life expectancy of a year or recent hospital admissions. One program is restricted to cancer patients, another to patients with chronic obstructive pulmonary disease and chronic heart failure, (when diagnoses within a program vary, the range of cancer patients is between 33% and 65%). Case managers are mostly nurses.

Studies from the UK show mixed results. In an evaluation of the home care service of St Christopher's Hospice in the late seventies, it was found that the service enabled patients to stay at home until a later stage in their illness than would otherwise have been the case, and almost halved the length of time which they spent in hospital (Parkes, 1980). It did not prevent stress on the family or reduce the need for them and the primary care team to provide adequate care. On the contrary, the care given by these people became all the more important and the stresses somewhat greater. Because of the selection of patients for referral to the home care service, the St Christopher's group seem to have had more nursing needs than the patients in the control group. This gave rise to a bias in matching. Surviving family members expressed very positive feelings about the help that they had received from the service.

Although the quality of palliative care in the community improved with the introduction of specialist hospice services, unmet needs in palliative care patients were still observed (Wilkes, 1984; Jones et al, 1993). In the UK, a randomised controlled trial was undertaken in 1987 in which two nurse coordinators were employed 'to ensure that all terminally ill cancer patients received appropriate, adequate, and well-coordinated services, tailored to their changing needs and circumstances' (Addington-Hall et al, 1992). The coordinators did not provide practical nursing care or specialist palliative care advice; but offered advice on services and how to obtain them. The rationale was that inadequate care can result from a lack of coordination and planning between different health, local authority and volunteer services that provide care to palliative care patients. This is a 'broker'

¹ An organisation that uses a variety of 'managed care techniques' or provides those techniques as services to other organisations, intended to reduce the cost of providing health benefits (insurance for health care expenses) and improve the quality of care. These techniques can include: economic incentives for physicians and patients to select less costly forms of care; programs for reviewing the medical necessity of specific services; increased beneficiary cost sharing; controls on inpatient admissions and lengths of stay; the establishment of cost-sharing incentives for outpatient surgery; selective contracting with health care providers; and the intensive management of high-cost health care cases.

model of case management in which the patient is linked to a network of providers and services; and the primary goal is to increase the likelihood that clients will receive the right services, in proper sequence, and in a timely fashion (Huber, 2002). This intervention did not lead to better service coordination or improved patient or family outcomes.

For the Macmillan nurses evidence is lacking. Studies are descriptive (e.g. Skilbeck et al, 2002; Clark et al, 2002; Seymour et al, 2002), focussing on the case-load and tasks of the Macmillan nurse. In a longitudinal mixed-methods study (Corner et al, 2003) following 76 patients referred to 12 Macmillan specialist palliative care nursing services, no control group was used, but repeated measures were taken during care over 28 days. Data from formal measures of quality of life, whilst limited by patient attrition and the small sample size, indicated improvements in emotional and cognitive functioning in patients and in patient and family anxiety. Positive remarks from patients or carers concerning the Macmillan nurse were linked to six themes: 1) emotional support, e.g. the client felt comforted; 2) provision of (medical/nursing) information and acting as an intermediary with doctors; 3) provision of help for practical, social or financial matters; 4) advice on symptom management and medication; 5) information, advice and support for informal carers; 6) care coordination in complex situations. Negative remarks were linked to: 1) the association with death when referred to Macmillan nurse; 2) the involvement of too many healthcare professionals with no clarity on the role of the Macmillan nurse for patients and carers; 3) gaps in service provision, such as out of office hours and at weekends, or where a referral was made at the end of a week and no visit was made until after the weekend; 4) perceived reluctance on the part of the Macmillan nurse to spend time with the patient (mentioned in two cases).

With a rapid surge of initiatives involving case managers in primary care in the Netherlands (see Figure 3), more insight was needed into the phenomenon of the case manager. Studies from the US showed positive results regarding case management, whilst studies from the UK showed mixed results. A literature review (Gomes et al, 2013a) has shown that specialised palliative care at home increases the chance of dying at home and reduces symptom burden, in particular for patients with cancer. However, a generalist palliative care model can also result in good quality palliative care, as indicated by a low percentage of patients with hospitalisations in the last month of life (de Korte-Verhoef, 2014). In the Dutch healthcare system there is a strong emphasis on primary care. The GP and home-care nurse are main care providers for patients with palliative care needs living in the community. The number of non-sudden deaths per GP per year is estimated to be 12 to 13 on average (IKNL, 2014). Home-care nurses and home support workers who are confronted with end-of-life care see, on average, 10 palliative care patients a year (Nursing Staff Panel, 2011). Patients have a broad range of symptoms and it is difficult to keep up to date with the new, advanced and complex treatment options now available in palliative care (Groot et al, 2005; Becker et al, 2010; Shipman et al, 2008). To ensure continuity of care, a case manager should collaborate with the patient, their informal carers and the professionals involved in the care of the patient, such as the GP, home-

care nurse or medical specialist.

Figure 3. Surge of initiatives involving case managers in primary palliative care in the Netherlands between 1998-2009



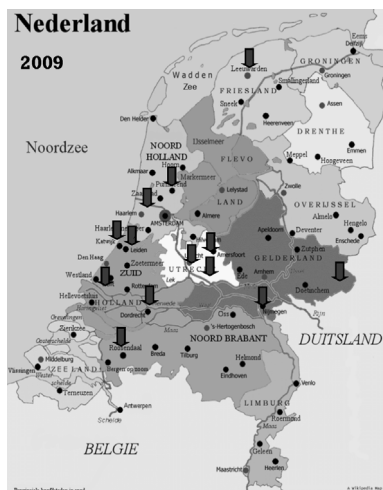
1998: first initiative (palliative care consultation team)



Five years later, in 2003: three initiatives



Five years later, in 2008: nine initiatives



One year later, in 2009: fourteen initiatives

General objectives of this thesis

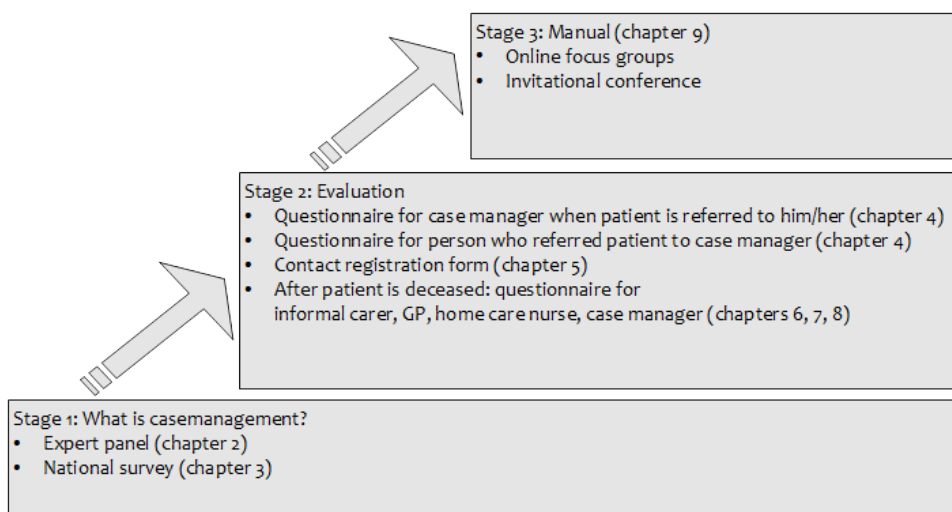
This thesis addresses the lacunae in research concerning primary palliative care case managers in the Netherlands. The organisation of case management in the Netherlands varied (Agora, 2008) and it was unclear what case management was, or aimed to do. Similar confusion surrounded how and where initiatives for case managers in palliative care were implemented, which patients were referred to case managers, what support

was provided by the case managers, and what outcomes of support were. Therefore this thesis examines 1) what case management in palliative care is, 2) what kind of support or care is offered to whom, and 3) whether the case manager has added value.

Methods

The study into the Dutch initiatives for case managers in primary palliative care (the CaPalCa study) was conducted in three stages. The second stage was executed based on results from stage one, and stage one and two together were the basis for stage three. Figure 4 gives an overview of the study methods, followed by a short description of each stage. The methods are discussed in detail in the following chapters.

Figure 4. Overview of methods used in the study



The CaPalCa study involved different methods. In stage 1 we began with an expert panel of 46 participants, to identify the aims and characteristics important for successful implementation of case management in palliative care. Following this, we conducted a nationwide survey amongst all palliative care networks in the Netherlands to investigate how many case management initiatives for palliative care there are for patients living at home, and to describe the characteristics of these initiatives with regard to content and organisation of care. We looked at 33 possible initiatives using telephone interviews combined with written questionnaires.

The evaluation (stage 2) was done by a prospective cross-sectional questionnaire study. The case manager filled in a questionnaire when a patient was referred to him/her (n=794). At that point (s)he also sent a questionnaire to the person who referred the patient to the case manager (n=526). For each contact the case manager had with the patient and/or informal carer, the case manager filled in a contact registration form (we received 4447 forms on 755 patients). After the patient died, the case manager filled in a questionnaire (n=570), and sent questionnaires to the informal carer (n=183), GP (n=173), and home-care nurse (n=126).

In stage 3 we conducted online focus groups. The results of the evaluation study were discussed in seven groups with a total of 75 participants (14 case managers, 8 GPs, 12 home care nurses, 13 professionals from hospital, 7 informal carers and 21 other stakeholders such as coordinators from palliative care networks). A manual was written, containing recommendations on the function, tasks, and position of case managers in primary palliative care (van der Plas et al, 2015b). The CaPalCa study ended with an invitational conference, in which 20 participants discussed the content of this manual. Some small adaptations were made to the manual based on the discussion, then it was subsequently published online.

Thesis structure

This thesis consists of three parts.

Part 1: What is case management in palliative care? (chapter 2 and 3)

Chapter 2 reports on a set of criteria for, and characteristics of, case management in palliative care as formulated by an expert panel. In chapter 3 we describe how, and how often, case management is implemented in the Netherlands. Different choices in implementation are highlighted.

Part 2: What support is provided and to whom? (chapters 4 and 5)

Chapter 4 describes the type of patients that are referred to case management. In chapter 5, support provided by the case managers to patients and their informal carers is described.

Part 3: Does the case manager have added value? (chapters 6, 7 and 8)

In chapter 6, experiences of bereaved informal carers are highlighted. Chapter 7 reports on the appraisal of the general practitioner (GP) and home-care nurse on support provided by the case manager. Chapter 8 reports on a comparison of palliative care provided by the GP when a case manager is or is not involved in care.

Finally, in chapter 9 all findings are summarized and conclusions are discussed, together with strengths and limitations of the studies.