Case management in primary palliative care

Annicka van der Plas

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promotor: prof.dr. B.D. Onwuteaka-Philipsen

copromotoren: prof.dr. L.H.J. Deliens

prof.dr. A.L. Francke

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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).

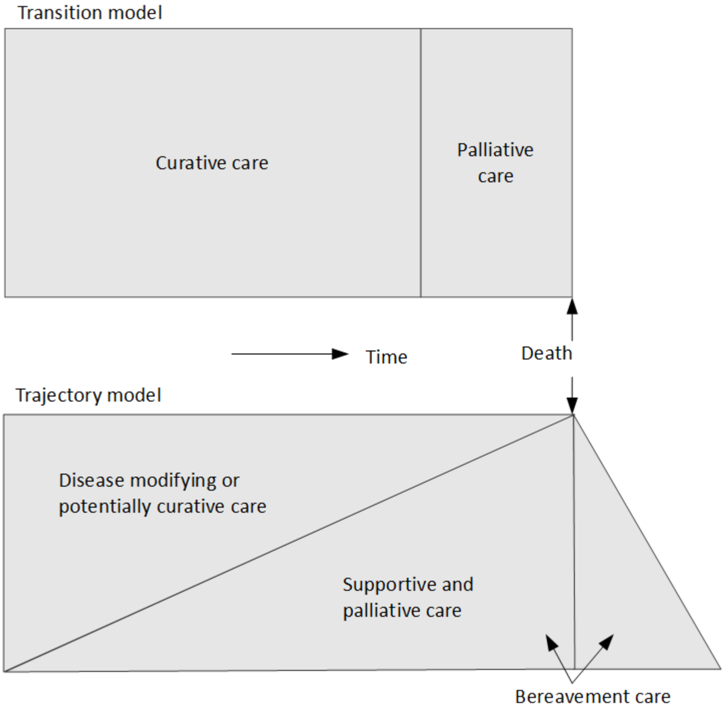
Since the mid 1990s the development of palliative care has been supported by the government. Palliative care is considered to be a part of regular care (Ministerie van VWS, 2007). Generalist care providers, for instance GPs and home care nurses, as well as institutions such as nursing homes and hospitals, 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' (Examplary 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

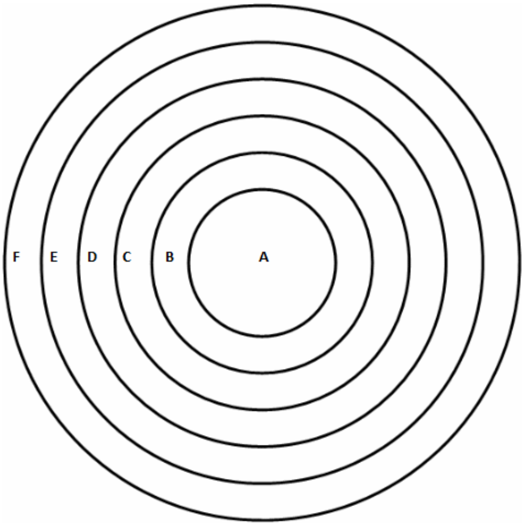


Case management

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 Organizations[1]. 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'

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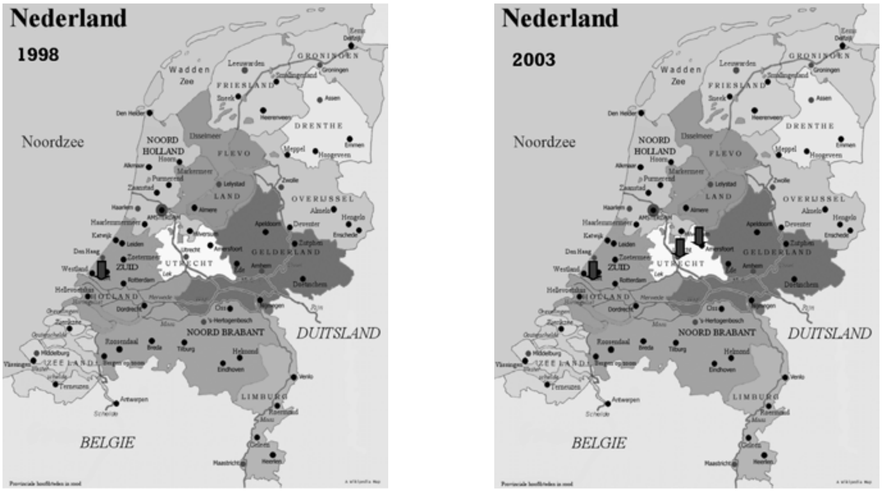
[1] An organisation that uses a variety of 'managed care techniques' or provides those techniques as services to other organisations, intended to reduce the cost of providing health benefits (insurance for health care expenses) and improve the quality of care. These techniques can include: economic incentives 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).

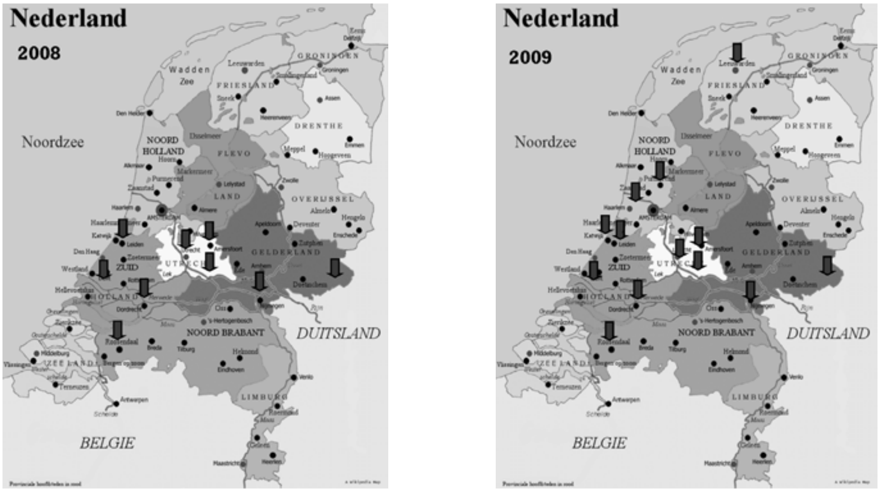
With a rapid surge of initiatives involving case managers in primary care in the Netherlands (see Figure 3), more insight was needed into the phenomenon of the case manager. Studies from the US showed positive results regarding case management, whilst studies from the UK showed mixed results. A literature 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

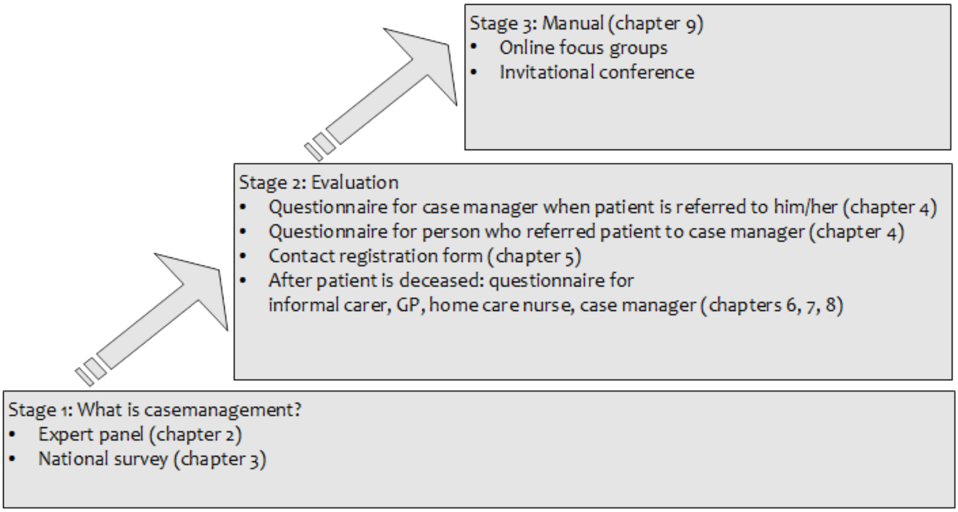
General objectives of this thesis

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.

PART 1. WHAT IS CASE MANAGEMENT IN PALLIATIVE CARE?

Verhaal van een casemanager (1)[1]

De huisarts belt me. Hij maakt zich zorgen om mevrouw De Wit en wil graag dat ik bij haar op huisbezoek ga. Mevrouw De Wit is een 36 jarige gescheiden vrouw met twee kinderen van 9 en 11 jaar (Minke en Thomas). Ze heeft gemetastaseerd pancreaskanker en haar prognose is erg slecht. De huisarts voelt geen opening om met mevrouw in gesprek te gaan over het levenseinde. “Het lijkt alsof de realiteit nog niet goed doordringt”. Verder wil mevrouw nog geen thuiszorg over de vloer. Na veel aandringen van de huisarts is mevrouw akkoord gegaan met een kennismakingsgesprek met mij.

“Vertel eerst maar eens wat je functie nu precies inhoudt?” Zo start mevrouw zelf het gesprek. Toen ik 5 jaar geleden begon als casemanager vond ik het erg lastig om zo’n vraag concreet te beantwoorden. Nu kon ik, inspelend op haar situatie, vertellen wat ik voor haar zou kunnen betekenen. Daarna heb ik een uur lang niets meer gezegd. Ze vertelt dat ze ’s nachts wakker ligt en in paniek raakt als ze denkt dat ze er straks niet meer is om haar kinderen te zien opgroeien. Ze probeert zich voor te stellen hoe het verder gaat met ze zonder moeder. Ze probeert ze voor te bereiden op het naderende afscheid, maar weet niet hoe. Ze voelt zich schuldig dat zij dit haar kinderen aandoet. Thomas en Minke trekken nu nog sterker naar haar toe, maar ze vraagt zich af of ze misschien nu al wat meer afstand moet nemen. Dan is het gemis straks niet zo groot. Ze wil haar kinderen over de grens van leven en dood tot steun zijn. Ze is op zoek naar een balans tussen leven, genieten van het leven en voorbereiden op de dood. Alle praktische zaken heeft ze geregeld, maar nu dat allemaal klaar is, weet ze niet meer hoe ze invulling moet geven aan de tijd tot aan haar dood. Ze huilt en de tranen blijven stromen. Ze is verbaasd over haar eigen emoties en haar eigen verhaal.

In de gesprekken die volgen laat ik mevrouw vertellen en ik probeer samen met haar alle overstromende gedachten op een rijtje te zetten. Ik ben vooral een klankbord. Ik overleg met de huisarts en regel op den duur ook praktische zaken, zoals thuiszorg, hulpmiddelen en begeleiding voor de kinderen. Ze probeert met iedereen rekening te houden, maar, zo zegt ze lachend en een beetje verontschuldigend; ”Met jou hoef ik geen rekening te houden, ik kan alles zeggen”.

Esther Mulders, Transmuraal Palliatief Verpleegkundige, Netwerk Roosendaal, Bergen op Zoom, Tholen (tekst onverkort eerder verschenen in CaPalCa nieuwsbrief 2, juli 2011)

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[1] In dit proefschrift zijn drie verhalen opgenomen, om een inkijkje te geven van het dagelijks werk van een casemanager. De verhalen zijn door de casemanagers zelf opgesteld, en bieden daarom geen objectief beeld. De namen van de betrokkenen in de verhalen zijn veranderd om de identiteit van patiënten en naasten te beschermen.

CHAPTER 2.

WHAT IS CASE MANAGEMENT IN PALLIATIVE CARE? AN EXPERT PANEL STUDY.

Annicka G. M. van der Plas

Bregje D. Onwuteaka-Philipsen

Marlies van de Watering

Wim J. J. Jansen

Kris C. Vissers

Luc Deliens

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Abstract

Background: Case management is a heterogeneous concept of care that consists of assessment, planning, implementing, coordinating, monitoring, and evaluating the options and services required to meet the client's health and service needs. This paper describes the result of an expert panel procedure to gain insight into the aims and characteristics of case management in palliative care in the Netherlands.

Methods: A modified version of the RAND/University of California at Los Angeles (UCLA) appropriateness method was used to formulate and rate a list of aims and characteristics of case management in palliative care. A total of 76 health care professionals, researchers and policy makers were invited to join the expert panel, of which 61% participated in at least one round.

Results: Nine out of ten aims of case management were met with agreement. The most important areas of disagreement with regard to characteristics of case management were hands-on nursing care by the case manager, target group of case management, performance of other tasks besides case management and accessibility of the case manager.

Conclusions: Although aims are agreed upon, case management in palliative care shows a high level of variability in implementation choices. Case management should aim at maintaining continuity of care to ensure that patients and those close to them experience care as personalised, coherent and consistent.

Introduction

Patients facing a life-threatening illness are likely to experience palliative care needs (Jaul & Rosin, 2005; McIlfatrick, 2007). According to the World Health Organization (WHO), palliative care aims at improving the quality of life of patients and their families, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, emotional, and spiritual (Sepulveda et al, 2002). Palliative care is complex care. Firstly because it demands attention to and knowledge of not only disease, pain and symptom management, but also a range of other non-medical issues from reimbursement structures to availability of social services and spiritual care (Sepulveda et al, 2002). Gaps in the general and specialist knowledge required by the health care provider must be filled by access to reliable knowledge from others. Secondly, communication plays a pivotal role; several professionals and informal caregivers across settings can be involved and round-the-clock continuity of information is necessary to deliver consistent care sensitive to rapidly changing needs. In 98% of their palliative care patients, Dutch General Practitioners (GPs) cooperate with at least one other caregiver, with a mean number of four (Borgsteede et al, 2007). In the Netherlands, about half of patients experience one or more transfers in their last month of life (Abarshi et al, 2010), implying the need for communication across settings at least at the start of the transfer period. This will probably be even more true in future with increasing life expectancy and a growing number of patients with multiple chronic diseases (van den Akker et al, 1998) resulting in, among other things, more health care needs and more need for the coordination of care.

Case management has developed as a means of ensuring continuity of care for patients with complex care needs. It is a heterogeneous term for care that consists of assessment, planning, implementation, coordination, monitoring and evaluation of the options and services required to meet the client's health and service needs (Commission for Case Manager Certification, 2010). It has been used for many years in psychiatry (Dixon et al, 2009), among frail elderly people (Bernabei et al, 1998) and many other populations. There have been varying research results on its effectiveness. There are numerous models of and variations in ways of delivering case management (Huber, 2002). Adding to the confusion is the multitude of names given to case management; care management, care coordination, disease management, and managed care being some of the most common in the nursing field. Most studies compare one application of case management with care as usual, there is little research comparing different models or applications of case management. It is difficult to compare studies due to differing methodologies and outcome measures, and unclear definitions and descriptions of case management (Wulff et al, 2008; Whellan et al, 2005; Pimouguet et al, 2010). Therefore, we conclude that based on current research, for most medical conditions there is no way of identifying the best model for delivering case management.

The same can be said for case management in palliative care. No reviews on case management in palliative care were found and there is no definitive evidence of its effectiveness in palliative care. Some positive results are reported. In a randomised trial among patients with advanced chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF) or cancer, case management resulted in increased patient satisfaction with care and the earlier development of advance directives (Engelhardt et al, 2006). In patients with advanced illness (mostly cancer) receiving case management, compared with a matched historical control group, hospice use and number of hospice days increased (Spettell et al, 2009). There appear to be variations in the application of case management in palliative care. Differences can be seen in target populations (e.g. cancer only (Seow et al, 2008) or a range of diagnoses (Head et al, 2010)), whether principles of disease management should be integrated (Aiken et al, 2006) or focus should be solely on terminal care (Back et al, 2005), whether case management should be delivered by a multidisciplinary team (Holley et al, 2009) or not (Spettell et al, 2009) and a broad range of other variations. Again, these studies cannot be compared, therefore, no conclusions can be drawn as to which application of case management should be preferred.

The question of how case management should best be delivered in palliative care is unanswered. The purpose of this study was to formulate the aims of case management and describe essential characteristics of case management in palliative care in the Netherlands, as perceived by experts. The expert panel procedure also gave insight into which topics there is consensus between experts and what are the main differences in opinion between them.

Methods

Design

The RAND / University of California at Los Angeles (UCLA) appropriateness method is developed to combine scientific evidence with the collective judgment of experts to yield a statement regarding the appropriateness of performing a procedure at the level of patient-specific symptoms, medical history and test results (Fitch et al, 2001). The aim of this method is to reach consensus on which medical procedures are appropriate in certain medical conditions and circumstances. With a modified version of this method it is possible to investigate whether there is consensus or disagreement for a diverse range of topics. In three written rounds we consulted experts to formulate and rate aims and characteristics of case management in palliative care. Purpose of round 1 and 2 was to formulate a list of aims and characteristics, in the third round experts rated the aims and characteristics on importance for successful implementation of case management in palliative care.

Expert panel

We invited 73 experts with experience in palliative care to participate in the expert panel: general practitioners, coordinators of palliative care networks, case managers working in palliative care, researchers and policy makers in palliative care. The perspective of district nurses was included in the expert panel through case managers and scientists in the field of nursing. Two experts declined but proposed four others to take their places and the colleague of another was added leading to the questionnaire being sent to 76 experts. Of those, 46 (61%) participated in at least one round. Twenty-four experts gave their reasons for not participating: lack of time (n = 13), lack of knowledge about case management (n = 7), prolonged illness (n = 4). Four reactions in the first round and two in the second were not traceable because they were returned anonymously. This study is exempt from approval from an ethics committee.

Selection of aims and characteristics

We drafted a first list of aims and characteristics of case management in palliative care based on information from existing initiatives, literature and previous research. We used four headings to partition our list of aims and characteristics: aims of case management in palliative care, characteristics of content of case management in palliative care, characteristics of structure of case management in palliative care and general conditions. The 16 characteristics in the fourth section, general conditions, related so commonly to care in general (e.g. ‘the caseload is in ratio with the terms of employment of the case manager and the necessary time investment for individual patients’) that they were omitted for the purposes of this paper.

For the aims of case management in palliative care, we made use of the conceptual framework of continuity of care by Bachrach (Bachrach 1981). She identified seven dimensions in continuity of complex care. The dimensions put together describe an ideal model for care in situations where several health care providers, settings and/or needs are involved. Case management does not necessarily incorporate all elements in itself, but its task is to make sure the patient receives continuity of care. Bachrach listed these dimensions specifically for people with long-term mental disorders, and we hypothesised that they would be useful as a starting point in identifying the aims of case management in palliative care. We reformulated the characteristics to reflect palliative terminology and discourse. Additional to the seven characteristics derived from Bachrach, we added two more, one specifically on palliative care (care or coordination of care is aimed at quality of life and death) and the other because the literature suggests that continuity of care across settings is problematic in palliative care (Hauser, 2009; Meier & Beresford, 2008) and we hypothesised that case management should pay special attention to that aspect. In Table 1 the dimensions of Bachrach and the aims of case management are reported.

Table 1. Transformation of dimensions of continuity of care to aims of case management in palliative care sent to the expert panel for feedback in round 1

	Aims of case management, sent to the expert panel at start of round 1	Dimensions of continuity of care
1	Delivery and/or coordination of care is aimed at quality of life and death (not at curing the patient)	
2	Care is longitudinal; it lasts for a minimum of two weeks and lasts as long as necessary	Continuity of care has a temporal dimension, it is longitudinal in nature; the patient's treatment parallels his or her progress even though the individual health care provider, specific treatment modalities, or specific site of care may change. Episodes are consecutive and related
3	Care is individual: it is tailored to the individual needs of the patient	Continuity of care has an individual dimension, the care is planned with and for the patient and family with consideration for their specific needs
4	Care is flexible; it is adjusted to the pace of the patient. This means for example that the frequency of contacts can vary over time	Continuity of care is characterized by flexibility. A flexible service system relieves the patient of pressures that may be placed on him or her to exhibit 'progress' or to move 'forward' along a continuum. The flow in services should correspond to changes in the patient's circumstances and needs
5	The relationship with the patient is central in care; the patient experiences care as familiar and close	Continuity of care has a relationship dimension, either in contacts with an individual provider or in an 'institutional alliance' in which the patient develops closeness with more than one service provider at a time. The patient is able to rely, over time, on having associations with a person or persons who are interested in him or her and who respond to him or her on a personal level
6	Care is comprehensive; the patient can receive a diverse array of care and support according to needs and wishes	Continuity of care as a cross-sectional dimension; it is comprehensive in a sense that it consists of a variety of services related to the many needs of the patient. It has a distinctly interdisciplinary quality
7	Care is characterised by communication; between the case manager and the patient and between the case manager and other care providers communication is clear and sufficient	Continuity of care has a dimension of communication, both between the patient and service providers and among the various service providers involved in the care. One aspect of this is continuity in information
8	Care is accessible; the case manager can be reached and care is low-threshold and financially accessible	Continuity of care is characterized by accessibility, the patient will be able to reach the service system when she/he needs it and in a way in which she/he can handle, both psychologically and financially. The patient does not experience barriers to service delivery, whether they be of a physical, psychological, or economic nature. Implicit in this dimension is the patient's access to 24-hour crisis intervention
9	Care is delivered at home or where the patient is staying	

Procedure

In three written rounds the experts were asked to formulate and rate aims and characteristics of case management in palliative care. In the first round we presented the first draft of the list of aims and characteristics and the expert was asked to add and remove some, give textual feedback and feedback on the aims and characteristics included. For readability characteristics were clustered around themes within the sections; aims of case management in palliative care, characteristics of content of case management, characteristics of structure of case management, and general conditions. In the second round we sent a new draft based on the respondents' feedback, with the same question. No reaction was required if the participant agreed with the content and formulation. In order to be rated independently in the third round, the clusters were then divided into separate characteristics (see Table 2 for an example). Thus, a list of 41 clustered aims and characteristics was divided into 104 separate aims and characteristics. In the third round the expert panel rated all aims and characteristics on a nine-point scale, a score of one indicating that the aim or characteristic was 'not important for successful implementation' and of nine that it was 'very important for successful implementation' of case management in palliative care.

Table 2. Example of a clustered characteristic in round 2 and division into separate characteristics for round 3

Clustered characteristic in round 2	Divided into separate characteristics in round 3
2.5. Within a week of referral to case management, the case manager contacts the general practitioner and district nurse and other relevant professionals …	
yes, to reach an understanding on cooperation	2.5.a Within a week of referral to case management, the case manager contacts the general practitioner and district nurse and other relevant professionals to reach an understanding on cooperation
yes, to match provision of care	2.5.b Within a week of referral to case management, the case manager contacts the general practitioner and district nurse and other relevant professionals to match provision of care
yes, to gain relevant information	2.5.c Within a week of referral to case management, the case manager contacts the general practitioner and district nurse and other relevant professionals to gain relevant information
other:	2.5.d Within a week of referral to case management, the case manager contacts the general practitioner and district nurse and other relevant professionals for other than aforementioned reasons
no	

Data analysis
We calculated the mean, standard deviation, median and median absolute deviation (M.A.D.) for all aims and characteristics. Agreement was calculated according to the procedure described by the RAND Corporation specifically designed for expert panels with more than nine participants (Fitch et al, 2001). Thus, according to the RAND criteria, for an aim or characteristic to be considered important for successful implementation of case management two requirements for agreement had to be met:

1) the expert panel agreed with the aim or characteristic, meaning that an aim or characteristic was scored 7 to 9 by 80% of participants,
2) the expert panel agreed with each other, meaning that the Interpercentile Range Adjusted for Symmetry (IPRAS) is larger than the Interpercentile Range (IPR). We used .30 and .70 percentile scores to calculate the lower and upper limit of the IPR.

All other results are categorised as ‘disagreement’. We used the M.A.D. as an estimator of dispersion to assess the level of disagreement within the expert panel. This measure is less susceptible to outliers than the standard deviation. To distinguish between a high and a moderate level of disagreement we used a cut off score of M.A.D. = 2.0.

Table 3. Background characteristics of respondents per round

	Round 1	Round 2	Round 3	One or more responses
Palliative care:				
- case management	8	3	6	9
- coordinator of palliative care network	6	3	10	10
General practitioners and other physicians	5	0	8	9
Other:				
- research	9	4	9	11
- policy makers	3	0	1	3
Anonymous reply[†]	4	2	0	4
Total[††]	35	12	34	46

[†] Some responses could not be traced, we are not certain whether the two unknown respondents from round two did or did not respond in round one. The total number may be between 4 and 6. [††] Some responses could not be traced, we are not certain whether the two unknown respondents from round two are unique, so the number of persons with one or more responses is between 46 and 48.

Results

Round 1 and 2

In the first round we received 35 reactions on the aims and characteristics. In Table 3 the response is shown differentiated by the discipline of the participants. Main topics addressed by the experts on the first draft were: inclusion of informal caregivers (family, partner) in case management, communication and role delineation between the case manager and other health care professionals and the necessity of tailoring care to individual needs and wishes. Also, wording of the aims and characteristics was altered accordingly to feedback from the expert panel. This resulted in an adapted draft sent around for round two. In the second round we received 12 reactions on the adapted draft. The feedback on this draft mainly concerned suggestions for improvements in detail. The complete list of aims and characteristics for case management in palliative care formulated after round two is reported in the Appendix.

Round 3

In the third round we received 34 reactions from the expert panel. Table 4 shows that agreement was reached on 35 aims and characteristics. Overall, about a third of the aims and characteristics met with agreement (34%), almost half with a moderate level of disagreement (49%), and less than a fifth (17%) with a high level of disagreement. Both aims and characteristics which are met with agreement and with a high level of disagreement are marked in Appendix 1. There were no notable differences between experts from different backgrounds on rating the aims and characteristics (see Appendix 1 for mean and median scores).

Aims of case management in palliative care

In section one on aims almost all aims were met with agreement (90%) and none with a high level of disagreement. The one aim with a moderate level of disagreement (Appendix 1, aim 1.2) used the term ‘care on demand’ (‘vraaggestuurd’), which is used by Dutch policy makers to indicate that the patient is central to care as opposed to ‘care as supplied’ (‘aanbod gestuurd’) which prioritises the habits, rules and regulations of the institution delivering it. This characteristic was added at the request of some of the experts because they felt that aim 1.4 on individual care did not adequately cover the aspect of care on demand. However, we received questions on this term (e.g. ‘does this mean that care should not be proactive?’) that made clear that the denotation of the term is not well known among the expert panel. At the same time we received feedback indicating that the expert panel agrees that the patient should be at the centre of care and that it should be tailored to the individual needs of the patient and aim 1.4 was met with a high level of agreement.

Content of case management in palliative care

In section two on content of case management most characteristics were met with a moderate level of disagreement (44%), while another 40% were met with agreement and a small proportion with a high level of disagreement (17%). Within this section the highest level of disagreement (M.A.D. = 2.33) was on nursing care tasks (characteristic 2.1.a). This stems from the opinion of some experts that the number of health care providers surrounding the patient should be kept as low as possible. The district nurse can perform case management next to other duties. Others believe that district nurses, due to their busy schedules, do not have time to offer patients adequate comfort, reassurance and information and this will take second place to their nursing tasks. Comfort, reassurance and information may also be needed by patients who are not yet using care from a district nurse.

Structure of case management in palliative care

In section three on structure of case management most characteristics were met with a moderate level of disagreement (63%), while 22% encountered a high level of disagreement and only 15% were met with agreement. Within this section there were three characteristics with a joint highest level of disagreement (M.A.D. = 2.24): whether the case manager should combine case management with other tasks (e.g. consultation) (characteristic 3.5.b), whether she or he should be accessible 24 hours a day, seven days a week (characteristic 3.8.a), and if the target group she or he works for includes all patients with a life-threatening disease (characteristic 3.7.c).

Table 4. Scoring of the aims and characteristics by the expert panel

Section	Number of clustered characteristics	Number of separate characteristics	Characteristics of agreement (%)	Characteristics of moderate disagreement	Characteristics of high disagreement
				M.A.D. < 2	M.A.D. ≥ 2
Aims	10	10	9 (90%)	1 (10%)	0
Content	20	48	19 (40%)	21 (44%)	8 (17%)
Structure	11	46	7 (15%)	29 (63%)	10 (22%)
Total	41	104	35 (34%)	51 (49%)	18 (17%)

Discussion

This study shows that agreement was high on the aims of case management. However, how case management should be implemented, and exactly which elements of care it should include, is more open for debate. Disagreement was highest on topics regarding whether the case manager should perform hands-on nursing care themselves or not, on the target group, on accessibility of the case manager and on performance of other tasks besides case management.

Strengths and limitations

This is the first study using a structured procedure to report on the importance of the aims and characteristics of case management in palliative care. The expert panel reflects the opinions of case managers, coordinators of palliative care networks, general practitioners and other physicians, researchers and policy makers. There were no marked differences between experts from different backgrounds on rating the aims and characteristics. However, these opinions not necessarily reflect practice and we lack information on how often and how case management is implemented in the Netherlands. Also, our results may only be representative for mixed public-private health care systems with a strong primary care gatekeeper that resemble the Dutch system. The characteristics of case management may be different in other health care systems.

Aims of case management in palliative care

The aims that met agreement are in accordance with the general principles of palliative care and also reflect the patient advocacy model of case management (Long & Marshall, 2000). This model offers comprehensive coordination of services aimed at quality of care and is distinguished from the interrogative model, which is more focused on clinical decision-making and emphasises cost-effectiveness. The aims also underline the importance of the seven dimensions of continuity of care formulated by Bachrach for psychiatric care (Bachrach, 1981). This conceptual framework appears to be valid for complex continuous care in general, whether it is psychiatric care or palliative care.

Content of case management in palliative care

Translation from aims to content of care is apparently relatively straightforward, with 40% agreement and only 17% strong disagreement on what care should be included. Offering information and support, identifying needs and adjusting care to match the patient's needs are the main tasks of the case manager. This can also be seen in descriptions of case management in palliative care (Holley et al, 2009; Head et al, 2009), for cancer patients (Howell et al, 2008) and in a Delphi study on case management for patients with dementia (Verkade et al, 2010). Delivery of hands-on patient care is the most important area of disagreement within the expert panel. As mentioned in the results section, this stems from task alignment between the district nurse and case manager and whether these should be two different people or not. Besides, this also touches on the discussion whether palliative care should be part of primary (generalist) care, delivered by specialised palliative care providers, or in a cooperation between the two (Gott et al, 2012). Case management could be delivered in a multidisciplinary team taking over all care, or case management can be guiding and assisting the primary health care providers (GP and district nurse) in their care for the patient. Another notable topic of disagreement is whether case management should stop before bereavement support is provided. The panel agrees that bereavement support is part of palliative care, reflected in agreement with characteristic 2.18.c. and aim 3. Whether there can be other endpoints for case management may be related to the target group, which is also a point of disagreement for the expert panel (reflected by characteristics 3.7 a, b and c). In a mixed-method study on case management for cancer patients, there are two distinct case management trajectories for patients receiving curative care and those receiving palliative care (Howell et al, 2008). For curative patients case management can be short-term and stops when information needs are met. The discussion on bereavement support may also be a reflection of the Dutch reimbursement system, where it is not financed by public means and therefore any time the case manager spends on delivering it is not compensated.

Structure of case management in palliative care

Translation from aims to structure of case management is apparently less straightforward, with only 17% agreement and 22% strong disagreement. Characteristics such as the target group and the accessibility of the case manager may reflect the scope and depth of the case manager's task: when can she or he work with the patient themselves and at what point does she or he refer to another professional? In the aforementioned Delphi study on case management for patients with dementia, no agreement could be reached on similar topics (Verkade et al, 2010). Apparently, in correspondence with applications of case management in cancer (Wulff et al, 2008), CHF (Whellan et al, 2005) and dementia (Pimouguet et al, 2010; Verkade et al, 2010), also in palliative care there is no unique best way to deliver case management according to experts.

Conclusions

Case management in palliative care should aim at maintaining continuity of care to ensure that patients and those close to them experience palliative care as personalised, coherent and consistent. There is a high level of agreement about the underlying dimensions of continuity of care (Bachrach, 1981). The most important issues in implementation preferences are defining the target group of case management, the performance of other tasks besides case management, accessibility of the case manager and delivery of hands-on nursing care by the case manager. Research into the feasibility of different options and their effects on implementation could help health care planners make informed decisions on the best way to deliver case management.

See also the Appendix: Aims and characteristics of case management in palliative care.
The appendix contains a full list of all aims and characteristics of case management in palliative care, as formulated and rated by the expert panel.

CHAPTER 3.

PALLIATIVE CARE CASE MANAGEMENT IN PRIMARY CARE SETTINGS: A NATIONWIDE SURVEY.

Annicka G.M. van der Plas

Luc Deliens

Marlies van de Watering

Wim J.J. Jansen

Kris C. Vissers

Bregje D. Onwuteaka-Philipsen

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Abstract

Background: In case management an individual or small team is responsible for navigating the patient through complex care. Characteristics of case management within and throughout different target groups and settings vary widely. Case management is relatively new in palliative care. Insight into the content of care and organisational characteristics of case management in primary palliative care is needed.

Objectives: To investigate how many case management initiatives for palliative care there are in the Netherlands for patients living at home; to describe the characteristics of these initiatives with regard to content and organisation of care.

Design and participants: A nationwide survey of all 50 coordinators of networks in palliative care in the Netherlands was conducted. Additional respondents were found through snowball sampling. We looked at 33 possible initiatives using interviews (n = 33) and questionnaires (n = 30).

Results: We identified 20 initiatives for case management. All stated that case management is supplemental to other care. In all initiatives the case managers are registered nurses and most possess higher vocational education and/or further training. All initiatives seek to identify the multidimensional care needs of the patients and the relatives and friends who care for them. Almost all provide information and support and refer patients who need care. Differences are found between the organisations offering the case management, their target groups, the names of the initiatives and whether direct patient care is provided by the case manager.

Conclusions: In the Netherlands, case management in primary palliative care is new. Several models of delivery were identified. Research is needed to gain insight into the best way to deliver case management. By describing characteristics of case management in palliative care, an important first step is made in identifying effective elements of case management.

What is already known about the topic?

- District nurses and general practitioners play an important role in palliative care provision to patients and their families. However, offering high quality palliative care is a challenge for the district nurses and general practitioners.
- Specialised palliative care services providing case management can support the primary care providers. Although there are some positive results reported, there is no definitive evidence on the effectiveness of case management in palliative care. Research on effectiveness is hampered by unclear definitions and descriptions of case management.

What this paper adds

- This nationwide survey showed that key tasks in palliative care case management were: identifying patient needs, providing information and support and organising care for patients. Whether direct (hands on) patient care was provided by the case manager him or herself differed between initiatives.

- Main organisational differences were found in the organisational base and target group. No case management initiative was accessible outside office hours. All case managers in the initiatives were nurses.

Introduction

Palliative care aims at improving the quality of life of patients and their families facing the problems associated with life-threatening illness (Sepulveda et al, 2002). Most patients prefer to die at home (Bell et al, 2010), so community based palliative care should be an important pillar to help meet patients' palliative care needs. Traditionally, the general practitioner and district nurse are the primary care providers offering palliative care in the Dutch health care system. Although patients with palliative care needs are a high priority for them, offering high quality palliative care may be difficult. For instance, a growing number of general practitioners work part-time and continuity of patient care is dependent on transfer of information. Out-of-hours general practitioners feel under time–pressure constraints, may experience stress because of unfamiliarity with the needs of a patient and their relatives and lack information from the in-hours general practitioner (Schweitzer et al, 2009; Taubert & Nelson, 2010). Cooperation between nurses and general practitioners is not always satisfactory (de Veer et al, 2003; Neergaard et al, 2010; Walshe et al, 2007). Furthermore, in the Netherlands, 77,000 people die each year of non-acute illnesses and 31% of these die at home (van der Velden et al, 2009). General practitioners see on average four to six palliative patients a year (Groot et al, 2005), district nurses and home support workers who are confronted with end-of-life care see on average 10 palliative patients a year (Nursing Staff Panel, 2011). Patients have a broad range of symptoms and it is hard 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). Additionally, general practitioners and district nurses may have difficulties or discomfort assessing and discussing prognosis, psychological and spiritual/existential issues (Abarshi et al, 2011; Griffiths et al, 2010; Slort et al, 2011).

Case management can be helpful in meeting patient needs and ensuring continuity and quality of care across settings (Wilson et al, 2008). Case management is delivered by an individual or a small team, responsible for navigating the patient through a complex process in the most efficient, effective and acceptable way (Zwarenstein et al, 2000). This is done by advocating the patient's needs to other care providers or by supporting the patient and their carers in doing this themselves. In case management the focus is not only on the somatic needs of the patient but also on their psychological and social circumstances in an integrated multidimensional context. There is no definitive evidence of the effectiveness of case management in palliative care; we found no review papers and only one randomised trial (Engelhardt et al, 2006), which showed that case management resulted in increased patient satisfaction with care and the earlier development of advance directives.

Different models of case management exist (Huber, 2002) which consequently result in different outcomes. In a review of case management among cancer patients (Wulff et al, 2008), the authors urged future researchers to eliminate the 'black box' by adding a thorough description of the specific intervention studied so as to increase knowledge of which aspects of case management contribute to its overall effect. We found no studies comparing models in palliative care. However, in a comparison of five case management projects for frail elderly people in the United States, major differences were found in characteristics such as the aims, target groups and scale of the projects (Capitman, 1986). Content of care, however, appeared to show similarities since all projects targeted the needs associated with the (instrumental) activities of daily living and mental ability status. None of the projects reduced acute care days in hospital. One showed a reduction in the use of home health services and another, which identified eligible patients through their application for nursing home services, showed reduced use of nursing home care. A comparison of two models of case management and usual care in dementia care is underway (MacNeil et al, 2012).

Gaining more insight into the content of care and the organisational characteristics of case management in palliative care can be instrumental in evaluating it. Therefore, in this paper we focus on content and organisation of care in case management initiatives in the Netherlands for adult patients with palliative care needs in primary care settings. The criteria used for defining case management are in the methods section. Our current study has two goals: the first is to count and generally present case management initiatives in palliative care in the Netherlands; the second is to investigate the characteristics of these case management initiatives with regard to content and organisation of care.

Methods

Setting

The Netherlands is a small densely populated country in North-West Europe with 16.6 million inhabitants. Basic health care insurance (primary care, hospital care and certain types of medication) is compulsory for inhabitants of 18 years or older, children are insured together with their parents. Additional insurance covering for instance dentistry or paramedical care is optional. On January 1st 2011 there were 8884 General Practitioners working in the Netherlands (Hingstman & Kenens, 2011). The mean number of inhabitants per one full time equivalent of General Practitioners is 2371 (in 2011). In 2011, 72% of all inhabitants living at home (not in an institution) had one or more contacts with their General Practitioner (Statistics Netherlands, 2012). Home care is financed through a law on long-term care for people with chronic conditions and also by private funding. The most recent available information on the number of home care organisations is from 2007, in that year there were 248 home care organisations in the Netherlands and a further 255 care- or nursing homes that also offered home care (Deuning, 2007). In 2009, home care was delivered to 378,309 persons, a mean number of 29 persons per 1000 inhabitants of 18 years or older received home care (RIVM, 2010). There is variation in the services offered by different home care organisations (for instance, some but not all offer domestic help and/or specialised technical nursing help). To facilitate organisational cooperation in palliative care, regional networks covering all of the Netherlands were established. In these networks, hospices, care homes, hospitals, home care organisations, general practitioners, and other providers of palliative care, work together to optimise delivery of palliative care in that region.

Criteria for defining case management

The criteria that were used to define case management resulted from an Nationwide survey study on case management in palliative care (van der Plas et al, 2012). To be labelled as case management in palliative care, the following criteria all had to be met:

- Case management is aimed at improving quality of life and limiting suffering close to time of death.
- Case management is longitudinal; it starts when needed and lasts until the patient is deceased and the informal support system has received bereavement support (or until the patient and informal carer no longer need case management).
- Case management is tailored to the individual needs and wishes of the patient and informal support system.
- Case management is flexible; content, duration and frequency of contacts are adjusted according to the needs of the patient and informal support system.
- The relationship with the patient and informal support system is familiar, close and personal.
- Case management is comprehensive; the patient and informal support system receive a diverse array of care and support according to their needs and wishes (not necessarily by the case manager him- or herself, but the case manager ensures referral and delivery of care).
- Communication is a cornerstone; there is ongoing sufficient and clear communication between the case manager, the patient and the informal support system and between other care providers involved.
- Case management is accessible and low-threshold; contact information is readily available and case management is financed through health care insurance (or other arrangement without costs to the patient), the patient and the informal support system can request case management themselves, no referral by a health care professional is needed to access case management.
- Case management is primarily delivered in the community and follows the patient regardless of place of stay of the patient.

Data collection

Data were collected (by A.v.d.P.) in 2010 through a written questionnaire and an additional interview by telephone. All interviews were recorded and transcribed. Both the questionnaire and the interview were based on the results of a Nationwide survey study on case management in palliative care (van der Plas et al, 2012), and amongst other items, incorporated core tasks of case management that are also identified by others (Reilly et al, 2010). The questionnaire and interview were divided into the following sections: I. Enrolment of the patient, introduction and assessment, II. Content of care, III. End of case management, IV. Structure of case management, V. Preconditions for case management. In the written questionnaire another section (VI) was added with general questions on case management. All questions were multiple choice (some questions included an open option 'other, namely. . .'). Two examples of questions are:

- What is the task of the case manager regarding social wellbeing of the patient and carer (more than one answer possible)? Answering options: identifying needs; providing information and support; referring the patient or organising care; provide care his- or herself; no task.
- When can the case manager be contacted/reached? Answering options: 24 h a day, 7 days a week; office hours, 5 days a week; other, namely/being. . .

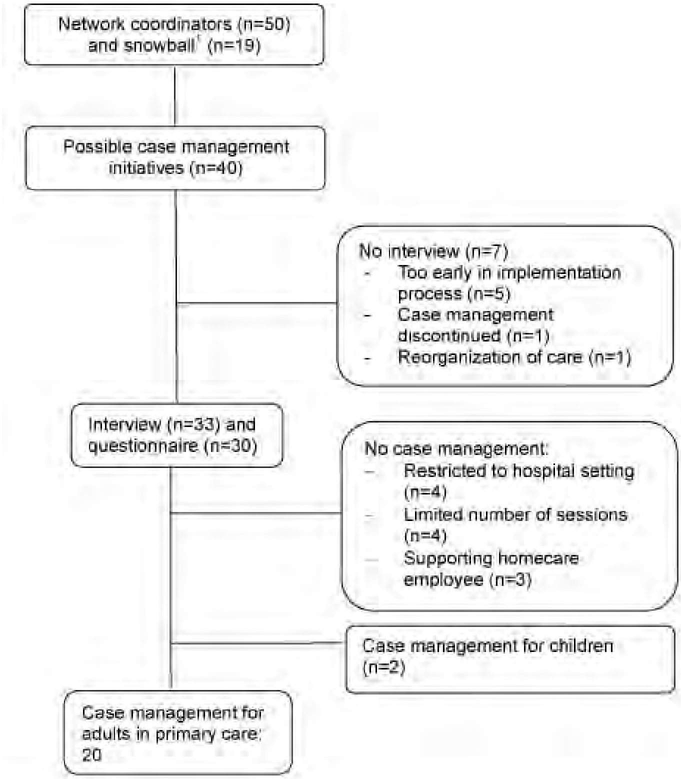
Questions that were expected to need some clarification from the researcher or for which additional information was needed from the respondent, were asked during the interview by telephone. Both the interview by telephone and questionnaire provided data for our two research questions (number of initiatives and characteristics of initiatives). Frequencies were calculated for all questions.

Procedure

Contact information of all 50 palliative care network coordinators working for 71 networks (some coordinators worked for several networks) covering all of the Netherlands was provided by Agora, the national advice centre for palliative care. All coordinators were sent an email explaining the purpose of the study and saying that a telephone call would follow. Additional information and clarification was offered during the phone call. All palliative care network coordinators were asked whether they knew about case management initiatives within their network. If so, contact information of potential initiatives was requested. This resulted in the identification of 21 possible case management initiatives. Through snowball sampling (every respondent was asked: 'Do you know of any other case management initiative?') another 19 possible initiatives were identified. Of the 40 possible initiatives, seven were not interviewed (see Fig. 1). Thus, we conducted 33 interviews and received 30 questionnaires about potential case management initiatives. See Fig. 1 for a flow chart of the procedure. This study is exempt from approval from an ethics committee.

Data were also collected in cases where there was doubt about whether an initiative could be labelled as case management or involved another type of care; in these cases the data were presented to the research group to clarify the boundaries of case management and agreement was reached on how to label it.

Figure 1. Flow chart of response



[1] Respondents were asked at the end of their interview: 'do you know of any other case management initiative?'

Results

Number and general description of initiatives

We identified 20 case management initiatives in the Netherlands (Fig. 1). Most of these are in the western and more urban parts of the Netherlands; however, the three largest cities of the Netherlands have no case management initiatives (Fig. 2).

All case management initiatives stated that their care is supplemental to other care, they have no intention of taking over or substituting for care normally provided by others (e.g. general practitioners and district nurses). In all initiatives the case managers were nurses; most nurses were trained at the level of higher vocational education (50%), another 40% were trained at that level with further education in palliative care, oncology or another relevant field of specialist care, 10% were nurses with other levels of education (e.g. nurse practitioner or level 4).

Figure 2. Map of the Netherlands with the locations of the case management initiatives.

Fewer than half of the initiatives use the term case management or case manager in their titles (n = 8). The term ‘continuity visits at home’ is used by four initiatives, another four use a name in which the terms ‘support’ or ‘assistance/relief’ are present, three have general titles (e.g. the name of the company with ‘At Home’ added), and one initiative had not yet decided on a name.

Not all initiatives had begun to include patients at the time of the interview; three were still in the initiation process preceding implementation (information gathering, conceptualising and planning). Another three were in their first year, ten had already been operational for between one and five years and three had been providing case management for more than five years (data is missing in one case). Case management was a regular or structural part of local care in 13 initiatives (65%), in the other seven case management was a pilot, temporary in nature.

Table 1. Tasks of the case manager in nursing care, social wellbeing, spiritual/existential wellbeing and practical matters (number and valid % reported, n = 19) [a]

	Identifying needs	Providing information and support	Refer/ organise care	Provide care	No tasks
Nursing tasks	19 (100%)	19 (100%)	18 (95%)	4 (21%)	0 (0%)
Social wellbeing	19 (100%)	18 (95%)	19 (100%)	8 (42%)	0 (0%)
Spiritual/existential wellbeing	19 (100%)	19 (100%)	19 (100%)	8 (42%)	0 (0%)
Practical help	19 (100%)	18 (95%)	19 (100%)	0 (0%)	0 (0%)

[a] This question was from the written questionnaire, one case management initiative did not respond.

Characteristics of case management initiatives: content of care

In all initiatives case managers have the task of identifying patient needs with regard to nursing care and social and spiritual/existential wellbeing and of identifying the practical needs of both the patient and their carers; almost all of them also provide information and support and refer patients with regard to their nursing, social and spiritual/existential wellbeing and practical needs. Whether it is the role of the case manager to provide care in these fields themselves differs between initiatives (Table 1).

With regard to the administrative and financial affairs of the patient, the content of care is variable but none of the initiatives rule out involvement in these areas. Most case managers provide additional services such as consultation and education on palliative care to other health care professionals. Casefinding (actively looking for potential patients) is – at least sometimes – a part of the case manager’s job in 55% of initiatives. For almost all initiatives, the case managers – at least sometimes – identify and report deficiencies in local care provision to the regional palliative care network coordinators (Table 2).

Table 2. Content of care of case management initiatives with regard to administrative and financial matters and additional tasks of the case manager [a]

Characteristic	Total N = 20 (unknown)	Total valid %
Administrative needs of the patient: the case manager. . .		
Negotiates on behalf of the patient in applications for care and support	5 (1)	26%
Fills in forms directly related to care and support on behalf of the patient	7 (1)	37%
Fills in forms with regard to financial matters of the patient like income, retirement, funeral and inheritance	1 (1)	5%
Supports the patient	11 (1)	58%
Has no task	0 (1)	0%
Financial matters: the case manager. . .		
Gives information on procedures directly related to care (e.g. reimbursement, application procedures)	15 (1)	79%
Gives information on regulations considering income, retirement, funeral and inheritance	5 (1)	26%
Refers the patient to a specialist when necessary	11 (1)	58%
Has no task	0 (1)	0%
Additional tasks of the case manager		
Providing other services (such as consultation, education) besides case management	15 (1)	79%
Actively looking for potential patients (case-finding)	Yes: 2 (0) Sometimes: 9 (0) No: 9 (0)	Yes: 10% Sometimes: 45% No: 45%
Identifying deficiencies in local care provision for patients in need of palliative care and discussing them with the regional coordinator of palliative care services	Yes: 10 (1) Sometimes: 8 (1) No: 1 (1)	Yes: 53% Sometimes: 42% No: 5%

[a] Questions came from the interview or questionnaire, one case management initiative did not respond to the questionnaire.

Characteristics of case management initiatives: organisation of case management
As can be seen in Table 3, there are different kinds of organisations offering case management; the most common is a cooperation of institutions within a palliative care network (n = 7; 35%) and the most uncommon is case management delivered by a specialised organisation (n = 1) or by a hospice (n = 2). Five initiatives (25%) are organised by a home care organisation and five by a cooperation of institutions (e.g. a hospital and a home care organisation working together).

Table 3. Organisational characteristics of case management initiatives [a]

Characteristic	Total	Total valid %
	N = 20 (unknown)	
Organisation offering case management		
A cooperation of institutions within a palliative care network	7 (0)	35%
A cooperation of institutions (other than within a palliative care network, for instance a cooperation between a hospital and a home care organisation)	5 (0)	25%
A home care organisation	5 (0)	25%
A hospice	2 (0)	10%
An organisation specialised in psychosocial support of patients receiving palliative care	1 (0)	5%
The target group for case management		
Patients receiving palliative care (no curative of life-prolonging treatment)	8 (0)	40%
Patients receiving life-prolonging treatment (no curative treatment)	5 (0)	25%
Patients with a diagnosis of a life threatening disease	7 (0)	35%
Accessibility of the case manager		
Office hours	19 (1)	100%
Team composition		
Only case managers (no other disciplines)	15 (1)	79%
Case managers are part of a home care (nursing) team	2 (1)	11%
Multidisciplinary team	2 (1)	11%
Support and extra training of the case manager		
Team meetings on a regular basis to discuss cases, work related matters and events	18 (1)	95%
Training courses	17 (1)	90%
Intervision/peer review	13 (1)	68%
Training on the job at the beginning of his/her employment	3 (1)	16%
Supervision	3 (1)	16%
Patient records and registration		
In case of emergency or when a case manager is unavailable, patient records are available for colleagues	Yes: 15 (2)	Yes: 83%
	For some: 2 (2)	For some: 11%
	No: 1 (2)	No: 6%
A registration system or procedure is available for case managers to keep record of their activities	15 (1)	79%
Policy in writing		
Tasks of the case manager	13 (1)	68%

Criteria for referral to case management	11 (1)	58%
Vision: what an initiative wants to achieve with case management	10 (1)	53%
Targets of case management	9 (1)	47%
Views on the role of the patients in case management (e.g. level of self-management expected)	4 (1)	21%
Mission: how the initiative wants to provide case management	4 (1)	21%
Views on the role of those close to the patient in case management	3 (1)	16%

[a] Questions came from the interview or questionnaire, one case management initiative did not respond to the questionnaire.

Most initiatives offer case management to patients receiving palliative care (n = 8; 40%), case management for patients receiving life-prolonging treatment and/or palliative care was offered by five (25%) and seven (35%) offered case management to all patients with a diagnosis of a life threatening disease.

For all initiatives, the case manager is accessible to patients only during office hours. In the majority of the initiatives (79%) the case management team consists only of case managers, two teams are multidisciplinary (one from a hospice and one from a hospital and home care organisation collaboration), in two initiatives case managers are members of a home care team. The most common means of support and training are team meetings (95%), training courses on palliative care (90%) and intervision (a form of peer review) (68%) for case managers. For most initiatives (79%), a registration system or procedure is available to keep a record of activities. Patient records are available for colleagues to ensure continuity of care for 15 initiatives, and for a further two this is the case for some colleagues (this can vary when case managers are from a collaborative initiative). The most common written policies are on the tasks of the case manager (68%), criteria for referral to case management (58%) and on vision on case management (53%).

Discussion

We found 20 initiatives for case management in palliative care in the Netherlands. These are mainly located in the most urban part of the Netherlands and the majority have been operational for less than five years. All initiatives identify the care needs of patients and their carers with regard to nursing care, spiritual/existential and social wellbeing and practical matters. Ninety-five percent of all initiatives also provide information and support and refer patients to nursing care, spiritual/existential and social support and help with practical matters if needed. Variation in the content of care is mostly dependent on whether the case manager delivers hands-on care him- or herself and on the care available regarding the patient's or family's financial and administrative affairs. Most variation can be seen in the organisational characteristics of case management, with the organisational base, the target group and the naming of case management being the most varied characteristics.

Strengths and limitations

This is the first national study to count the number of case management initiatives for adults with palliative care needs in primary care, and to describe their characteristics systematically. We found no similar studies in palliative care in other countries. The characteristics are derived from an Nationwide survey procedure (van der Plas et al, 2012), so they cover characteristics that are important to case management in palliative care. Because we did not approach all home care service providers we might have missed some initiatives. However, palliative care network coordinators are generally well aware of the palliative care that is provided within their region. Another limitation is that our results may only be representative for mixed public–private health care systems with a strong primary care gatekeeper as in the Dutch system. The need for and characteristics of case management may be different in other health care systems. The literature indicates that other countries face similar problems in offering high quality palliative care (Taubert & Nelson, 2010; Neergaard et al, 2010; Slort et al, 2011). It would be interesting to make a comparison across countries to gain insight into differences in case management between health care systems (questionnaires available on request). Finally, this is a descriptive study. We cannot tell whether variations in characteristics result in differences in outcome between initiatives. Also, in this study we asked for general information on case management, data on how often certain tasks are actually executed in patient care are now being collected and will be reported in future publications.

Number of initiatives and general description

Although most initiatives are located in the most urban part of the Netherlands, there are none in the three largest cities. This may be explained by the differences in health care provision between rural and urban areas. In rural areas health care providers may know each other and work together more closely whereas in the largest cities health care professionals are unable to maintain working ties, and in highly fragmented care with many different organisations knowledge of available relevant services and organisations is difficult to find and to keep up-to-date with. The semi-urbanised regions may provide the most fertile ground for case management although urban areas may be most in need of it.

Content of care of case management

There is little variation in the content of care. Identification of care needs, providing information and support, referral or organisation of nursing care, spiritual/existential and social support and help with practical matters are all offered by most if not all initiatives. These tasks can also be seen in studies on other case management initiatives (Holley et al, 2009; Howell et al, 2008; Reilly et al, 2010). The main differences are whether the case manager provides care her- or himself with regard to hands-on nursing tasks and social and spiritual/existential wellbeing of the patient. This may reflect the depth or specificity of palliative care training of the case manager and may also relate to what is provided by other care providers since all initiatives state that what they provide is supplemental to the care provided by general practitioners, district nurses or others. Other important differences can be found in tasks undertaken by the case manager in the area of the patient's administrative and financial affairs; the priority afforded to these areas in provision and training may be lower than for other aspects of care. This is in line with the literature on patient and carer needs for end-of-life care which shows that the focus is primarily on providing information and support on topics like adjusting to the limitations of disease, to symptoms and to the future course of the illness (Bekelman et al, 2011) although financial and practical care needs should be properly addressed (McIlfatrick, 2007).

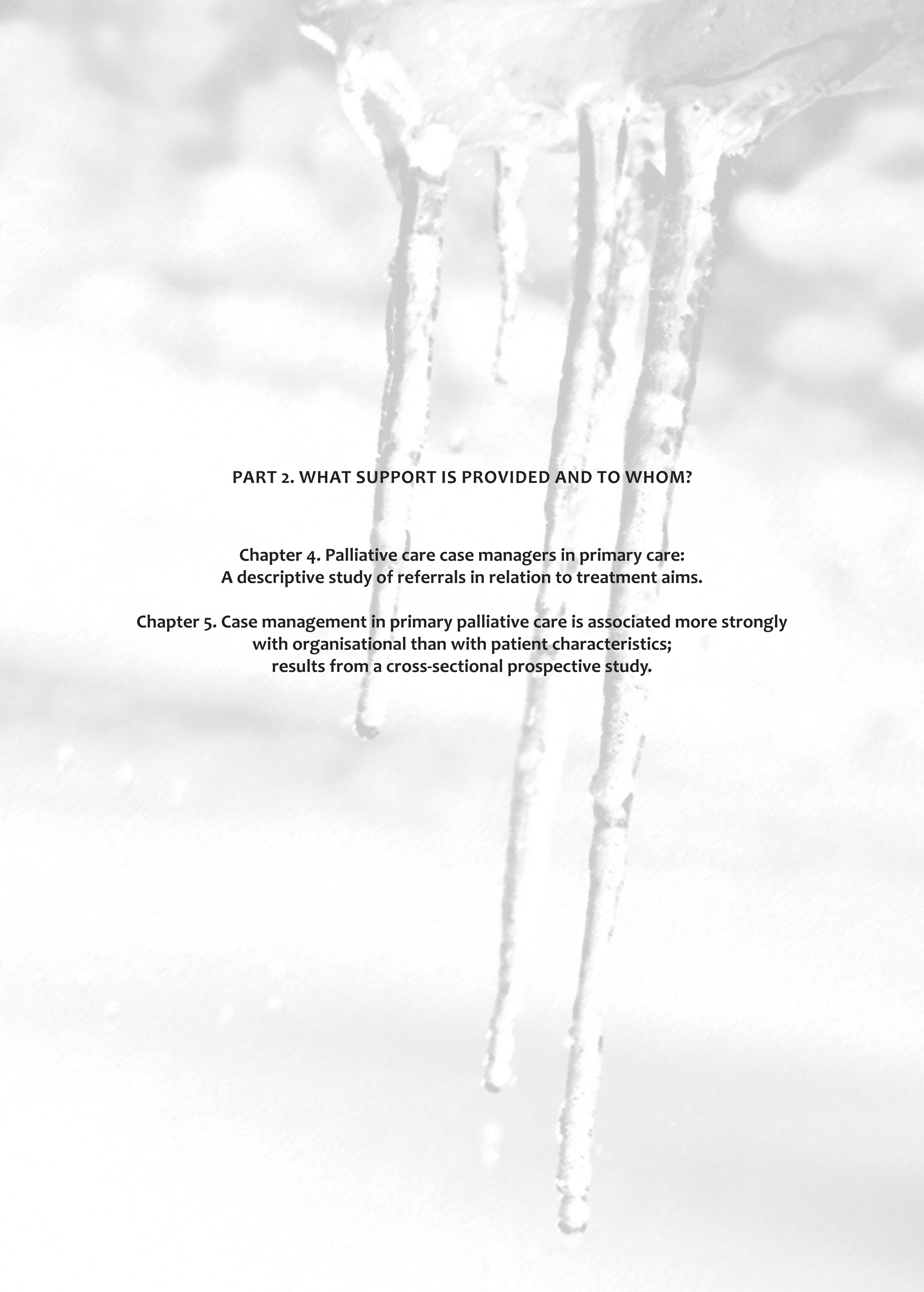
Organisational characteristics of case management initiatives
A surprising result is that case managers were accessible only during office hours. Some did offer their own phone number for contact outside office hours although this was of their own choice. Since the general practitioner remains the main care provider when case management is involved, out-of-hours care may be regarded as their core responsibility; however, as stated in the introduction, this is not always a guarantee of optimal care provision. Availability of case management outside office hours may provide an extra safeguard for continuity of care.

Team composition shows a large uniformity with 79% of the teams consisting only of case managers. One multidisciplinary team was located in a hospice and consisted of a general practitioner linked to the hospice, volunteers and nurses working in the hospice. Another multidisciplinary team was situated in a hospital in cooperation with a home care organisation, and the case managers were part of the multidisciplinary hospital team. In a review of case management for frail elderly people and patients with chronic illness, of the eight teams studied, half offered care by a case manager who was part of a multidisciplinary team and half offered care by an 'independent' case manager (Oeseburg et al, 2009). In the Netherlands, access to physicians and nurses with formal training and experience in palliative care is available in the form of local multidisciplinary consultation teams for palliative care, and some case management initiatives work closely with such a team. For other disciplines, such as social work, it may be that it is not necessary to be integrated into the case management initiatives because knowledge from and about these fields of care is accessible to case managers without incorporating them in the initiative. However, this may also indicate a gap in care provision by case management initiatives.

That few initiatives in case management originate from hospices can be expected because most hospices in the Netherlands offer care exclusively for their own residents. More than half of the initiatives investigated have as their organisational base a collaboration between institutions; it would be interesting to know whether such collaborations are more successful in communicating effectively with relevant parties in individual case management trajectories compared with initiatives based on a single organisation.

Conclusion

Case management in palliative care has only been established recently in the Netherlands and has no uniform concept so there is variation between initiatives in how they deliver case management. Lack of uniformity in descriptions of interventions makes it difficult to compare study results and to obtain insight into the usefulness of case management as a way of managing complex care processes. For interventions that do not use the term case management, it is difficult to ascertain whether an intervention can be labelled as case management or not. A clear definition of what case management is and what care it should and should not comprise, is fundamental in studies comparing interventions. For the sake of clarity in communication, uniformity of definition and description should be encouraged. Research is needed to gain insight into the best way to deliver case management.



PART 2. WHAT SUPPORT IS PROVIDED AND TO WHOM?

Chapter 4. Palliative care case managers in primary care: A descriptive study of referrals in relation to treatment aims.

Chapter 5. Case management in primary palliative care is associated more strongly with organisational than with patient characteristics; results from a cross-sectional prospective study.

Verhaal van een casemanager (2)[1]

Begin augustus word ik door een wijkverpleegkundige gebeld over mevrouw Van Heeswijk. Ze is 72 jaar en woont alleen. Ze heeft sinds twee jaar baarmoederkanker, is geopereerd en bestraald en heeft chemokuren gekregen. De artsen dachten dat de kanker weg was, maar eind vorig jaar kreeg ze benauwdheidklachten. Bij onderzoek bleken er uitzaaiingen o.a. in lymfeklieren en longen te zitten. Ze is nog een aantal keren bestraald waardoor de benauwdheid is afgenomen maar ze is erg misselijk, eet en drinkt nauwelijks. Ik ga bij haar op bezoek om kennis te maken. Ze vertelt over zichzelf, zegt dat ze bij de dag leeft en niet lang vooruit wil kijken. Verder spreken we af dat ik met de huisarts zal overleggen over andere medicatie voor de misselijkheid.

Twee weken later ben ik weer bij haar. Ze eet en drinkt weer voldoende, de huisarts heeft andere medicatie voorgeschreven waar ze goed op reageert. We spreken over de relatie met haar kinderen. Ze vraagt zich af of ze wel een goede moeder is geweest. Ze vertelt over haar jeugd en de drie verschillende partners in haar leven.

Tijdens mijn volgende bezoek zijn haar kinderen er ook allemaal. Ze willen praten over hoe het zal gaan als ze naar de hospice gaat. Ook vragen ze hoe het overlijden zal gaan. Een schoondochter heeft geen goede ervaringen met het overlijden van haar vader en moeder, dus wil ze weten hoe wij er mee omgaan. Euthanasie en de uitvaart komen ter sprake. De kinderen reageren allemaal verschillend, de een wil er niets van weten en loopt soms even weg, de ander wil zo veel mogelijk details. Mevrouw reageert erg nuchter op het gesprek: ‘ik zie wel hoe het gaat’.

Ze willen nog allerlei uitstapjes maken, naar Artis, Ikea en naar Duinrell. Ik zoek contact met Duinrell en ook met speciale leveranciers om alles te regelen; een huisje waar een hoog-laagbed in kan staan en een po-stoel waar ze ook op kan zitten onder de douche.

Een week later, het is begin oktober, belt mevrouw me. Ze is erg achteruit gegaan, vraagt of ik het bed heb geregeld. Als ik de dag erna bel om te vragen hoe het gaat, krijg ik haar zoon aan de telefoon, mevrouw is in het ziekenhuis opgenomen. Ze was erg benauwd. Twee dagen later belt hij op dat zij in het ziekenhuis is overleden terwijl de kinderen naast haar zaten.

Hans van der Graaf, coördinator Hospice Issoria en Issoria Thuis (verhaal onverkort eerder verschenen in CaPalCa nieuwsbrief 7, maart 2013)

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[1] In dit proefschrift zijn drie verhalen opgenomen, om een inkijkje te geven van het dagelijks werk van een casemanager. De verhalen zijn door de casemanagers zelf opgesteld, en bieden daarom geen objectief beeld. De namen van de betrokkenen in de verhalen zijn veranderd om de identiteit van patiënten en naasten te beschermen.

CHAPTER 4.
PALLIATIVE CARE CASE MANAGERS IN PRIMARY CARE: A DESCRIPTIVE STUDY OF REFERRALS IN RELATION TO TREATMENT AIMS

Annicka G. M. van der Plas

Bregje D. Onwuteaka-Philipsen

Anneke L. Francke

Wim J. J. Jansen

Kris C. Vissers

Luc Deliens

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Abstract

Background: Three important elements of the World Health Organization (WHO) definition of palliative care are: 1) it includes patients who may have cure or life prolongation as treatment aims besides palliative care; 2) it is not exclusively for cancer patients; and 3) it includes attention to the medical, psychological, social, and spiritual needs of the patients and their families. Case managers (nurses with expertise in palliative care) may assist generalist primary care providers in delivery of good palliative care.

Objectives: This study investigates the referral of patients to case managers in primary care with regard to the three elements mentioned: diagnosis, treatment aims, and needs as reflected in reasons given for referral.

Methods: In this cross-sectional survey in primary care among case managers and referrers to case management, case managers completed questionnaires for 687 patients; referrers completed 448 (65%).

Results: Most patients referred have a combination of treatment aims (69%). Life expectancy and functional status of patients are lower for those with a treatment aim of palliation. Almost all (96%) of those referred are cancer patients. A need for psychosocial support is frequently given as a reason for referral (66%) regardless of treatment aim.

Conclusions: Referrals to case managers reflect two of three elements of the WHO definition. Mainly, patients are referred for support complementary to medical care, and relatively early in their disease trajectory. However, most of those referred are cancer patients. Thus, to fully reflect the definition, broadening the scope to reach other patient groups is important.

Introduction

According to the World Health Organization (WHO) definition of palliative care, the aim is to improve the quality of life of patients and their families facing the problems associated with life-threatening illness (Sepulveda et al, 2002). This definition has three key elements. First, the definition is not restricted to the terminal stages of disease, but the much broader term of "life-threatening illness" is used. There is an increasing awareness among palliative care experts that there is often no strict boundary between the curative and palliative phase, but rather a shift of emphasis in treatment goals; curative, life prolonging, and/or palliative treatments can coexist (Lynn & Adamson, 2003) and may complement each other according to the needs of the patient. Second, palliative care is not only provided to terminally ill cancer patients, but also to those with other life-threatening diseases and conditions such as chronic obstructive pulmonary disease (COPD), heart failure, and age related frailty. Third, the definition states that palliative care is aimed at improving the quality of life. This may include physical well-being; psychological, existential, and social factors; and the system surrounding the patient (family, friends). These key elements are not always reflected in actual care provision; palliative care still mostly involves cancer patients in the terminal stages of disease and is often provided with a strong focus on physical symptoms (Murray et al, 2002; Klinger et al, 2013; Claessen et al, 2013; Evans et al, 2013b).

In the Netherlands, palliative care for home-dwelling patients is mainly provided by generalist care providers, that is, general practitioners (GPs) and home care professionals (Schafer et al, 2010). Palliative care case managers, nurses with expertise in palliative care, were introduced to assist GPs and district nurses (DNs) in the delivery of primary palliative care and patients and carers in obtaining the care they prefer (van der Plas et al, 2013). Case management is a heterogeneous concept of care that consists of assessment, planning, implementing, coordinating, monitoring, and evaluating the options and services required to meet the client's health and service needs (Commission for Case Manager Certification, 2010). The patient advocacy model (Long & Marshall, 2000) of case management used in the Netherlands (van der Plas et al, 2012) offers multidimensional coordination of care aimed at quality of care and is distinguished from the interrogative model that is more focused on clinical decision making and emphasises cost-effectiveness.

The question arises of whether the introduction of case management initiatives can facilitate provision of care according to the WHO definition of palliative care. The answer depends, among other things, on which patients are referred to case managers and if so at what stage of their disease trajectory. Therefore, this study examines the referral of patients to palliative care case management with the following research questions:

1) To what extent do patients referred to a case manager have curative or life-prolonging treatment aims or palliative treatment aims or a combination of these? And how does this relate to their life expectancy and functional status?

2) What are the patient and care characteristics of those referred to a case manager (including diagnosis), and are there differences in patients with differing treatment aims with regard to patient and care characteristics?
3) What are the reasons patients are referred to a case manager (including how these relate to different domains of palliative care), and are there differences in reasons for referral of patients with differing treatment aims?

Methods

Setting

In the Netherlands, there are 16.9 million inhabitants. Each year, about 77,000 people die of non-acute illnesses and 31% of these die at home (van der Velden et al, 2009). GPs see on average three to five palliative care patients a year (Groot et al, 2007). DNs 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). Less than 1% of GPs and of DNs have had advanced education to specialize in palliative care (IKNL, 2014). There is a wide range of short courses available on palliative care.

Case management initiatives were identified in a nationwide survey (van der Plas et al, 2013) and 13 of the 20 initiatives identified participated in the current study. Case management is provided by a nurse case manager; he or she visits the patient and their carers at home to discuss options for support. The case manager monitors whether care is delivered according to the patient's and carers' wishes. If patients and their carers wish, informational and psychosocial support is provided by the case manager. The case managers do not provide hands-on nursing care but can be part of a team that does. In the Netherlands, there are case management initiatives for patients with dementia (MacNeil et al, 2012), but such initiatives are not included in this study.

Procedure

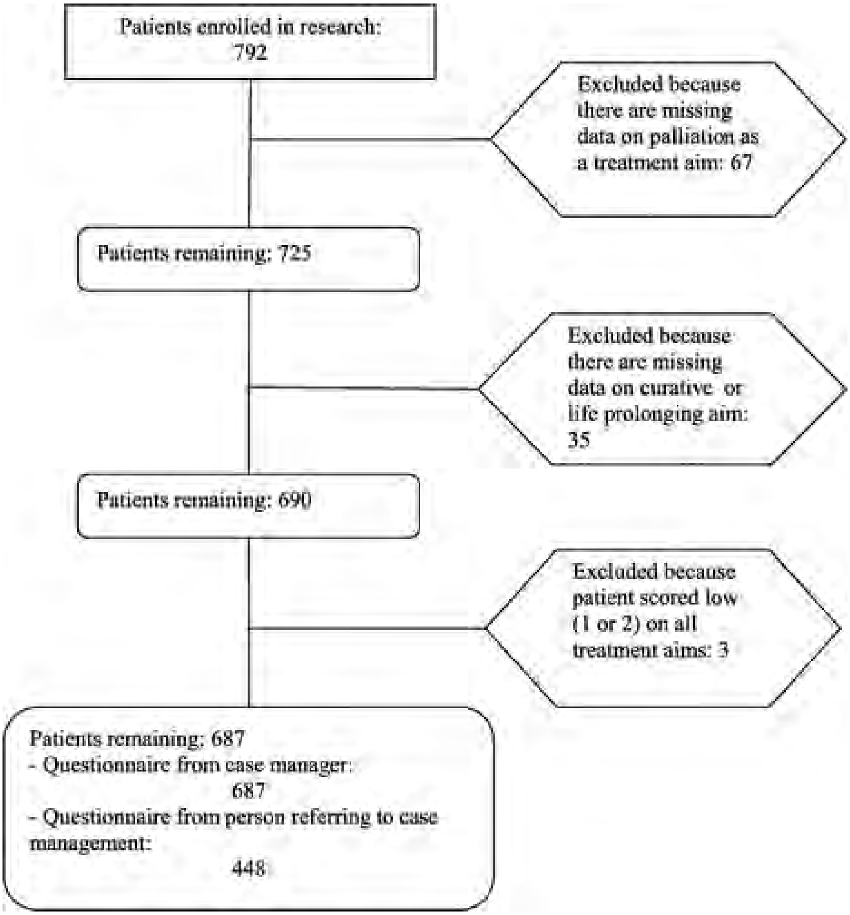
For this study, when a patient was referred for case management the case manager filled in a questionnaire and sent a questionnaire to the person who referred the patient. The two questionnaires used the same unique identification number. If a patient was entered into the study but no questionnaire from the person referring had been returned, the researcher asked the case manager to send a reminder. Data were gathered from March 2011 until the end of February 2013. Initiatives with many patients could include every second person in the study instead of every patient, for time management reasons. This study is exempt from approval from an ethics committee.

Questionnaires

The questionnaire filled in by the case manager at the start of case management contained structured questions regarding characteristics of the patient, such as demographic data and questions on diagnosis, prognosis, and treatment aims. Treatment aims were measured with the question, “How important are the following treatment aims for the patient at this moment?” for cure, life prolongation, and palliation; answers ranged on a 5-point Likert scale from “not important” (score = 1) to “very important” (score = 5).

The questionnaire for the person who referred to a case manager had three sections: 1) characteristics of the person who referred; 2) characteristics of patient care in the 30 days before referral; and 3) reasons for referral to and expectations from the case manager. All but one were structured questions; the question on reason for referral was open. The questionnaires were drafted to study implementation and support provided by the case manager. The questionnaires were piloted on a small sample of respondents to ascertain that the questions were clearly formulated and relevant.

Figure. 1. Flow chart of patient exclusion criteria



Data analysis

Patients were grouped according to the treatment aims at the time of referral using data from the questionnaire from the case manager. For cure and life prolongation a combined score was composed in which the highest score on either cure or life-prolongation prevailed. Three groups were defined:

1. Patients with cure/life prolongation as the main treatment aim (score 3 to 5) and for whom palliative care was not a treatment aim (score 1 or 2),

2. Patients with both cure/life prolongation and palliative care as treatment aim (both scores ranging from 3 to 5),

3. Patients with palliation as the main treatment aim (score 3 to 5) and for whom cure/life prolongation was not a treatment aim (score 1 or 2).

Patients who had either a missing score on the importance of palliation (n = 67) or importance of cure/life prolongation (n = 35) and those who scored low (score of 1 or 2) on all treatment aims (n = 3) were excluded (see Fig. 1 for a flow chart of exclusion criteria). For the visualization of these three groups in Table 1, the "trajectory model" of Lynn and Adamson is used (Lynn & Adamson, 2003).

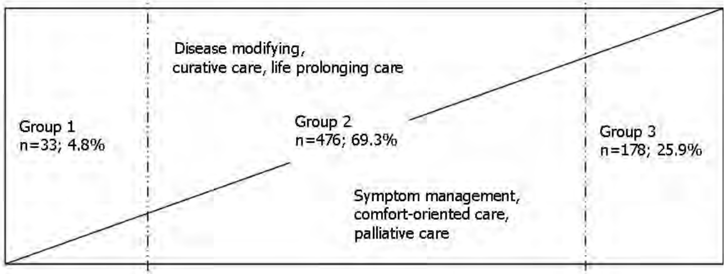
The open question on reasons for referral to a case manager was categorized by the first author (AvdP). A sample of answers was also categorized by the second author (BO-P). Categorization was then discussed between AvdP and BO-P. This resulted in "fine-tuning" of categorization choices. For answering the research question on the relationship between the treatment aims and life expectancy and functional status, data were reported and tested on all three groups with differing treatment aims. For the second and third question, comparisons were made between two groups: "early" (patients with a curative aim and a combination of treatment aims) versus "late" (palliative care treatment aim only). Fisher's exact test was calculated for categorical variables except functional status, where Monte Carlo simulation was used, and the student's t test was performed for the one continuous variable (age). To allow for multiple testing, a Bonferroni adjusted p value was chosen for significance (calculated by dividing the value of 0.05 by the number of tests used to answer the research question).

Results

Response

A total of 687 patients were included in this study and 448 (65.2%) questionnaires from referrers were received. Questionnaires from referrers were mostly from professionals (n = 421; 94.0%) with a minority from non-professionals (n = 27; 6.0%). Professionals were mostly nurses (81.1%); a further 9.4% were GPs and the remaining 9.5% were other professionals (e.g., social workers or medical specialists). Work setting of the professional was

Table 1. Life expectancy and functional status in relation to treatment aims for patients referred to a case manager in primary palliative care



	Sole curative aim (n=33) n (%)	Combination of aims (n=476) n (%)	Sole palliative aim (n=178) n (%)	p-value†
Life expectancy of patient at start of case management				**0.001**
- estimation not given	16 (48.5)	240 (50.4)	60 (33.7)	
- estimation given	17 (51.5)	236 (49.6)	118 (66.3)	
Life expectancy of patient when estimated				**>0.000**
- less than 3 months	0	39 (16.5)	58 (49.2)	
- 3 to 6 months	2 (11.8)	55 (23.3)	43 (36.4)	
- 6 months or longer	15 (88.2)	142 (60.2)	17 (14.4)	
Functional Status (ECOG)	(n=33)	(n=474)	(n=177)	**>0.000**
- fully functional	6 (18.2)	43 (9.1)	5 (2.8)	
- limited to small / light activities	16 (48.5)	187 (39.5)	39 (22.0)	
- bedridden less than 50% of the time	8 (24.2)	101 (21.3)	36 (20.3)	
- bedridden more than 50% of the time	2 (6.1)	96 (20.3)	56 (31.6)	
- fully in need of support	1 (3.0)	47 (9.9)	41 (23.2)	

† Boldfaced numbers are significant according to Bonferroni adjusted p <.017 in Fisher's exact test (life expectancy) or Monte Carlo simulation (functional status)

hospital for 62.3% and primary care for 37.7%. Non-professional referrers were children of the patient (36.0%), the partner of the patient (24.0%), the patient him or herself (20.0%), or others (e.g., friends or relatives) (20%).

Patient and care characteristics of patients referred to a case manager

The life expectancy and functional status of patients referred to a case manager can be seen in Table 1. Patients with a palliative treatment aim were older (mean age 71 years, standard deviation [SD] 12 years, $p < 0.000$) and more often male (61%, $p = 0.002$) than those with combined treatment aims (mean age 65 years, SD 13 years, male 47%). There are no other differences between the two groups with different treatment aims (see Table 2).

Table 2. Characteristics of patients in relation to treatment aims for patients referred to a case manager in primary palliative care; n (%)

	Total (n=687)	**Combination of aims (n=509)**	**Palliative aim only (n=178)**	**p-value[††]**
Main diagnosis				0.476
- cancer	663 (96.5)	493 (96.9)	170 (95.5)	
- other than cancer	24 (3.5)	16 (3.1)	8 (4.5)	
Type of cancer[†††]				0.003
- lung	166 (25.5)	124 (25.6)	42 (25.1)	
- colon	90 (13.8)	68 (14.0)	22 (13.2)	
- breast	68 (10.4)	56 (11.5)	12 (7.2)	
- haematological / lymphatic	40 (6.1)	38 (7.8)	2 (1.2)	
- prostate	37 (5.7)	27 (5.6)	10 (6.0)	
- other	251 (38.5)	172 (35.5)	79 (47.3)	
At least one secondary diagnosis	283 (42.4)	198 (39.7)	85 (50.3)	0.019
Most common secondary diagnoses (more than 1 answer possible)[††††]				
- heart diseases	89 (31.4)	60 (30.3)	29 (34.1)	0.577
- diabetes	70 (24.7)	54 (27.3)	16 (18.8)	0.176
- lung diseases	59 (20.8)	37 (18.7)	22 (25.9)	0.202
Service use of patient in 30 days before referral to case management (more than 1 answer possible)[†††††]				
- general practitioner	298 (67.4)	204 (63.8)	94 (77.0)	0.009
- out of hours gp	38 (8.6)	22 (6.9)	16 (13.1)	0.056

- district nurse	86 (19.5)	58 (18.1)	28 (23.0)	0.282
- specialist (from hospital)	366 (82.8)	276 (86.2)	90 (73.8)	0.003
- social worker	46 (10.4)	41 (12.8)	5 (4.1)	0.008
- palliative care consultant or consultation team	32 (7.2)	19 (5.9)	13 (10.7)	0.101
- spiritual counsellor	23 (5.2)	17 (5.3)	6 (4.9)	1.000
Residential circumstances				0.003
- with partner and children	92 (13.5)	79 (15.6)	13 (7.5)	
- with partner	363 (53.4)	264 (52.2)	99 (56.9)	
- with children	27 (4.0)	23 (4.5)	4 (2.3)	
- alone	171 (25.1)	126 (24.9)	45 (25.9)	
- other (e.g. living in an institution or temporarily living with family)	27 (4.0)	14 (2.8)	13 (7.5)	
Informal carers (more than 1 answer possible)				
- none	5 (0.7)	3 (0.6)	2 (1.2)	0.606
- partner	415 (61.3)	316 (62.7)	99 (57.2)	0.207
- children	459 (67.8)	332 (65.9)	127 (73.4)	0.073
- other family	210 (31.0)	163 (32.3)	47 (27.2)	0.217
- other (e.g. friends, neighbours)	233 (34.4)	188 (37.3)	45 (26.0)	0.007

† Number of missing observations between 0 and 19 ; †† Boldfaced numbers are significant according to Bonferroni adjusted p<.002 in Fisher's exact test ; ††† Percentages of types of cancer given in relation to cancer patients; n = 663 ; †††† Percentages of types of secondary diagnoses given in relation to patients with at least one secondary diagnosis; n = 283 ; ††††† Lower number of respondents because this question is from the questionnaire the referrers filled in (group with combined aims n=320, group with palliative aims n=122, total n=442).

Reasons for referral to a case manager

The question, "Why did you refer this patient for case management?" was answered by 440 (98.2%) referrers. However, 33 answers gave no insight into the reason for requesting case management (e.g., "We refer every patient" or "terminal cancer"). When disregarding these, 407 (92.5%) answers remained. Most referrers gave answers that could be allocated to one (46.9%) or two (40.0%) categories, but a single open answer was allocated to up to five categories. In Table 3 examples of open answers are given. All categories were mentioned in both groups, with psychosocial support being the largest category in both groups; there were no differences between the two groups in treatment aims (see Table 4).

Table 3. Examples of reasons for referral to a case manager as reported in an open question

Reason given for referral
Support from the General Practitioner leaves something to be desired. Husband and wife communicate poorly with each other. Hopefully the situation at home can be improved with case management. There is not much time left.
(Referral of a patient with combination of treatment aims)
The patient was admitted through the emergency department with acute stomach pains. Expected diagnosis was appendicitis or perforated cecum. During surgery an inoperable tumour was found. The patient was very shaken by this unexpected bad news. Went home without knowing ‘what next’. Desperation and tension were high. A lot of questions.
(Referral of a patient with sole palliative care treatment aims)
- bad prognosis – exhaustive treatment with chemo and radio therapy – the spouse is overburdened – the patient has a high risk of spinal cord injury, but he insisted on going home - receives probe feeding.
(Referral of a patient with combination of treatment aims)
The capacity of the patient and carer to bear this burden is insufficient. Extra support is necessary in monitoring chemotherapy. Psychosocial support.
(Referral of a patient with combination of treatment aims)
- support for the patient and family – provide information and reassure – timely identification of problems and proactive care (e.g. pain, tightness of the chest) – it is important that the patient and family see a familiar face and have one contact person.
(Referral of a patient with combination of treatment aims)
The husband and wife did not want home care, wanted to be independent as long as possible with help from family and friends. The wife was worried about when to arrange for extra help and how to do this quickly when the situation deteriorates fast.
(Referral of a patient with sole palliative care treatment aims)

Table 4. Reasons for referral to a case manager in relation to treatment aims, as reported in an open question; n (%) [†]

	Total (n=407)	Combination of aims (n=297)	Palliative aim only (n=110)	p-value[††]
Need for psychosocial support (at least one reason mentioned)	309 (75.9)	236 (79.5)	73 (66.4)	0.009
- support for the patient and carer	180 (44.2)	141 (47.5)	39 (35.5)	0.033
- acceptance of disease and/or dying	45 (11.1)	32 (10.8)	13 (11.8)	0.726
- living situation of patient; patient is living alone	37 (9.1)	31 (10.4)	6 (5.5)	0.173
- extra attention for carer, prevention of overburdening the carer	34 (8.4)	24 (8.1)	10 (9.1)	0.840
- living situation of the patient; partner is ill as well	15 (3.7)	11 (3.7)	4 (3.6)	1.000
- living situation of the patient; relationship problems	9 (2.2)	9 (3.0)	0	0.121
- living situation is inadequate for other reasons than above (e.g. lack of social support)	45 (11.1)	40 (13.5)	5 (4.5)	0.012
- difficulty with accepting medical or nursing care	12 (2.9)	5 (1.7)	7 (6.4)	0.020
- patient needs more time for information or support than can be provided within regular care	8 (2.0)	4 (1.3)	4 (3.6)	0.220
Need for medical / nursing knowledge (at least one reason mentioned)	142 (34.9)	104 (35.0)	38 (34.5)	1.000
- anticipating care needs	65 (16.0)	47 (15.8)	18 (16.4)	0.880
- monitoring of pharmacotherapy (e.g. oral chemo therapy or pain medication)	35 (8.6)	31 (10.4)	4 (3.6)	0.029
- specialised palliative care knowledge is needed	31 (7.6)	18 (6.1)	13 (11.8)	0.060
- high symptom burden or co morbidity	27 (6.6)	21 (7.1)	6 (5.5)	0.659
Need for information and care coordination (at least one reason mentioned)	134 (32.9)	87 (29.3)	47 (42.7)	0.013
- practical information for the patient and carer	62 (15.2)	45 (15.2)	17 (15.5)	1.000

- guiding the patient to care in accordance with preferences of the patient / supporting patient in arranging care as preferred	47 (11.5)	26 (8.8)	21 (19.1)	0.005
- coordination of care	29 (7.1)	16 (5.4)	13 (11.8)	0.031
- there are problems with care providers (e.g. difference of opinion between family and GP on care provision)	7 (1.7)	6 (2.0)	1 (0.9)	0.680

[†] More than one category per answer possible ; [††] Boldfaced numbers are significant according to Bonferroni adjusted p<.003 in Fisher's exact test

Discussion

The majority of patients referred to a case manager have a combination of treatment aims and are almost exclusively cancer patients. Reasons for referral cover all aspects of palliative care but psychosocial aspects are mentioned most. Patients with treatment focussing on palliative care are more often male and older than those with a combination of treatment aims. There are no differences in reason for referral for patients with a sole palliative care treatment aim compared with patients with combined treatment aims.

Strengths and limitations of this study

This article is part of a prospective study on case managers and information was gathered at the moment of referral; recall bias therefore will be low. However, of the 20 case management initiatives identified in the Netherlands, 7 did not participate in the current study. Also, this study is conducted within the Dutch healthcare system where almost all patients are enrolled with a GP, one of the main providers of primary palliative care. Referral to and expectations of case management may be different in healthcare systems with other characteristics. Furthermore, we do not know why patients are not referred to a case manager as we asked only about those who are referred. Further research is needed to investigate whether case managers actually meet expectations.

Case management is delivered to patients with a combination of treatment aims

A majority of patients referred to a case manager are receiving a combination of curative/life prolonging and palliative care. The data on life expectancy and functional status suggest that prognosis and functional status govern the balance between treatment aims; both life expectancy and functional status were highest in the group with a sole curative treatment aim, lower in the group with combined aims, and lowest in the group with a sole palliative treatment aim. In our study, most patients were relatively able to function in everyday life, had an estimated life expectancy of more than 3 months, and had curative and/or life-prolonging treatment aims along with palliative care. This suggests that patients are referred to case managers relatively early in their disease trajectory, when discussions on the balance of treatment aims are still relevant and they are still able to engage in discussions on preferred care, including shifts from focus on curative or life-prolonging to palliative treatment aims.

Case management is delivered to cancer patients

Those referred to case managers are almost exclusively cancer patients. The high proportion of cancer patients in palliative care services is common; in a recent comparison between Canada, the United States, Germany, and England, only the United States had a percentage of 41% patients in hospice and palliative care with a cancer diagnosis, the other countries had percentages of 90% or higher (Klinger et al, 2013). This can be explained by the relatively predictable illness trajectory of cancer. However, we did not find a difference in diagnosis between the earlier and later referred group, whereas one would expect more late referrals with a diagnosis other than cancer given the more unpredictable trajectory. Another cause might be that palliative care originated in cancer care; this may mean that it is easier to establish a working relationship with oncology departments in hospitals so palliative care services receive more referrals of oncology patients. To broaden the scope of palliative care case managers, incorporation of medical and nursing knowledge with regard to non-cancer patients, for instance by involving nurses with other specializations (such as heart disease), is needed. Use of tools developed for administrative identification of patients with palliative care needs, specifically including non-cancer patients (Gomez-Batiste et al, 2013; O'Callaghan et al, 2014), may provide an aid. For a more general change of culture among care providers, impact of interventions such as Gold Standards Framework (Shaw et al, 2010) and PaTz (van der Plas et al, 2014) on knowledge and skills of palliative care provision to non-cancer patients should be assessed.

Psychosocial support is mentioned most as reason for referral to case managers

Whereas all domains of palliative care are mentioned by referrers, the need for psychosocial support is mentioned most. In a study on nurse specialists in palliative care (MacMillan nurses), emotional support was the most common reason for referral (Skilbeck et al, 2002). Psychosocial support transcends disease-specific knowledge. It might be that the patient's need for psychosocial support may be a more suitable pointer for the start of palliative care than life expectancy or diagnosis, because life expectancy is difficult to assess and diagnosis bears the risk of a focus on cancer patients. Existential or spiritual aspects are rarely mentioned explicitly, but acceptance of disease and/or dying is mentioned for 10% of patients. This resonates with a generally found lack of attention to spiritual issues in palliative care (Evans et al, 2013a). On the other hand, it would be unlikely that the need for existential/spiritual care was mentioned as a main reason for referral to a case manager, as referral to an existential/spiritual counsellor would be the more obvious path in that situation. It appears that patients are referred when the referrer expects that care may be complex or time-consuming, either because the situation at home is considered inadequate or because the referrer considers that the patient and carer may benefit from some psychosocial assistance in dealing with their situation. This seems especially true for referral earlier in the palliative care trajectory for patients with combined treatment aims. This group had less contact with their GP and DN than the group with a sole palliative treatment aim (although not significant). Also, the GPs and DNs may have less time to address psychosocial issues or may find addressing them difficult (Griffiths et al, 2010; Slort et al, 2011). It remains to be seen whether case management is the best solution, or whether the GP and DN should be involved earlier.

Conclusion

Case management referral in primary palliative care fulfils two of the three relevant elements of the WHO definition of palliative care in that it attracts referrals before the terminal stage of the disease and covers all domains of palliative care, with an emphasis on psychosocial support, making it complementary to medical care provided in the hospital and by primary care providers. However, those referred to a case manager are almost exclusively cancer patients. Future efforts to improve palliative care case management should focus on broadening the scope to include patients with diagnoses other than cancer.

CHAPTER 5.

CASE MANAGEMENT IN PRIMARY PALLIATIVE CARE IS ASSOCIATED MORE STRONGLY WITH ORGANISATIONAL THAN WITH PATIENT CHARACTERISTICS: RESULTS FROM A CROSS-SECTIONAL PROSPECTIVE STUDY

Annicka G. M. van der Plas

Anneke L. Francke

Kris C. Vissers

Wim J. J. Jansen

Luc Deliens

Bregje D. Onwuteaka-Philipsen

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Abstract

Background: Case managers have been introduced in Dutch primary palliative care; these are nurses with expertise in palliative care who offer support to patients and informal carers in addition to the care provided by the general practitioner and home care nurses. This study aims to describe support and investigate what characteristics of patients and the organisational setting are related to the number of contacts and to the number of times topics are discussed between the case manager and patients and/or informal carers.

Methods: Prospective study following cancer patients (n=662) receiving support from a palliative care case manager in Dutch primary care, using registration forms filled out by the case manager after contact with the patient and/or informal carer. In backward linear regression, the association was studied between patient or organisational characteristics and the number of contacts and the number of times conversation topics were discussed.

Results: Organisational characteristics add more to explained variability in data than patient characteristics. Case managers provide support in a flexible manner with regard to the number, mode, persons present, and duration of contacts. Support covered all domains of palliative care, with most attention given to physical complaints, life expectancy and psychological aspects.

Conclusions: Support offered by the case managers is prompted by characteristics of the organisation for which they work. This is contradictory to the idea of patient centered care highly valued in palliative care.

Background

Most people prefer to die at home (Gomes et al, 2013b), so the availability of community based palliative care is important to help meet patients' needs. In the Netherlands, palliative care for home-dwelling patients is mainly provided by generalist care providers i.e. general practitioners (GPs) and home care professionals (Schafer et al, 2010). The World Health Organization (WHO) (Sepulveda et al, 2002) stresses that physical, emotional, and spiritual care needs of the patient are all considered important concerns in palliative care. Patients have a broad range of symptoms and it is hard 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). Additionally, GPs and home care nurses may have difficulties or discomfort assessing and discussing prognosis, psychological and spiritual/existential issues (Griffiths et al, 2010; Abarshi et al, 2011; Slort et al, 2011). Case managers with specific expertise regarding palliative care have been introduced to help patients with palliative care needs and their informal carers obtain the palliative care that matches their preferences (van der Plas et al, 2013).

Case managers' work covers two complementary levels (Minkman et al, 2009). At an individual level the case manager provides advice or referral to patients and their informal carers. At the level of the organisation of care, the case manager has a central position and collaborates with multiple healthcare providers, and provides continuity between professionals and organisations. Tasks can include assessment, planning, implementing, coordinating, monitoring and evaluating the options and services required to meet the client's health and service needs (Commission for Case Manager Certification, 2010). The case manager provides support in addition to the care provided by the home care nurse and general practitioner. The organisational affiliation of the case managers in the Netherlands varies; case managers can be employed by a home care organisation, by a hospice or by a collaborative venture between institutions (e.g. a home care organisation working together with a hospital). Another distinctive feature was their target group; varying from patients from diagnosis onwards to patients in the final stage of their life.

The relationship to the patient should be central in palliative care and support from the case manager should be tailored to the individual needs of the patient (van der Plas et al, 2012). Topics discussed between the case manager and the patient and informal carer should cover physical, emotional, and spiritual care needs of the patient. Important aims of case management are that support is flexible, delivered according to the needs of the patient and informal carer at that moment, and delivered as long as necessary. This should be reflected in characteristics of contacts such as the number of contacts, modes of contact, an duration of contacts. There is paucity in research describing these characteristics for case management in primary palliative care.

Since both palliative care in general (Sepulveda et al, 2002) and case management in palliative care in particular (van der Plas et al, 2012) aim to be highly patient centered, characteristics of patients should be more guiding in content of care than characteristics of the organisation providing care. Therefore this study aims to answer the following two questions:

1) What support is provided by the palliative care case manager with regard to number of contacts, mode of contact, duration of contacts, time between the first and last recorded contact, persons present during contacts, and content of contacts?
2) What characteristics of patients and the organisational setting are related to the number of contacts with the patient and to the number of conversations the palliative care case manager has per topic with patients and/or informal carers?

Methods

Design

Prospective study in a group of Dutch cancer patients (n=662) receiving support from a palliative care case manager.

Setting

The population of the Netherlands is 16.9 million (Statistics Netherlands, 2014). Each year, about 77,000 people die of non-acute illnesses, 31% of them dying at home (van der Velden et al, 2009). The number of not-unexpected deaths per GP per year is estimated to be 12-13 on average (IKNL, 2014). Home care nurses who are confronted with end-of-life care see on average 10 palliative care patients a year (Nursing Staff Panel, 2011). There is a wide range of short courses available on palliative care for GPs and home care nurses. Specialized palliative care knowledge is available to GPs and home care nurses through consultation teams operating all over the Netherlands, mainly offering advice by telephone. These teams are consulted approximately 6000 times a year (6% of the number of not-unexpected deaths) (IKNL, 2014). And in some regions, nurse case managers with specific expertise regarding palliative care have been introduced to visit the patients at home (for a map of the Netherlands with the locations see Van der Plas et al, 2013).

Case management initiatives in primary care were identified in a nationwide survey (van der Plas et al, 2013). Of the 20 initiatives identified in that survey, 13 were investigated in the current study. The term ‘initiative’ is used to do justice to organisational differences, since not all case managers work in a team of case managers; there was one initiative with one case manager, for example, while another case manager is part of a team in which not all members offer case management. See Table 1 for more information on the participating initiatives, and for a more in depth discussion of initiatives please refer to (van der Plas et al, 2013). For the present analysis, we used data about cancer patients

(96% of all referred patients) with at least one registered contact with the case manager (94% of all referred patients), for whom data collection had stopped before the end of the research period (91% of all referred patients).

Table 1. Characteristics of participating case management initiatives

	Number of initiatives (n = 12)[†]	Percentage of patients (n =662)
Organisation offering case management		
- home care organisation	5	48.6%
- collaboration between institutions [††]	5	28.4%
- hospice	2	23.0%
Target group of the initiative		
- from curative care onwards	3	27.8%
- from life prolonging care onwards	3	23.6%
- only palliative care patients	6	48.6%
Number of years the initiative was active/operational at start of the study		
- less than a year	3	11.9%
- one – five years	7	61.0%
- five years or longer	2	27.0%
Number of case managers employed	mean = 3.6 (SD 2.2)	
- one case manager	1	1.7%
- two case managers	4	50.9%
- three or four case managers	4	34.9%
- five or more case managers	3	12.5%
Number of full time equivalents (fte)	mean = 1.3 (SD 0.8)	
- unknown	1	0.6%
- 0,5 fte or less	1	1.7%
- between 0,5 and 1 fte	5	45.7%
- between 1 and 2 fte	2	24.5%
- 2 fte or more	3	27.6%
Number of patients enrolled in the study		
- less than 50 patients	6	6.9%
- 50 – 100 patients	2	19.9%
- 100 or more patients	4	73.1%

[†] Of the 13 participating initiatives, one was specifically focussed on patients with COPD and was not included in this paper (only initiatives involving cancer patients were included in this paper).
[††] An example of a collaboration of institutions is a hospital working together with a home care organisation.

Questionnaires

A questionnaire was filled out by the case manager at the moment of referral of a patient to the case manager. It contained structured questions regarding characteristics of the patient, such as demographic data and questions on diagnosis and prognosis.

A registration form was filled out by the case manager after each contact with the patient and/or informal carer. It contained structured questions on the contact such as mode (phone, visit or other) location and attendees, content of the contact (dichotomous questions on topics of conversation and actions of the case manager during the contact), and the duration of the contact.

Both questionnaires were drafted to study implementation and support provided by the case manager. The questionnaires were piloted on a small sample of respondents to ascertain that questions were clearly formulated and relevant.

Ethical considerations

Under Dutch law this study is exempt from approval from an ethics committee since it did not involve imposing any interventions or actions (Centrale Commissie Mensgebonden Onderzoek, 2014). Data were anonymized by the case manager before being handed over to the authors. The authors provided information material about the study to the case managers, so they could inform the patients on the study and get consent.

Procedure

Data were gathered from March 2011 until the end of 2013. When a patient was referred to the case manager, the case manager filled out a questionnaire. For every contact the case manager had with the patient and/or informal carer, a registration form was filled out. The questionnaire and registration forms used the same unique patient identification number. When a period of 'silence' (not returning registration forms) ensued after a patient was entered into the study, the researcher asked the case manager whether provision of support was still ongoing. Initiatives with many patients could include every second person in the study instead of every patient, for time management reasons. When not including all patients, case managers were stressed not to 'choose' the patients they included in the study, but to keep strictly to the 'every second patient rule'.

Data analysis

Frequencies were calculated to describe patients, characteristics of contacts, and content of contacts. To explore if there were any patient or organisational characteristics associated with the number of contacts and the number of times conversation topics were discussed during contacts, backward linear regression (removal at $p < .05$) was performed. The number of contacts and the number of conversations per topic were skewed, but did not follow a Poisson distribution (variance was larger than the mean in all variables). Therefore the log transformation of the number of contacts and the number of conversations per topic were used in the model (Field 2009). Logtransformed data are to be interpreted like odds ratios (even when they are transformed back like in table 5). To reduce the number of missing observations after logtransformation, a fixed number (1) was added to the number of contacts and the number of conversations per topic before logtransformation (Field, 2009). Separate regression models were fitted for each conversation topic. The following patient characteristics were entered into the analysis: age, sex, living situation of the patient (alone or not), whether the patient had an additional diagnosis (none versus at least one), functional status, and starting point of case management (early or later in disease trajectory). The following organisational characteristics were entered into the analysis: organisation where the case manager was employed (home care organisation, hospice, or collaboration between institutions), target group of the initiative (patients receiving support from the case manager from diagnosis onwards, patients receiving life prolonging or palliative care, patients receiving palliative care). To investigate the separate contribution of patient characteristics and organisational characteristics, these were added as separate blocks in the regression models. To control for the number of contacts, this variable was added as a first block to the models investigating the conversation topics. As a measure of the goodness of fit of the models, the value of R^2 is used to determine the proportion of variability in a data set that is accounted for by the statistical model (reported in Table 6). Data were analyzed using SPSS, IBM Statistics for Windows version 20.0.

Results

General characteristics of patients

Patients had a mean age of 66.8 years (SD 12.3; range 29 - 98), and half of patients were male (49.5%) (Table 2). A quarter (26.6%) had a diagnosis of lung cancer, and 42.4% of patients had at least one other diagnosis besides cancer. Most (69.5%) patients had a combination of treatment aims when they entered case management, 3.9% had cure or life prolongation as treatment aim and 26.6% had a palliative care treatment aim. Also, 8.0% of patients were fully functional at start of case management, 35.4% was limited to light activities, and 21.5% of patients was bedridden for less than half a day. For half (52.2%) of the patients, an estimation of life expectancy was given at start of support by the case manager, and when given, 44.3% of patients had an estimated life expectancy of six months or longer. Patients were mostly living with a partner (53.7%) or alone (24.7%), a further 13.8% lived with partner and children. Most mentioned informal carers were the partner (61.8%) and children (68.5%) of patients.

Table 2. Characteristics of patients receiving support from a case manager

	Total (n=662) n (%)†
Sex, male	328 (49.5)
Age, mean (SD)	66.8 (12.3)
Type of cancer	
- lung	174 (26.6)
- colon	85 (13.0)
- breast	75 (11.5)
- other	319 (48.9)
At least one additional diagnosis	269 (42.4)
Treatment aims	
- mainly palliative treatment aims	170 (26.6)
- mainly curative or life prolonging treatment aims	25 (3.9)
- combined treatment aims	445 (69.5)
Functional Status (ECOG)	
- fully functional	52 (8.0)
- limited to small / light activities	230 (35.4)
- bedridden less than 50%	140 (21.5)
- bedridden more than 50%	149 (22.9)
- fully in need of support	79 (12.2)
Life expectancy of patient at start of case management, estimation given	345 (52.2)
Life expectancy of patient when estimated	
- less than 3 months	92 (26.7)
- 3 to 6 months	100 (29.0)
- 6 months or longer	153 (44.3)
Residential circumstances	
- with partner and children	90 (13.8)
- with partner	350 (53.7)
- with children	25 (3.8)
- alone	161 (24.7)
- other (e.g. living in an institution or temporarily living with family)	26 (4.0)
Informal carers (more than 1 answer possible)	
- none	7 (1.1)
- partner	401 (61.8)
- children	444 (68.5)
- other family	200 (30.9)
- other (e.g. friends, neighbours)	225 (34.7)

† Number of missing observations between 0 and 27

Characteristics of the contacts between the case manager and patient and/or informal carer
The number of contacts ranged from 1 to 36 (Table 3), with a median of 4 contacts. Contacts were mostly with the patient and informal carer together. Both home visits and telephone contacts occurred, with telephone calls being shorter in duration than home visits.

Table 3. Characteristics of contacts of the case manager with patients and/or carers

	Total **(n=662)** **n (%)**
Number of contacts with patient and/or informal carer, median (range)	4.0 (1-36)
- one	104 (15.7)
- two – five	297 (44.9)
- six - ten	160 (24.2)
- eleven - twenty	85 (12.8)
- twenty-one or more	16 (2.4)
Number of contacts with patient only, median (range)	0 (0-30)
Number of contacts with informal carer only, median (range)	1 (0-19)
Number of contacts with both patient and informal carer, median (range)	2 (0-18)
Mode of contact	
- visits, median (range)	2.0 (0-23)
- by telephone, median (range)	2.0 (0-19)
Duration of contact in minutes by mode	
- visits, median (range)	60.0 (2-190)
- by telephone, median (range)	15.0 (2-120)
Time between first and last recorded contact in days	
- zero	108 (16.3)
- up to one week	38 (5.7)
- up to one month	128 (19.3)
- one to three months	143 (21.6)
- three to six months	131 (19.8)
- half year to a year	84 (12.7)
- more than a year	30 (4.5)

Content of contacts
The topics discussed at least once with most patients and/or informal carers were physical complaints (93.5% of patients/informal carers), life expectancy (79.5% of patients/informal carers), and psychological aspects of being ill (79.3% of patients/informal carers) (Table 4). The information given at least once to most patients and/or informal carers was on care services, illness and nursing or physical care. Physical complaints and psy-

chological aspects were discussed most often per patient.

Table 4. Content of contacts of the case manager with patients and/or carers

	Number of times the patient / carer had…	Number of patients / carers who had at least once...
	(n=662)	(n=662)
	median (range)	n (%)
A conversation about:		
- physical complaints	3.0 (0-26)	619 (93.5)
- life expectancy	1.0 (0-16)	526 (79.5)
- psychological aspects	2.0 (0-22)	525 (79.3)
- incurability of disease	1.0 (0-13)	502 (75.8)
- medical treatment(s)	1.0 (0-17)	456 (68.9)
- possibilities of palliative care	1.0 (0-12)	456 (68.9)
- social aspects	1.0 (0-22)	443 (66.9)
- main diagnosis	1.0 (0-11)	432 (65.3)
- burden of treatment(s)	1.0 (0-15)	413 (62.4)
- spiritual aspects	0 (0-12)	312 (47.1)
- possible medical complications	0 (0-7)	274 (41.4)
- other	0 (0-12)	302 (45.6)
Been given information on:		
- care services	1.0 (0-13)	468 (70.7)
- illness	1.0 (0-13)	441 (66.6)
- nursing / physical care	1.0 (0-16)	403 (60.9)
- medical treatment(s)	1.0 (0-15)	354 (53.5)
- coping	1.0 (0-14)	347 (52.4)
- home care technology	0 (0-6)	215 (32.5)
- other	0 (0-13)	296 (44.7)
An assessment of care needs	2.0 (0-22)	577 (87.2)
Coordination of care	0 (0-15)	318 (48.0)

Table 5. Statistically significant relationships between number and content of contacts and patient and organisational characteristics †,††

	Patient						Organisation; Affiliation		Organisation; Target group		Care
	Age††	Sex female	Living situation alone	At least one additional diagnosis	Functional status	Start of case management	Home care organisation	Hospice	From life prolonging care onwards	Only palliative care patients	Number of contacts
Number of contacts		1.12 (1.01 – 1.24)			0.89 (0.85 – 0.93)	1.22 (1.08 – 1.38)	0.54 (0.41 – 0.71)	0.57 (0.50 – 0.66)	0.71 (0.62 – 0.82)	0.65 (0.49 – 0.86)	
Number of conversations about:											
- physical complaints					0.96 (0.93 – 0.98)		1.47 (1.37 – 1.58)	1.52 (1.40 – 1.65)			1.12 (1.12 – 1.13)
- psychological aspects			0.87 (0.79 – 0.96)		0.95 (0.91 – 0.98)		1.22 (0.97 – 1.53)	1.14 (1.01 – 1.28)	0.87 (0.77 – 0.98)	1.01 (0.80 – 1.27)	1.10 (1.09 – 1.11)
- life expectancy									1.40 (1.25 – 1.56)	1.04 (0.95 – 1.14)	1.08 (1.07 – 1.09)
- incurability of disease							1.69 (1.37 – 2.10)	0.90 (0.81 – 1.01)	1.54 (1.38 – 1.73)	1.68 (1.34 – 2.09)	1.08 (1.07 – 1.08)
- possibilities of palliative care	1.01 (1.00 – 1.01)		0.90 (0.82 – 0.99)			0.81 (0.73 – 0.89)	1.08 (0.98 – 1.20)	1.47 (1.31 – 1.67)			1.07 (1.06 – 1.07)

	Patient						Organisation; Affiliation		Organisation; Target group		Care
Table 5 continued	**Age**	**Sex female**	**Living situation alone**†	**At least one additional diagnosis**	**Functional status**	**Start of case management**	**Home care organisation**	**Hospice**	**From life prolonging care onwards**	**Only palliative care patients**	**Number of contacts**
- medical treatment(s)	1.00 (0.99 – 1.00)				0.92 (0.89 – 0.96)	1.24 (1.12 – 1.37)	1.48 (1.19 – 1.86)	1.20 (1.07 – 1.36)	1.16 (1.03 – 1.30)	1.13 (0.90 – 1.42)	1.08 (1.07 – 1.09)
- social aspects					0.94 (0.91 – 0.98)	0.89 (0.79 – 1.00)	1.14 (0.88 – 1.48)	1.39 (1.21 – 1.59)	0.74 (0.65 – 0.85)	1.07 (0.82 – 1.40)	1.07 (1.06 – 1.08)
- main diagnosis						1.09 (1.00 – 1.18)	1.84 (1.52 – 2.23)	0.95 (0.86 – 1.06)	1.36 (1.23 – 1.50)	1.22 (1.00 – 1.49)	1.03 (1.03 – 1.04)
- burden of treatment(s)	0.99 (0.99 – 1.00)		1.11 (1.00 – 1.23)		0.93 (0.89 – 0.97)	1.22 (1.09 – 1.36)	1.62 (1.27 – 2.06)	1.52 (1.33 – 1.73)	1.25 (1.10 – 1.43)	1.21 (0.94 – 1.56)	1.07 (1.06 – 1.08)
- spiritual aspects			0.88 (0.80 – 0.97)						0.79 (0.70 – 0.86)	0.90 (0.82 – 0.99)	1.05 (1.04 – 1.06)
- possible medical complications							1.35 (1.24 – 1.47)	1.27 (1.15 – 1.40)			1.04 (1.04 – 1.05)

†N = 662, number of missing values range from 0 to 24. Reported are unstandardized regression coefficients with 95% confidence intervals. All dependent variables were logtransformed due to skewed data, and can therefore be interpreted like odds ratios. In the presented models all variables have p-values of 0.05 or below (the affiliation of the case manager and the target group of the organisation are both nominal variables, all categories are reported when at least one of them has a p-value of 0.05 or below). ††Reference groups in analyses: Sex male = reference; Living situation not alone = reference; No additional diagnosis = reference; Start of case management late in disease trajectory = reference; Affiliation is collaboration between institutions = reference; Target group of organisation from curative care onwards = reference. For functional status higher score = lower status (in Table 4; the higher the score and therefore the lower the status, the less conversations on a topic).

Patient and organisational characteristics associated with number and content of contacts
The number of contacts was higher for female patients; female patients and/or their informal carers had 12% (B = 1.12, CI 1.01 – 1.24) more contacts with a case manager than male patients (Table 5). Lower functional status (B = 0.89, CI 0.85 – 0.93) was associated with fewer contacts and first contact early in the disease trajectory (B = 1.22, CI 1.08 – 1.38) was associated with more contacts. Case managers from a home care organisation (B = 0.54, CI 0.41 – 0.71) or from a hospice (B = 0.57, CI 0.50 – 0.66) had fewer contacts with patients compared to case managers from a collaboration between institutions. Organisations with a target group of patients receiving either life prolonging care and/or palliative care (B = 0.71, CI 0.62 – 0.82) and organisations targeting palliative care patients only (B = 0.65, CI 0.49 – 0.86) had fewer contacts with patients compared to organisations with a target group of patients receiving care from diagnosis onwards. The relation between discussion topics, patient characteristics, and organisational characteristics is detailed in Table 5.

Table 6. Proportion of variability that is accounted for by the statistical model

	Number of contacts (Block 1)	Block 1 and patient characteristics (Block 2)	Final model †: Block 2 and organisation characteristics (Block 3)
	R^2	R^2	R^2
Number of contacts	NA	0.063	0.170
Number of conversations about:			
- physical complaints	0.661	0.670	0.727
- psychological aspects	0.463	0.478	0.491
- life expectancy	0.345	NA	0.386
- incurability of disease	0.316	NA	0.410
- possibilities of palliative care	0.239	0.265	0.317
- medical treatment(s)	0.354	0.431	0.472
- social aspects	0.277	0.289	0.358
- main diagnosis	0.065	0.080	0.365
- burden of treatment(s)	0.239	0.327	0.389
- spiritual aspects	0.190	0.198	0.217
- possible medical complications	0.145	NA	0.205

† This is the model presented in table 5.

Contribution of patient and organisational characteristics to the models
Models on conversation topics which included number of contacts and organisational characteristics consistently explained most variability in data (Table 6). Patient characteristics did not contribute to the explanation of variability in data in conversations on life expectancy, incurability of disease and possible medical complications. Furthermore,

in other conversation topics, patient characteristics contributed relatively little to explanation of variability in data, only in three models did they add more to explain variability than organisational characteristics.

Discussion

Organisational characteristics are important in prediction of the number of times topics are discussed with patients; they add more to explained variability in data than patient characteristics. Differences were most articulate between organisations targeting patients from diagnosis onwards and organisations targeting patients receiving life prolonging and/or palliative care. Furthermore, case managers working from a hospice and from a home care organisation have more conversations on topics than case managers from a collaboration between institutions. Case managers provide support in a flexible manner with regard to the number, mode, persons present, and duration of contacts. Time between the first and last contact also varied. Support covered all domains of palliative care, with most attention given to physical complaints, life expectancy and psychological aspects of being ill.

Number and content of contacts

The variability in number of contacts and content of contacts could be an indication that support is offered according to the patient's needs or wishes. However, we did not study who initiated or requested actions and conversations during contacts. Assessment of specialist palliative care nurses with regard to quality of life may differ from assessment by patients (Horton 2002), and also perceived needs of the patient and informal carer may differ between nurses and patients (Skilbeck & Payne, 2003). So, it could be that different topics would ensue when the case managers initiated the actions as compared to when patients and informal carers initiated actions. However, it is likely that both the case manager and the patient and/or informal carer had an influence on the kind of support given. In a study on patients' view on the specialist palliative care nurse (Chapple et al, 2006), patients valued the nurses' work, particularly their advice on practical matters, information given about their disease, emotional support, advice on symptoms, and help with communication. The persons who refer patients to palliative care case managers expect psychosocial support to be given, since this was mentioned as a reason for referral in more than three quarters of patients with a combination of treatment aims and in two third of patients with a sole palliative care treatment aim (van der Plas et al, 2015c).

Functional status of the patient at the start of support by the case manager and start of case management early or late in disease trajectory are the patient characteristics most often related to conversation topics. Since models are controlled for the number of contacts, this is not simply an issue of opportunity (more chance of discussing topics when there is more time). Patients for whom the start of case management was early in the disease trajectory more often had conversations on medical treatments, main diagnosis and burden of treatment; all three topics may be particularly relevant to patients still receiving life prolonging or curative treatment. Likewise, possibilities of palliative care may have been discussed less with patients for whom support by the case manager started early, because they were still focused on life prolonging or curative treatment. In a study on palliative care by the GP, having end-of-life conversations was related to the provision of palliative care and not to functional status (Abarshi et al, 2011).

Importance of organisational characteristics in the provision of support by the case manager

With regard to target group of the organisation, the biggest differences were found between case managers working from an organisation targeting patients from diagnosis (curative care) onwards compared to case managers working from an organisation targeting patients receiving life prolonging and/or palliative care. It is remarkable that the difference is not bigger between organisations targeting patients receiving palliative care only compared to organisations targeting patients from diagnosis (curative care) onwards. Specific attention is paid to patients receiving life prolonging care, not just in line with a continuously heightened or intensified attention to discussion topics during the process of treatment from curative to ultimately terminal care. More attention is paid to life expectancy, incurability of disease, medical treatments, main diagnosis and burden of treatment, but conversations on psychological, social and spiritual aspects occur less with case managers from an organisation targeting patients receiving life prolonging and/or palliative care (compared to organisations targeting patients from diagnosis onwards).

The number of conversations per topic was higher for case managers working from a home care organisation and a hospice, compared to case managers from a collaboration between institutions. Again, since models are controlled for the number of contacts, this is not simply an issue of opportunity. Differences in palliative care between settings may be explained by differences in availability of care and culture (Lysaght Hurley et al, 2014; Gallagher & Krawczyk, 2013), but current findings are all within the primary care setting. Organisational aspects played a role in provision of advance care planning in community-based care management organisations (Baughman et al, 2014); in that study, amongst other things availability of training and resources was linked to advance care planning. It is notable that characteristics of the organisation for which the case manager works add more to explain the number of conversation per topic than patient characteristics. Further research is needed to determine why some case managers within the primary care setting discuss topics less or more often, depending on the organisation they work for. Aspects that should be taken into account in future research may be: whether some case managers go less in depth and are therefore able to discuss topics more often, whether they are more efficient with their time, and how much time during contacts is spent on conversations, providing information and care coordination.

Strengths and limitations of this study

This study is an important step in opening the 'black box' of case management in palliative care (Wulff et al, 2008). This is the first study to investigate the relationship between organisational characteristics of primary palliative care case management and provision of support. Information on contacts was gathered continuously during support from the case manager; recall bias therefore will be low. However, our study has some potential limitations that should be kept in mind. This study is conducted within the Dutch health care system where primary palliative care is mostly delivered by generalist care providers (the GP and home care nurses), with case managers offering additional support. This could influence the way case management is delivered and the topics discussed. The patient characteristics used in our analyses were found relevant for prediction of service use in previous studies (Masucci et al, 2013; Kozlov et al, 2013; Aldridge et al, 2015). However, they may not be suitable specifically for patients receiving case management. Future studies should explore whether other patient characteristics than those used would better predict the number of contacts and conversation topics; for instance characteristics better detailing the complexity of the home or medical situation of the patient may be more appropriate.

Conclusion

Case managers provide support in a flexible manner and support covered all domains of palliative care. Despite the generally agreed upon goal of palliative care providing patient centered care, our data suggest that characteristics of the organisation are more important in prediction of what topics are discussed between the case manager and the patients and informal carers than patient characteristics. So even though case managers provide support in a flexible manner, this flexibility is 'colored' by organisational characteristics. It is notable that organisational characteristics are guiding in care provision, but it is impossible to make recommendations without further research.

PART 3. DOES THE CASE MANAGER HAVE ADDED VALUE?

Chapter 6. Informal carers' experiences with primary palliative care when a case manager is involved; a questionnaire study.

Chapter 7. Appraisal of cooperation with a palliative care case manager by general practitioners and community nurses: a cross-sectional questionnaire study.

Chapter 8. Involvement of a case manager in palliative care reduces hospitalisations at the end of life in cancer patients; a mortality follow back study in primary care.

Verhaal van een casemanager (3)[1]

Mevrouw De Jong is 55 jaar, gehuwd en heeft 2 volwassen dochters. Ze is 4 jaar geleden gediagnosticeerd met gemetastaseerde borstkanker. Er zijn nu echter geen 'curatieve' behandelingen meer mogelijk. De levensverwachting is maximaal enkele maanden.

Na dit slecht-nieuws-gesprek in het ziekenhuis zijn mevrouw en haar echtgenoot erg verdrietig. De oncoloog meldt haar bij mij aan voor begeleiding. Ik ga op huisbezoek. Mevrouw doet haar verhaal over haar ziektegeschiedenis en wat er in die periode allemaal voor haar is veranderd. Op mijn vraag wat voor haar nú erg belangrijk is in haar leven geeft ze aan dat ze zoekende is naar de zin van het leven in deze laatste fase. In hoeverre kan ze nog betekenisvol blijven voor anderen, in plaats van zichzelf soms alleen nog te kunnen zien als iemand die anderen tot last is omdat ze zo weinig meer kan doen.

Maar ja, wanneer ben je van betekenis voor anderen? Ze vertelt wat de ziekte haar óók heeft opgeleverd. Vanuit een negatief zelfbeeld is ze in vier jaar tijd gegroeid naar een vrouw die er mag zijn en voor veel mensen uit haar omgeving een bron van steun en inspiratie is. Ze kan zich hier nog erg over verwonderen. Ze vertelt in de afgelopen jaren veel schillen -die ze in de loop van haar leven om zich heen heeft gekregen- te hebben afgepeld. Ze is nu weer terug bij haar oude kern; hoe ze zich voelde als kind; sprankelend en blij, blij met zichzelf. Ondanks alle beperkingen, zorgen en verdriet.

Ze kan het zo prachtig vertellen! Ik vertel haar over de scholing 'spirituele zorg' voor verpleegkundigen die ik samen met anderen aan het ontwikkelen ben. En hoe lastig het is om dit onderwerp te ontdoen van de 'zweverigheid' die bij veel mensen weerstand oproept. Haar persoonlijke verhaal zou daarin heel goed kunnen passen. Wij kunnen nog zoveel van haar leren! Mevrouw geeft aan dat ze aan deze les graag een bijdrage wil leveren. De eerste les heeft ze inmiddels gegeven en de verpleegkundigen mochten haar alles vragen. Ze waren onder de indruk van het verhaal, ook door de herkenbaarheid en de alledaagsheid ervan. We hebben allemaal, bewust of onbewust, 'schillen' om ons heen gekregen in de loop van ons leven. Welke 'schillen' heb ik en wat betekenen ze voor mij? Een hele bewustwording.

Het was een prachtige les. En er was niets zweverigs aan!

Diana Geers, gespecialiseerd verpleegkundige Palliatieve Zorg, Zorgbrug (tekst onverkort eerder verschenen in CaPalCa nieuwsbrief 4, februari 2012)

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[1] In dit proefschrift zijn drie verhalen opgenomen, om een inkijkje te geven van het dagelijks werk van een casemanager. De verhalen zijn door de casemanagers zelf opgesteld, en bieden daarom geen objectief beeld. De namen van de betrokkenen in de verhalen zijn veranderd om de identiteit van patienten en naasten te beschermen.

CHAPTER 8.

INVOLVEMENT OF A CASE MANAGER IN PALLIATIVE CARE REDUCES HOSPITALISATIONS AT THE END OF LIFE IN CANCER PATIENTS; A MORTALITY FOLLOW-BACK STUDY IN PRIMARY CARE.

Annicka G. M. van der Plas

Kris C. Vissers

Anneke L. Francke

Gé A. Donker

Wim J. J. Jansen

Luc Deliens

Bregje D. Onwuteaka-Philipsen

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Abstract

Background: Case managers have been introduced in primary palliative care in the Netherlands; these are nurses with expertise in palliative care who offer support to patients and informal carers in addition to the care provided by the general practitioner (GP) and home-care nurse.

Objectives: To compare cancer patients with and without additional support from a case manager on: 1) the patients' general characteristics, 2) characteristics of care and support given by the GP, 3) palliative care outcomes.

Methods: This article is based on questionnaire data provided by GPs participating in two different studies: the Sentimelc study (280 cancer patients) and the CaPalCa study (167 cancer patients). The Sentimelc study is a mortality follow-back study amongst a representative sample of GPs that monitors the care provided via GPs to a general population of end-of-life patients. Data from 2011 and 2012 were analysed. The CaPalCa study is a prospective study investigating the implementation and outcome of the support provided by case managers in primary palliative care. Data were gathered between March 2011 and December 2013.

Results: The GP is more likely to know the preferred place of death (OR 7.06; CI 3.47-14.36), the place of death is more likely to be at the home (OR 2.16; CI 1.33-3.51) and less likely to be the hospital (OR 0.26; CI 0.13-0.52), and there are fewer hospitalisations in the last 30 days of life (none: OR 1.99; CI 1.12-3.56 and one: OR 0.54; CI 0.30-0.96), when cancer patients receive additional support from a case manager compared with patients receiving the standard GP care.

Conclusions: Involvement of a case manager has added value in addition to palliative care provided by the GP, even though the role of the case manager is 'only' advisory and he or she does not provide hands-on care or prescribe medication.

Introduction

The aim of palliative care is to improve the quality of life of patients and their families facing the problems associated with life-threatening illness, as stated in the World Health Organisation (WHO) definition (Sepulveda et al, 2002). Most people prefer to die at home (Gomes et al, 2013b) and home is also considered to be the preferred place of care at the end of life. A high percentage of patients with home deaths and a low number of hospitalisations are considered outcomes of high quality palliative care (De Roo et al, 2014; Earle et al, 2003). Therefore, the availability of community-based palliative care is important in enabling patients' palliative care wishes and needs to be met.

In the Netherlands, the general practitioner (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 hard to keep up to date with the new, advanced and complex treatment options now available in palliative care (Becker et al, 2010; Groot et al, 2005; Shipman et al, 2008). Nurse case managers with specific expertise regarding palliative care have been introduced in some regions to help patients and their informal carers obtain the palliative care that matches their preferences. Most patients are referred to the case manager early in the palliative care trajectory and they are mostly referred by hospital staff (62% of referrals) (van der Plas et al, 2015c). The majority (69%) of patients referred to a case manager received a combination of curative or life-prolonging treatment and palliative care (van der Plas et al, 2015c). To ensure continuity of care, a case manager collaborates with the patient, their informal carers and the professionals involved in care for the patient, such as the GP or the medical specialist (Minkman et al, 2009). The case manager provides advice to patients and their informal carers and refers them to other care providers when necessary. Additionally, the case manager may offer advice and information about good palliative care to other healthcare providers involved with the patient, mostly the GP and the home-care nurse.

A literature review 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 (Gomes et al, 2013a). 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). For sustainable palliative care in an aging society, it is argued that basic palliative care should be provided by generalist healthcare professionals and that specialist palliative care should be reserved for more complex situations (Quill & Abernethy, 2013). This is the care model that is used in the Netherlands.

It is unclear whether there is additional value in having a case manager for patients with palliative care needs. Therefore, in this paper we compare patients primarily receiving palliative care from their GP alone with patients who were also referred to a case manager for additional support. The following data were compared: 1) the patients' general characteristics, 2) characteristics of care and support given by the GP (number of patients with contact with their GP, number of contacts between the patient and the GP, involvement of a home-care nurse and palliative care consultant other than the case manager), 3) palliative care outcomes (preferred place of death is known by the GP, place of death, number of transfers, number of hospitalisations in the last 30 days).

Methods

Setting

The population of the Netherlands is 16.9 million. Each year, about 77,000 people die of non-acute illnesses, 31% of them dying at home (van der Velden et al, 2009). Almost all Dutch residents are registered with a GP, who functions as a gatekeeper for more specialised forms of care. Palliative care is part of the educational programme for GPs and home-care nurses, and there are also a wide range of short courses available on palliative care. Fewer than 1% of GPs and home-care nurses have had advanced education to specialise in palliative care (IKNL, 2014). Specialised palliative care knowledge is available to GPs and home-care nurses through consultation teams operating all over the Netherlands, mainly offering advice by telephone. Nurse case managers with specific expertise in palliative care who visit patients at home have also been introduced in some regions (for a map of the Netherlands showing which regions, see Van der Plas et al, 2013).

Case management is provided by a nurse with expertise in palliative care who functions as a case manager (van der Plas et al, 2013); he or she visits the patient and their informal carers at home to offer support and advice on care and treatment options. The case manager monitors whether care is being delivered according to the patient's and informal carers' wishes and needs. Information and psychosocial support are provided by the case manager if patients and their informal carers wish so. The case managers do not provide hands-on nursing care themselves but can be part of a team that does. Most case managers (62%) were trained in nursing at the bachelor level with further education in oncology or another relevant field of specialist care. The organisational affiliation of the case managers varies; case managers can be employed by a home-care organisation, by a hospice or by a collaborative venture between institutions (e.g. a home-care organisation working together with a hospital). Detailed information on the content of the support provided by case managers can be found elsewhere (van der Plas et al, 2015a). There are case managers in the Netherlands for patients with dementia (MacNeil et al, 2012) but they are not included in this paper.

Design and sample

This article is based on questionnaire data provided by GPs participating in two different studies: the Sentimelc study (Van den Block et al, 2013) and the CaPalCa study. The Sentinel-Monitoring End-of-Life Care (Sentimelc) is a mortality follow-back (retrospective) study. It provided the data for this paper on standard GP care. The CaPalCa study is a prospective study. It provided the data on care where case managers were involved. Both studies were conducted within the same research team, and several questions were made to match to enable the comparison of the data from the CaPalCa and Sentimelc studies.

Standard GP Care. The aim of the Sentimelc research project is to monitor the quality of care provided by GPs to a general population of end-of-life patients in the Netherlands. Data were collected via the Sentinel practices in the Nivel Primary Care Database, a pre-existing continuous monitoring system based on a representative sample of GPs reporting on several diseases and interventions (Van den Block et al, 2013). For this paper end-of-life data from 2011 and 2012 were analysed.

Care where case managers were involved. The CaPalCa study was set up to investigate the implementation and outcomes of the support provided by case managers in primary palliative care. A nationwide survey was conducted to identify initiatives involving case managers (van der Plas et al, 2013). The term 'initiative' is used to do justice to organisational differences, since not all case managers work in a team of case managers; there was one initiative with one case manager, for example, while another case manager was part of a team in which not all members offer case management. Of the 20 initiatives identified in that survey, 13 were investigated in this paper. Case management as provided to the patient was monitored prospectively by questionnaires. Case managers who support many patients could include every second patient in the CaPalCa study instead of every patient (i.e. half of the patients who received support from the case manager were included in the study), for time management reasons. Data were gathered from March 2011 until the end of 2013.

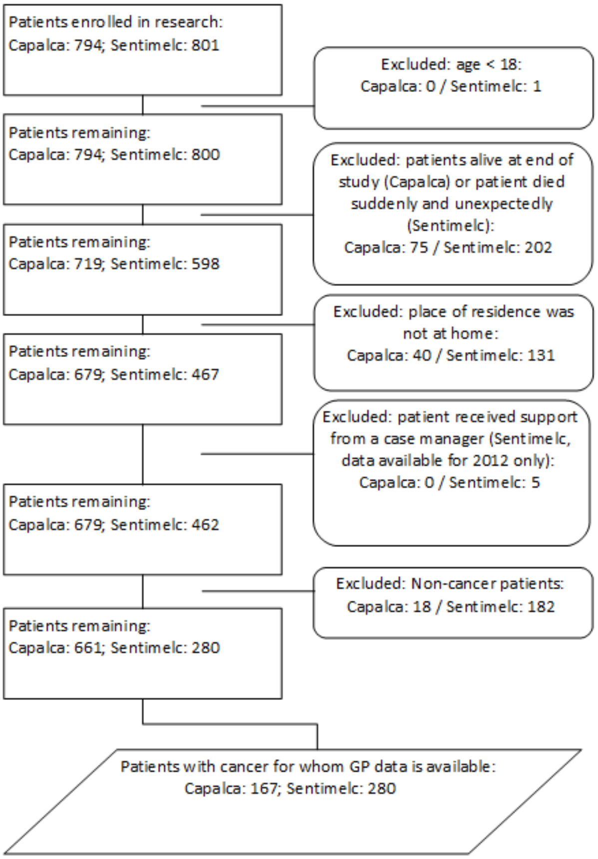
The following criteria were used to select data from the two studies that were suitable for a comparison: the patients' age was at least 18, the patients had not died suddenly and unexpectedly (the study on standard GP care) and had died during the data collection period (the study on case managers), their place of residence was 'at home' or 'with informal carers', and patients did not receive support from a case manager (the study on standard GP care). Furthermore, only cancer patients were included since the main diagnosis is expected to influence the care provided and the diagnosis composition differed between the two samples.

Ethics statement
Under Dutch law, both the Sentimelc and CaPalCa studies are exempt from approval from an ethics committee. Ethical approval was not required since the studies did not involve imposing any interventions or actions (Centrale Commissie Mensgebonden Onderzoek, 2014) and posthumous collection of anonymous patient data is allowed in the Netherlands (Dutch Government, 2014; College Bescherming Persoonsgegevens, 2014). We have not requested a waiver from the ethics committee. All data from both the CaPalCa and Sentimelc study, was anonymised before being handed over to the authors. The researchers in the study on case managers did not interact with the patients. The case managers informed their patients that they were collecting information on care provision. To facilitate this, the researchers provided information material about the research project that the case managers could hand to their patients.

Questionnaires and procedure
Standard GP Care. Within one week of reporting a patient's death, participating sentinel GPs were asked to fill in a registration form surveying information regarding the care the deceased received in the last three months of life. On completion, the registration forms were returned to NIVEL where they were scrutinised for missing data and errors, duplicated and then sent to the researchers for analysis. The questionnaire included structured questions on the following: the patient's age and sex, main diagnosis, place of death, whether the GP was aware of the preferred place of death, the places of care in the three months before death and the number of days spent per place of care, the number of contacts (home visits and consultations) in the last week, in weeks two to four, and in months two and three before death, and the involvement of other care providers. In order to clearly identify which patients would have qualified for palliative care in their final days and which not, GPs were asked if the death in question had been both 'sudden and totally unexpected'.

Care where case managers were involved. If a patient was referred for case management, the responsible case manager filled in a questionnaire. After the patient's death, the case manager sent a questionnaire to the GP. The two questionnaires used the same unique identification number. If no questionnaire was received from the GP, the researcher asked the case manager to send a reminder. The case manager filled in a questionnaire with structured questions on the patient's demographic data and care characteristics. For this paper we used age, sex and the main diagnosis. Furthermore, GPs completed a questionnaire containing structured questions regarding the GP's characteristics and the care given to the patient, such as the number of contacts and place of death. If place of death was not available from the GP questionnaire, either it was obtained from the questionnaire the case manager filled in after the patient's death, or the case manager was asked about the place of death in an open question by mail or phone; and the information was then recorded in the data management system for tracking questionnaires.

Figure 1. Flow chart of selection†



† CaPalCa = the study on case managers; Sentimelc = the study on standard GP care; GP = general practitioner.

Data analysis

In the study on standard GP care, the questions on place of death and preferred place of death were coded as 'don't know' if they had not been filled in by the GP. In the study on case managers, information from the case manager on place of death was coded according to the categories used in the GP questionnaire.

To compare patients who received additional support from a case manager with patients who received the standard care from their GPs, logistic regression analysis was performed on all variables with the source of the data as dependent variable (Standard GP care = 0; Study on case managers = 1). Age was included as a covariate for adjusted odds ratios.

Results

Response

A total of 794 adult patients were included in the study on case managers and 800 in the study on standard GP care. A flow chart of the effect of the exclusion criteria on the response is shown in Fig 1. For the comparison of care and outcome characteristics, data was available on 167 patients receiving support from a case manager and on 280 patients receiving standard GP care.

Table 1. General characteristics of cancer patients with additional support from a case manager and patients receiving standard GP care

	GP plus CM (n=167)[†] n (%)	Standard GP care (n=280)[†] n (%)	OR (CI)[††]	OR (CI) Adjusted for age[††]	p value[§]
Age, mean (SD)	66 (12)	72 (12)	0.97 (0.95 – 0.98)		<0.000
Sex, female	78 (47)	124 (45)	1.09 (0.74 – 1.60)	0.98 (0.66 – 1.46)	0.927
Type of cancer:					
- lung	41 (25)	64 (26)	0.97 (0.62 – 1.53)	0.93 (0.58 – 1.48)	0.757
- colon	21 (13)	40 (16)	0.77 (0.44 – 1.37)	0.85 (0.47 – 1.52)	0.575
- breast	14 (9)	18 (7)	1.21 (0.58 – 2.50)	0.99 (0.47 – 2.12)	0.987
- hematologic or lymphatic	4 (3)	18 (7)	0.32 (0.11 – 0.97)	0.38 (0.12 – 1.15)	0.085
- prostate	10 (6)	15 (6)	1.02 (0.45 – 2.33)	1.42 (0.61 – 3.33)	0.422
- other	73 (45)	94 (38)	1.34 (0.90 – 2.00)	1.26 (0.84 – 1.90)	0.266

[†] GP = general practitioner; CM = case manager. Total number of patients is 447. Missing values per variable: Age: no missing values, Sex: 2 missing values (Study on case managers 0; Standard GP care 2), Type of cancer: 35 missing values (Study on case managers 4; Standard GP care 31). [††] Dependent variables coded 'Standard GP care' = 0; 'Study on case managers '= 1. OR = Odds ratio; CI = 95% confidence interval. Confidence intervals not including the value 1 are considered statistically significant. [§] Logistic regression analysis, adjusted for age

Characteristics of cancer patients with and without additional support from a case manager
With regard to patients' general characteristics (Table 1), patients referred to a case manager for additional support were younger (OR = 0.97; CI 0.95–0.98) compared with patients receiving the standard GP care.

Table 2. Characteristics of care and support for cancer patients with additional support from a case manager and patients receiving standard GP care

	GP plus CM (n=167)[†] n (%)	standard GP care (n=280)[†] n (%)	OR (CI)[§]	OR (CI) Adjusted for age[§]	p value[‡]
Number of patients with contact with the GP					
- contact in the last week	150 (90)	234 (84)	1.74 (0.96 – 3.14)	1.91 (1.04 – 3.52)	0.038
- contact in weeks 2 – 4	152 (91)	242 (86)	1.59 (0.85 – 2.99)	1.67 (0.87 –3.20)	0.121
- contact in months 2 – 3	143 (86)	233 (83)	1.20 (0.71 – 2.05)	1.25 (0.73 – 2.16)	0.417
Number of contacts between GP and patient[††]					
- in the last week	4.0 (2.9)	4.2 (2.7)	0.98 (0.91 – 1.06)	0.98 (0.90 – 1.05)	0.514
- in weeks 2 – 4	1.7 (0.8)	1.8 (1.2)	0.87 (0.71 – 1.07)	0.86 (0.70 – 1.07)	0.174
- in months 2 – 3	2.1 (1.4)	2.4 (1.8)	0.90 (0.79 – 1.03)	0.86 (0.74 – 0.99)	0.032
Involvement of home-care nurse, yes[§§]	120 (75)	106 (71)	1.22 (0.74 – 2.01)	1.41 (0.84 – 2.39)	0.197
Involvement of a palliative care consultant / consultation team in last 90 days, yes	37 (24)	23 (9)	3.27 (1.86 – 5.76)	3.23 (1.81 – 5.74)	<0.000

[†] GP = general practitioner; CM = case manager. Total number of patients is 447. Missing values per variable between 0 and 32. [††] There are 63 patients (Standard GP care 46; Study on case managers 17) with no contacts in the final week, 53 patients (Standard GP care 38; Study on case managers 15) with no contacts in weeks 2 to 4, and 71 patients (Standard GP care 47; Study on case managers 24) with no contacts in months 2 and 3 who are excluded in this variable. [§] Dependent variables coded 'Standard GP care' = 0; 'Study on case managers' = 1. OR = Odds ratio; CI = 95% confidence interval. Confidence intervals not including the value 1 are considered statistically significant. [§§] These data are not available for standard GP care from 2011. Study on case managers n=167 and standard GP care 2012 n=152. [‡] Logistic regression analysis, adjusted for age

Care characteristics of cancer patients with and without additional support from a case manager

Looking at the care and support provided to cancer patients (Table 2), after adjusting for age differences, patients referred to a case manager for additional support were more likely to have at least one contact with their GP in the last week of their lives (90% versus 84%; OR = 1.91; CI 1.04–3.52), had fewer contacts with their GP in the second and third months before death (1.4 versus 1.8 contacts; OR = 0.86; CI 0.74–0.99), and were more likely to have a palliative care consultant or consultation team involved in their care (24% versus 9%; OR = 3.23; CI 1.81–5.74) compared with patients receiving standard GP care.

Care outcomes of cancer patients with and without additional support from a case manager

Looking at the outcomes of care for cancer patients (Table 3) after adjusting for age differences, the GP was more likely to know the preferred place of death (94% versus 72%; OR = 7.06; CI 3.47–14.36), the patient was more likely to have died at home (82% versus 69%; OR = 2.16; CI 1.33–3.51) and less likely to have died in hospital (7% versus 20%; OR = 0.26; CI 0.13–0.52), and more likely to have had no hospitalisations in the last 30 days of life (79% versus 69%; OR = 1.99; CI 1.12–3.56) and less likely to have had one hospitalisation (20% versus 30%; OR = 0.54; CI 0.30–0.96), if the patient had been referred to a case manager for additional support compared with patients receiving standard GP care.

Table 3. Preferred place of death, place of death, and number of transfers and hospitalisations of cancer patients with additional support from a case manager and patients receiving standard GP care

	GP plus CM (n=167)† n (%)	Standard GP care (n=280)† n (%)	OR (CI)††	OR (CI) Adjusted for age††	p value§
Preferred place of death is known by GP	157 (94)	202 (72)	6.06 (3.04 – 12.09)	7.06 (3.47 – 14.36)	<0.000
Number of patients who died at the preferred place of death	138 (88)	181 (91)	0.76 (0.39 – 1.50)	0.75 (0.37 – 1.52)	0.428
Place of death					
- at home or with carer	137 (82)	193 (69)	2.01 (1.26 – 3.22)	2.16 (1.33 – 3.51)	0.002
- hospice or palliative care unit	14 (8)	22 (8)	1.07 (0.53 – 2.14)	1.12 (0.55 – 2.29)	0.753
- hospital	12 (7)	55 (20)	0.31 (0.16 – 0.61)	0.26 (0.13 – 0.52)	<0.000
- care or nursing home	3 (2)	8 (3)	0.62 (0.16 – 2.36)	0.70 (0.17 – 2.87)	0.623

- other	1 (1)	0	NA	NA	
Number of transfers in last 30 days					
- none	62 (66)	171 (62)	1.18 (0.72 – 1.93)	1.33 (0.80 – 2.21)	0.270
- one	22 (23)	60 (22)	1.10 (0.63 – 1.91)	1.04 (0.59 – 1.84)	0.886
- two or more	10 (11)	44 (16)	0.63 (0.30 – 1.30)	0.53 (0.25 – 1.13)	0.099
Number of hospitalisations in last 30 days					
- none	74 (79)	189 (69)	1.68 (0.97 – 2.94)	1.99 (1.12 – 3.56)	0.020
- one	19 (20)	82 (30)	0.60 (0.34 – 1.05)	0.54 (0.30 – 0.96)	0.037
- two or more	1 (1)	4 (2)	0.73 (0.08 – 6.60)	0.33 (0.03 -3.23)	0.343

† GP = general practitioner; CM = case manager. Total number of patients is 447. Missing values per variable: Preferred place of death known: no missing values, Died at preferred place of death: 90 missing values (Study on case managers 10; Standard GP care 80), Place of death: 2 missing values (Study on case managers 0; Standard GP care 2), Number of transfers: 78 missing values (Study on case managers 73; Standard GP care 5), Number of hospitalisations: 78 missing values (Study on case managers 73; Standard GP care 5). †† Dependent variables coded 'Standard GP care' = 0; 'Study on case managers' = 1. OR = Odds ratio; CI = 95% confidence interval. Confidence intervals not including the value 1 are considered statistically significant. § Logistic regression analysis, adjusted for age

Discussion

The GP was more likely to know the preferred place of death, and the place of death was more likely to be the home and less likely to be the hospital, for cancer patients referred to a case manager for additional support. Also, fewer hospitalisations occurred in the last 30 days of life, if a case manager was involved compared with patients receiving standard GP care. Cancer patients referred to a case manager for additional support were younger than patients receiving standard GP care. Also, they were more likely to have at least one contact with their GP in the last week of their lives, had fewer contacts with their GP in the months two and three before death, and were more likely to have a palliative care consultant or consultation team involved in their care compared with patients receiving standard GP care.

More home deaths and fewer hospitalisations

The finding that a greater proportion of the patients receiving additional support from the case manager died at home and that they experienced fewer hospitalisations in the last 30 days of life is likely to be linked to the higher percentage (94%) of patients for whom the preferred place of death was known. For patients receiving palliative care from their GP, the percentage of patients with a known preferred place of death (72%) was similar to that of cancer patients in a previous study using Dutch Sentimelc data from 2005–2006 (70%) (Abarshi et al, 2009). In that study, the preferred place was the same as the actual place of death for four-fifth of patients. In a comparison of four European countries (Belgium, Italy, Spain and the Netherlands), the percentage of patients whose GP knew their preferred place of death ranged from 27% (Italy) to 72% (the Netherlands); when known, the preference was met for 68% (Italy) to 92% (Spain) of patients (Ko et al, 2013).

Our findings are in line with a literature review in which specialised home palliative care increased the chance of dying at home (Gomes et al, 2013a). Different models of specialised home care were included in the review study; our paper focusses on case managers who offer advice and support while the GP and home-care nurses continue to be main care providers. Underlying mechanisms should be further investigated, with attention to both the direct and indirect influences of the case manager on the care provided by the GP. The case manager can directly influence care provision by the GP, for instance by giving information to the GP about palliative care and supporting the GP in providing palliative care. The case manager can also indirectly influence care provision by the GP by encouraging and helping the patient to discuss palliative care options with their GP. Just getting a notification that a palliative care case manager is involved with the patient might trigger the GP’s awareness of the patient’s palliative care needs. End-of-life conversations between the GP and the patient occur more frequently when there is a palliative care treatment goal, and discussion of end-of-life issues is also associated with the GP being informed about the preferred place of death (Abarshi et al, 2011). Hospital costs make up 40% of the total healthcare costs in the last six months of life (Rolden et al, 2014). An economic evaluation of the case management initiatives should be conducted to investigate whether the cost reduction due to fewer hospitalisations outweighs the cost of implementing case managers in palliative care.

More patients with contacts in the last week of life, fewer contacts with the patient in months two and three

The number of contacts between the GP and the patients is lower in months two and three before the patients’ death when a case manager is involved, but the proportion of patients with contacts with their GP in the last week of life is higher. Although not significant, the proportion of patients with contacts with their GP is higher and the number of contacts between the GP and the patient is lower for all time frames when a case manager is involved. This could be an effect of coordinated care between the case manager and GP; it may be that the case manager and GP take turns in visiting the patient and therefore the GP will visit a patient less often when a case manager is involved. At the same time, the number of patients with some contact with the GP may be higher because the GP may be more aware that a patient has palliative care needs when a case manager is involved and the case manager may encourage the GP to visit a patient.

Strengths and limitations of this study

This paper provides valuable information on care provision with and without the involvement of an additional case manager in primary palliative care. Information on standard GP care came from GPs who are part of the Sentinel network, which is designed to be nationally representative. The GPs in the study on case managers received a questionnaire from the case manager without any advance notice. The response rate for the study on case managers is low and the response may be skewed towards GPs with more positive experience of case managers and/or palliative care. Patients were not randomly assigned, and the patients with a case manager were younger than the patients receiving standard GP care. This limitation was allowed for by adjusting for age in the analyses. Other differences between the two groups, for example in the complexity of the disease may have been missed. Furthermore, the results may only be representative for mixed public–private healthcare systems with a strong primary care gatekeeper, which is the situation in the Netherlands. The case managers had an advisory role with respect to patients and other healthcare professionals. In other healthcare systems, task demarcation between generalist and specialist palliative care providers may be different, for instance because there are ‘hospice-at-home’ teams providing more comprehensive care that extends to prescribing medication and providing hand-on care. Also, care provision and outcomes may be different for patients with diagnoses other than cancer. Finally, further research is needed to better understand the experiences of patients, relatives, home-care nurses and GPs with the support provided by the case manager. A more detailed paper on the content of the support provided by the case manager will be published soon (van der Plas et al, 2015a).

Conclusion

Involvement of a case manager has added value in primary care in the model where generalist healthcare professionals cooperate with specialist palliative care providers. The percentage of patients who die at home is higher and the number of hospitalisations in the last 30 days of a patients’ life is lower when a case manager is involved offering advice and support.

CHAPTER 9.
GENERAL DISCUSSION.

Chapter 9. General discussion

This thesis presents research on how initiatives for case managers in palliative care were implemented in the Netherlands - including characteristics of patients referred to case managers, support provided by the case managers and outcomes of this support for patients with palliative care needs.

The final chapter of this thesis offers a summary and critical appraisal of the main findings. First, key findings regarding the three parts of the thesis are presented and discussed. Following this, some methodological issues are brought forward. Thirdly, implications for policy, practice and further research will be considered.

Main findings regarding part one: What is case management in palliative care?

The strength of case management is its applicability in different settings and fields. However, the downside to this strength is the numerous different ways of implementation, which can be confusing to patients, healthcare professionals and researchers trying to identify case management services. Case management in palliative care, just like case management in other fields of care, is implemented differently in different regions and institutions. Fortunately, the expert panel identified nine general aims for case management and these aims were used to define case managers in palliative care (chapter 2).

The aims reflect general desirable characteristics of continuity of care and highlight the notion that provision of palliative care is not limited to a single care provider or a single point in time. Furthermore, the aims give insight into important differences with other forms of care. For instance, when support is provided within a set amount of visits, this then becomes incompatible with the general aim which states ‘care is flexible and frequency of contacts can vary over time’ and ‘care lasts as long as necessary’ - thus this type of support does not adhere to our definition of case management.

The nationwide survey identified twenty case management initiatives (chapter 3). All of these stated that support provided by case managers was supplemental to care by the GP and home-care nurse. In all initiatives the case managers were nurses. The content of support provided was roughly the same in all initiatives. Identification of care needs, providing information and support and referral or organisation of care were all tasks of the case managers in most, if not all, initiatives. This may be in line with patients’ and informal carers needs regarding specialised forms of palliative care. In a study on the patients’ view of specialist palliative care nurses (Chapple et al, 2006), patients particularly valued the nurses’ advice on practical matters, information given about their disease, emotional support, advice on symptoms, and help with communication.

Differences between various case management initiatives mostly concerned the organisation of care. Two important differences were the organisational affiliation of the case manager (employed by a hospice, a home-care organisation or by a partnership of institutions) and the target group of the initiative (varying from case management available for patients from diagnosis onwards, to case management available exclusively for patients with a sole palliative treatment aim). Not all initiatives had begun to include patients at the time of the interview; three were still in the initial processes that precede implementation (information gathering, conceptualising and planning), another three were in their first year, ten had been operational for between one and five years and three had been providing case management for more than five years (these data are missing in one case). I will come back to these characteristics (organisational affiliation, target group and duration that initiatives were operational) in the next sections.

Main findings regarding part two: What support is provided and to whom?

To study referral to case managers, the WHO definition of palliative care (Sepulveda et al, 2002) was used as point of departure (chapter 4). Three elements of that definition were highlighted: 1) the definition includes patients who may still have curative or life prolonging treatment besides palliative care (see Figure 1 in chapter 1); 2) that palliative care is not exclusively for cancer patients; 3) that palliative care includes attention to the medical, psychological, social and spiritual needs of the patients and their families. Referrals to case managers typically reflect two of these three elements. The majority of patients referred to a case manager received a combination of curative or life-prolonging treatment and palliative care. Almost all (96%) patients referred were cancer patients. Whilst all domains of palliative care were mentioned by referrers, the need for psychosocial support was mentioned most often. Patients were referred to a case manager for support complementary to medical care, and relatively early in their disease trajectory. Thus, it might be that the patient's need for psychological, social or spiritual palliative care support may be a more suitable pointer for the start of palliative care than life expectancy or diagnosis, since life expectancy is difficult to assess and focussing on diagnosis bears the risk of a disproportionate focus on cancer patients.

Case managers provide support in a flexible manner (chapter 5). Support provided covered all domains of palliative care, with most attention given to physical complaints, life expectancy and the psychological aspects of being ill. The information given at least once to most patients and/or informal carers was on care services, illness and nursing or physical care. Support provided by case managers seems to be in line with the expectations of referrers. Organisational characteristics (affiliation of the case manager and the target group of the case management initiative) played a bigger role in the provision of support by the case manager than patient characteristics did. This is contradictory to the model of patient-centred care highly valued in palliative care. Differences between settings regarding the support given may be explained by differences in the availability of care and the culture within an organisation (Lysaght Hurley et al, 2014; Gallagher & Krawczyk, 2013). However, the case managers in our study all worked within the primary care setting. It may be that the schooling of case managers in addressing end-of-life issues differed between initiatives, which may then partially explain the difference in the support provided. The expectation that schooling makes a difference is based, amongst others, on a study about case managers who supported nursing-home-eligible older adults to remain in their own homes for as long as possible. In that study case managers at two agencies reported a higher rate of Advance Care Planning discussions than in the seven other agencies. Both of these agencies had Advance Care Planning training programs, follow-up protocols, and informational packets available that were not consistently available at the other agencies (Baughman et al, 2014).

Main findings regarding part three: Does the case manager have added value?
An important aspect of the work of case managers is contact with other care providers. Acceptation of, and cooperation with, the specialised palliative care case manager by the GP and home-care nurse is pivotal. A systematic review (Gardiner et al, 2012) on co-operation between generalist and specialist palliative care services identified five key facilitating factors: good communication between providers, opportunities for education, clear definition of roles and responsibilities, accessibility of specialist palliative care, and coordinated and continuous support. About half of GPs and home-care nurses thought that the case manager was helpful in facilitating appropriate care (chapter 6). Whether or not the case manager was helpful in realising appropriate care was associated with the tasks of the case manager, not with patient characteristics or number of contacts with the case manager. The case manager did not hinder the process of care and had added value for patients according to the GPs and home-care nurses. Since case managers are a relatively new addition to primary palliative care in the Netherlands, the working relationship may still improve. In other studies, the willingness to consult a palliative care specialist was seen to be dependent on previous experiences with collaboration (Dahlhaus et al, 2013; Walshe et al, 2008). To further enhance cooperation, case managers should invest in contact with GPs and home-care nurses, since GPs reported that in 42% of patients there was no contact between the GP and the case manager, and home-care nurses had no contact with the case manager in 34% of patients.

The informal carers valued palliative care provided by the GP and home-care nurse highly, as can be seen in chapter 7. According to the informal carers in our study, the number of healthcare professionals was appropriate. Another publication describes concerns from GPs and home-care nurses about the number of professionals involved in palliative care (Goldschmidt et al, 2005). In addition, communication issues can be a problem according to both GPs and patients (Borgsteede et al, 2006). This thesis shows that together, the primary care team and the case manager can support the large majority of the informal carers in all aspects asked. The case manager gave information on the possibilities of care and support for people with life threatening diseases and their informal carers to such carers more often than the primary care team did.

With regard to care at the end of life (chapter 8), the involvement of a case manager may have added value in addition to palliative care provided by the GP - even though the role of the case manager is ‘only’ advisory and (s)he does not provide hands-on care or prescribe medication. In cases of cancer patients referred to a case manager for additional support preferred place of death was more often known by the GP, place of death was more often at home and less often at hospital, and less hospitalisations occurred in the last 30 days of life, compared to patients without this additional support. Other research points to the fact that Dutch GPs are able to deliver high-quality palliative care (de Korte-Verhoef 2014; Ko et al, 2013). However, a main hurdle for the GP appears to be marking the approach of death. The involvement of a palliative care case manager might trigger the GPs awareness of the palliative care needs of the patient.

Methodological strengths and limitations

The CaPalCa study described in this thesis involved qualitative and quantitative methods. The study started with the consultation of an expert panel in three written rounds with questionnaires (chapter 2). The advantage of this was that it provided a structured approach that enabled us to consult a large group of people in a short period of time. The results reflect the opinions of case managers, coordinators of palliative care networks, GPs and other physicians, researchers and policy makers on aims and characteristics of case management in palliative care. However, these opinions do not necessarily reflect practice. Although we sought and found representation in an expert panel of persons with a range of backgrounds and interests in palliative care, the expert panel did not necessarily consist of a representative sample of all people involved in palliative care.

Subsequently, a nationwide survey was performed (chapter 3). Data were collected through a written questionnaire, and an additional interview by telephone. The questionnaires were derived from the expert panel procedure, so they covered a range of characteristics important to case management in palliative care. All 50 palliative care network coordinators working for 71 networks (some coordinators worked for several networks) participated. Because we did not approach all home care organisations we may have missed some initiatives. However, palliative care networks cover all of the Netherlands and coordinators are generally well aware of the range of palliative care that is provided within their region. Due to the fact that we asked all participants: ‘Do you know of any other case management initiatives?’ (snowball sampling), it is unlikely that we missed initiatives that were active/operational at the time of the survey. In addition data was collected where there was doubt about whether an initiative could be labelled as case management or involved another type of care; in these cases the data were presented to the research group to clarify the boundaries of case management and agreement was reached on how to label it. In the survey we asked for general information on case management, and did not measure whether aims were met and whether care was provided as planned.

Following this, a questionnaire-based evaluation study was conducted (chapters 4 to 8). The questionnaires were drafted to study the implementation of support provided by the case manager. The questionnaires were firstly piloted on a small sample of respondents to ascertain that questions were clearly formulated and relevant. The questionnaires contained mostly structured and a limited number of open ended questions, with a broad range of both objective and subjective topics regarding end of life care as provided by the case manager, GP and home-care nurse. This study only looked at referral and palliative care provision where a case manager was involved, with the exception of chapter 8 on outcomes of support.

Another limitation is the risk of recall bias. The questionnaires at the start of the involvement of the case manager (from the case manager and person who referred), and the information on contacts were collected at the moment of referral or contact; recall bias therefore will be low for this information. The questionnaires filled in after the patient’s death could have been subject to recall bias, because most questions related to the care that deceased patients had received in the last three months of life - though the questionnaires were sent shortly after the patient’s death (the longest two months for the informal carers) so effects of bias will be small.

The response rate of questionnaires that were sent after the patient’s death was low. With regard to informal carers, the response rate could be skewed towards informal carers who received higher quality palliative care. This is a response bias that has been reported before (Kross et al, 2009). With regard to the GP and home-care nurses, the response is likely to be skewed towards those who had enough contact with the case manager that they felt able to answer the questions. In some cases of little contact, GPs and home-care nurses were not sent a questionnaire, because the case manager believed it would harm future collaboration. Initiatives with many patients could include every second person in the study instead of every patient, for time management reasons. This ‘every second patient’ rule for inclusion, was given in advance to reduce the risk of selection bias in initiatives with a high case-load.

For the evaluation of outcomes of support provided by the case manager, it was not feasible to conduct a randomised controlled trial, the ‘gold standard’ for outcome evaluation, or gather data in a (matched) control group since cancer patients are more often referred to a case manager than patients with other life threatening diseases. Therefore, for comparisons of outcomes in palliative care where a case manager was and was not involved, data were used from the Sentinel Practices (Sentimelc) of NIVEL Primary Care Database. This is a pre-existing continuous monitoring system based on a representative sample of GPs reporting on several diseases and interventions (Van den Block et al, 2013). We aligned the data received from the two datasets with the following criteria: the patient died of cancer, age of the patient was 18 or higher, patients had not died suddenly and unexpectedly (Sentimelc) and had died during the period of data collection (CaPalCa), their place of residence was ‘at home’ or ‘with informal carers’ and patients did not receive support from a case manager (Sentimelc). However, it may have been that the groups differed in terms of the complexity of their social situation and/or in the management of symptoms. The outcome variables that we were able to use for comparison are important quality indicators for palliative care (De Roo et al, 2014; Earle et al, 2003).

Finally we performed online focus groups and an Invitational Conference was held. These gave us more in-depth insight into the work of case managers and their place within palliative care provision in the Netherlands. These insights were used in a manual for case managers in primary palliative care (van der Plas et al, 2015b), and for the recommendations in this chapter. The online focus groups and Invitational Conference could accommodate a limited number of participants, and those participating were likely to be more interested in case managers and palliative care than non-participants. This is what we sought out. We wanted an informed viewpoint, but this limits the generalizability of results to informal carers and healthcare professionals in general. Both online focus groups and the Invitational Conference offered a structured and transparent method to formulate recommendations.

For the CaPalCa study in general, an important limitation is that our results may only be representative for mixed public–private healthcare systems with a strong primary care gatekeeper - as in the Dutch system. The need for, characteristics of, and outcomes of case management may be different in other healthcare systems.

Recommendations for further research

As stated in the introduction, case management is reserved for situations that transcend regular care provision - for patients with complex care needs and/or a complex social environment, and where the patient and the informal carer cannot manage care themselves. However professional educations differ in the attention that palliative care receives in the curriculum (IKNL, 2014), and existing short courses vary in depth. In 2004 a set of skills for basic, advanced and specialist palliative nursing care was recommended by the EAPC Task Force on Palliative Nurse Education (De Vlieger et al, 2004). In terms of medical education, recommendations were made for basic skills and knowledge (undergraduate medical education) (EAPC steering group on medical education and training in palliative care, 2013) and for specialist palliative care (postgraduate education) (EAPC task force on medical education, 2009). Implementation of these recommendations should be investigated with regards to the impact and effectiveness of education, and whether there are remaining educational needs. Following from knowledge concerning basic and specialised skills, indication criteria for referral to the case manager could be drawn up. These criteria should be researched and implemented. Future studies on referral and care provision by the case manager should include a control group not receiving support from the case manager. This could further our understanding of the underlying mechanisms in care provision by generalist and specialist palliative care providers, which may then help in fine-tuning the education of all professionals involved.

In chapter 4 the recommendation is given that case managers in palliative care should work together with nurses specialised in care for patients with other diseases, such as chronic heart failure and lung diseases, in order to broaden their scope to include non-cancer patients. It would be interesting to take further steps and set up a team of case managers comprised of nurses with different specialisations, working together to offer comprehensive support to all patients with palliative care needs (regardless of diagnosis of the patient). This would enable in-team knowledge on principles of palliative care in general to be shared (e.g. psychological support and advance care planning), whilst disease-specific knowledge would be directly available to all case managers. By researching and implementing such a team, a model could be developed for timely multidimensional palliative care that transcends diagnosis. The model would be applicable in practice, as it is developed by studying moments where case managers learn from each other: when and what do they learn, what solutions do they come up with, which solutions work and which ones do not? Of course, this model should then be evaluated in terms of outcomes of care - preferably in a cluster randomised trial in which organisations (for example home care organisations or hospices) can be randomised to implement the function of case manager or not. Accordance between the preferred and actual place of death and the number of hospitalisations in the last months before the patients' death would be important outcomes in such a trial.

Recommendations for practice

A manual (van der Plas et al, 2015b) was written based on results from the evaluation study, online focus groups, and Invitational Conference where study results and practical experience were discussed. The manual gives fifteen recommendations for case managers concerning what kind of support they should provide, to whom, and how this should be organised. Care organisations starting to work with case managers can use this manual for implementation. Experienced case managers can use the manual to evaluate their working methods, and to change them when necessary or desirable. All fifteen recommendations are listed in Tables 1 and 2. Recommendations concerning the referral of patients and the place of the case manager in the whole of palliative care services are discussed in detail below.

Table 1. Recommendations on the function of case manager and on patients referred to the case manager, given in the manual for case managers in primary palliative care

The function of case manager
1. The case manager adheres to the nine aims for case management as agreed on by the expert panel (see chapter 2 of this thesis).
2. Case managers in primary palliative care offer support in addition to care from the GP and home-care nurse. This is in line with Dutch government policy which states that palliative care should be part of regular care provision by generalist care providers, supported by specialised palliative care professionals where needed. This means that:
- the case manager is specialised in palliative care,

- the case manager supports the generalist care providers in provision of palliative care,
- coordination and cooperation are main components of the daily work of the case manager,
- case managers coach generalist care providers through the means of ‘workplace learning‘ (working together, embedded in daily practice, and learn from each other).

Patients referred to a case manager

3. It is important to explicitly consider the need for a case manager. This is dependent on three factors: The wish of the patient and informal carers; the complexity of the situation; the extent to which the generalist care providers want to and can provide palliative care.
4. Patients and informal carers are well informed on the existence of case managers, so that they can determine themselves whether they want support from a case manager.
5. Case managers in palliative care should broaden their scope to include patients with other diseases than cancer. This can be accomplished by working together with specialised nurses for patients with, for instance, heart and lung diseases. The use of the ‘surprise’ question can also be an useful aid.
6. Palliative care has a timely start, and referral to the case manager is likewise timely. Use of the ‘surprise’ question is a practical aid for this.

Recommendations for policy and practice: Which patients should be referred to a case manager?

Case managers in primary palliative care offer support in addition to the care received from the GP and home-care nurse. This is in line with Dutch government policy, which states that palliative care should be a part of regular care provision by generalist care providers, and where needed supported by specialised palliative care professionals (Ministerie van VWS, 2011). Whether a patient should be referred to a case manager depends on three factors:

- The patient’s and carer’s wish / preferences,
- The complexity of the situation,
- The extent to which the generalist care providers are able and prepared to provide palliative care to the patient and informal carer.

These three factors should be explicitly discussed with the patient, informal carers and generalist care providers - ideally before referral but otherwise in the first contact between the case manager and the patient. It can be helpful to make indication criteria available (see recommendations for research) that incorporate these three factors, to aid referrers.

Case managers in palliative care should broaden their scope to include patients with diseases other than cancer. Other palliative care models in the Netherlands also serve high percentages of cancer patients, for instance in consultation teams the percentage of cancer patients is 82% and in hospices 80% (IKNL, 2014). It may be that this will gradually get lower as there is now more awareness of the need for palliative care in patients with other life threatening diseases than cancer. A systematic review found that there is as much variation within diagnostic groups as between groups in relation to the prevalence of palliative care related problems (Moens et al, 2014). The authors conclude that palliative care should be provided irrespective of diagnosis.

Whether patients are being referred to a case manager will also depend on the referrers' recognition that a patient is in need of palliative care. For a timely recognition of the need for palliative care, the 'surprise question' ('Would I be surprised if this patient was to die in the next 6–12 months?') can be used. This may enhance timely recognition of palliative care needs in patients with diagnoses other than cancer as well. The use of the surprise question is encouraged in the Netherlands, and is part of the national 'Care module' (Spreeuwenberg et al, 2013) that will be implemented in all types of palliative care settings across the country. The surprise question is used to mark the beginning of the palliative care phase in the 'Care module'. When the answer to the question is 'no', then it is time to put more emphasis on quality of life and adequate palliation of symptoms and problems. Referral to a case manager will be appropriate when these symptoms and problems are complex.

Table 2. Recommendations on the support provided by the case manager and on organisation of care, given in the manual for case managers in primary palliative care

Support provided by the case manager

1. The case manager uses her specialised knowledge to provide support. Support is given to the patient, informal carers and generalist care providers involved. The extent and content of support is assessed in dialogue with all those involved.

2. The case manager listens, offers emotional support, answers questions, refers and is accessible.

3. The risk that the case manager is 'yet another care provider' is minimised when the patient and informal carers receive clear information on what kind of care and support they can expect from whom, what the case manager can and can not do and when the case manager communicates with all other care providers involved.

4. The case manager proactively communicates and cooperates with the GP and home-care nurse; from the start the case manager contacts the GP and home-care nurse, continues to do so and is accessible to all involved.

Organisation

5. The organisational affiliation of the case manager can vary, as long as all secondary conditions are met and implementation is embedded within the local organisation of palliative care.

6. Case managers should be an integral / integrated part of local organisation of palliative care. They take part (when possible) in PaTz (for information on PaTz see Van der Plas et al, 2014) and multidisciplinary meetings in hospitals, work as palliative care consultants in local palliative care consultation teams, give schooling / courses for local care providers and are involved in activities of the local palliative care network.

7. For one-off questions on palliative care, a consultation team can be contacted. For complex situations where long time involvement of a specialised palliative care professional is needed, a case manager can be contacted.

8. The case manager has ample time to offer advice and support to generalist care providers, and to coordinate care for individual patients.

9. A national system for registration for case managers in palliative care has added value, since it can clarify the role of the case manager in palliative care provision. It is important that the outcome of support is part of this registration. This system should be developed by initiatives for case managers in accordance with other registration systems.

Recommendations for policy and practice: What knowledge and skills should a case manager have and what is the place of the case manager in the whole of palliative care services?

Involvement of case managers should only be reserved for patients and informal carers for whom the complexity of their social environment or care transcends possibilities of regular care provision. The Dutch government promotes the philosophy that palliative care should, as much as possible, be provided by generalist care providers and supported by specialist palliative care providers when needed. Therefore, the case manager should be specialised in palliative care.

Transcending palliative care, case managers should have skills that enable them to share knowledge and cooperate with generalist care providers where necessary. Furthermore, such skills should not only involve communication but also the ability to engage and teach others. Since case managers are not always welcomed from the start, being pro-active, persistent and even ‘thick-skinned’ might be helpful.

Case managers provide support to patients and informal carers in addition to the care provided by medical specialists, GPs and home-care nurses amongst others. To facilitate cooperation between care providers, it can be helpful if the case manager is (highly) visible and can easily be contacted - for instance when (s)he is part of a palliative care consultation team, takes part in multidisciplinary meetings at hospital wards and at community healthcare centres, or is otherwise meeting with professionals working for patients with palliative care needs of the region.

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APPENDIX.
AIMS AND CHARACTERISTICS OF CASE MANAGEMENT IN PALLIATIVE CARE.

Appendix - Aims and characteristics of case management in palliative care

In the three tables below all aims and characteristics that resulted from round 1 and 2 of the expert panel are listed (see chapter 2). In round 1 and 2 all aims and characteristics were clustered, for round 3 they were divided into separate aims and characteristics. The ratings from round 3 are in de columns behind the aims and characteristics. Some of the separated aims and characteristics were not rated by the expert panel, those cells remain empty (e.g. in the case of contact with those next to the patient after the patient is deceased, the option ‘yes, to evaluate and to offer bereavement support’ is not put before the expert panel because they already rated the evaluation and bereavement support separately).

Table 1. Aims of case management in palliative care[1]

	Ratings Palliative Care (n=16)		Ratings GPs and other physicians (n=8)		Ratings Other (n=10)		Ratings Total (n=34)
	mean	median	mean	median	mean	median	M.A.D.
1.1. Care is aimed at quality of life and death*	8.4	9	8.8	9	8.3	9	0.53
1.2. Care is offered on demand, care will only be delivered in agreement with and according to the wishes of the patient and informal support system	6.9	8	5.4	6	6.1	7	1.76
1.3. Care is longitudinal; it starts when needed and lasts until the patient is deceased and the informal support system has received bereavement support*	7.8	8	8.0	8	8.2	8.5	0.88
1.4. Care is tailored to the individual needs and wishes of the patient and informal support system*	8.4	9	8.4	8	8.8	9	0.50
1.5. Care is flexible; content, duration and frequency of contacts are adjusted according to the needs of the patient and informal support system*	8.5	9	8.0	8	8.6	9	0.58
1.6. The relationship with the patient and informal support system is familiar, close and personal*	8.5	9	7.8	8	8.5	9	0.70
1.7. Care is comprehensive; the patient and informal support system receive a diverse array of care and support according to their needs and wishes*	7.9	8	7.5	7.5	8.0	8	0.72
1.8. Communication is a cornerstone; there is ongoing sufficient and clear communication between the case manager, the patient and the informal support system and between the different care providers working with and for the patient*	8.8	9	7.9	8	8.4	9	0.53
1.9. Care is accessible and low-threshold; clear arrangements are made for round-the-clock care and it is financed through health care insurance (or other arrangement without costs to the patient), no referral is needed*	8.2	9	8.4	8	8.4	9	0.71

1.10. Care is primarily delivered in the community and follows the patient throughout the process of illness regardless of place of stay of the patient*	7.9	8	7.6	8	7.5	7.5	0.94

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[1] For indication of agreement and high level of disagreement, the following symbols are used: * agreement is reached on importance of this element for successful implementation of case management in palliative care; ^ high level of disagreement is reached on importance of this element for successful implementation of case management in palliative care.

Table 2. Characteristics of content of case management in palliative care[2]

	Ratings Palliative Care (n=16)		**Ratings GPs and other physicians (n=8)**		**Ratings Other (n=10)**		**Ratings Total (n=34)**
	mean	**median**	**mean**	**median**	**mean**	**median**	**M.A.D.**
2.1. The case manager:							
(a) provides hands-on patient care, including technical nursing interventions^	3.2	3	5.0	5	5.2	5	2.33
(b) does not provide hands-on patient care^	6.7	7	3.9	3.5	3.7	4.5	2.12
2.2. At the start the case manager draws up a care plan together with the patient and his/her informal support system. This care plan is part of the (medical) record of the patient. (yes / no)	6.2	7	6.1	6	7.1	7	1.26
2.3. The care plan describes the following:							
(a) the mental and physical health of the patient^	5.4	6	4.5	4.5	7.1	7.5	2.26
(b) the social and spiritual wellbeing and needs and preferences of the patient and informal support system	6.1	6.5	5.0	5	7.7	8.5	1.94
(c) the abilities, skills and limitations of the informal support system	6.1	7	5.4	7	7.5	7.5	1.82
(d) an assessment of possibilities and preferences with regard to care of patient and his/her informal support system (e.g. preferred place of care, preferred place of death)	6.4	7	6.2	7	7.8	8.5	1.59

(e) the aims and content of care to be received	6.3	7	5.7	6	7.9	7.5	1.59
(f) an agreed list of people responsible for all aspects of care and information on how and where to reach them	7.3	8	6.7	7	7.9	8.5	1.38
(g) the name and contact information of an authorised agent who acts and decides on behalf of the patient when necessary	7.0	8	7.0	7	8.1	9	1.35
2.4. The care plan is regularly evaluated by the case manager, the patient and his/her informal support system and adjusted if necessary (according to an established procedure outlining how and when this is done). The amendment is part of the patient file. (yes / no)	6.8	8	6.0	6	8.1	9	1.44
2.5. Within a week after referral to case management, the case manager gets in contact with the general practitioner and district nurse and other relevant professionals							
(a) yes, to reach an understanding on cooperation*	7.8	8	7.1	8	7.3	7.5	1.06
(b) yes, to match provision of care*	8.3	9	6.3	7	7.8	8	1.09
(c) yes, to gain relevant information*	7.2	8	6.6	7.5	7.4	7	1.36
(d) no							
(e) other:							
2.6. The case manager acts as an advocate for the patient and his/her informal support system. If the patient and his/her support system do not agree with each other on issues, the case manager strives to reconcile the needs and preferences. (yes / no)	7.6	8	6.1	6.5	7.9	8.5	1.09
2.7. The case manager clarifies treatment and care options and discusses who is responsible for treatment and care. * (yes / no)	7.4	8	6.8	7.5	8.1	8.5	1.15
2.8. The case manager assists the patient and his/her informal support system in making decisions on treatment, care and support by giving information and by discussing significant thoughts and emotions. * (yes / no)	8.0	8	6.6	7.5	8.4	9	1.12

2.9. The case manager has solid knowledge of relevant services and organisations and offers complete and independent information tailored to the needs and preferences of the patient and his/her support system. * (yes / no)	8.5	8.5	6.8	7	8.6	9	0.82
2.10. The case manager matches the patient and his/her support system to necessary and preferred care and services or aids the patient and support system in organising care.* (yes / no)	8.3	8	6.6	7	8.5	9	0.85
2.11. The case manager follows the course of illness and the situation of the patient and his/her informal support system, anticipates problems and tries to prevent crises.* (yes / no)	7.9	9	6.6	7.5	8.6	9	1.18
2.12. The case manager monitors progress and coordination of care and secures and writes down agreed courses of care. (yes / no)	7.6	8	6.1	7	8.5	8.5	1.21
2.13. The case manager clarifies financial matters:							
(a) yes, with regard to applications for care, if and when their own contribution is required, and on procedures for compensation or allowance.	6.8	7	6.1	7	7.8	8	1.29
(b) yes, with regard to income, pension, inheritance and funeral costs.^	4.9	6	4.3	4.5	5.5	5	2.12
(c) no, but the case manager aids in referral to a specialist if desired	7.0	7	5.4	6	5.8	6	1.38
(d) no							
2.14. With regard to nursing treatment the case manager should:							
(a) identify the needs and preferences of the patient and his/her informal support system*	7.6	8	6.6	7	8.2	8.5	1.06
(b) give information and support to the patient and his/her informal support system	7.3	7	6.4	7	8.2	8	1.12
(c) organise care	7.5	8	6.3	6.5	8.1	8	1.21
(d) give care^	3.4	4	3.0	2	5.5	5.5	2.09

	Ratings palliative care		Ratings physicians		Ratings other		Ratings total
	mean	median	mean	median	mean	median	M.A.D.
2.15. With regard to social and personal wellbeing of the patient and his/her informal support system the case manager should:							
(a) identify the needs and preferences of the patient and his/her informal support system*	8.1	8	6.6	7.5	8.5	8.5	0.85
(b) give information and support to the patient and his/her informal support system*	7.7	8	6.4	7	8.3	8.5	1.03
(c) organise care*	8.1	8	5.9	6.5	8.3	8	1.09
(d) give care^	5.9	6	3.3	2.5	5.2	5.5	2.06
2.16. With regard to spiritual care the case manager should:							
(a) identify the needs and preferences of the patient and his/her informal support system*	8.2	8	6.6	7.5	8.4	8	0.76
(b) give information and support to the patient and his/her informal support system*	7.7	8	6.1	7	8.0	8	1.06
(c) organise care*	8.0	8	6.0	7	8.1	8	1.09
(d) give care	5.4	6	3.0	2.5	4.5	5	1.91
2.17. With regard to practical help / assistance the case manager should:							
(a) identify the needs and preferences of the patient and his/her informal support system*	8.1	8	7.0	8	8.3	8.5	0.88
(b) give information and support to the patient and his/her informal support system*	7.8	8	6.3	7	8.4	8.5	0.94
(c) organise care*	7.6	8	6.0	6.5	8.0	8	1.24
(d) give care	3.9	3.5	3.0	2.5	4.2	5	2.00
2.18. Care from the case manager ends when:							
(a) a well-functioning network of care providers is put in place for the patient and his/her informal support system^	5.7	6	2.5	2	3.5	3	2.24
(b) the patient is deceased^	4.0	3	4.4	4.5	3.6	3.5	2.03

(c) the patient is deceased and bereavement support for his/her informal support system is in place or has been delivered*	7.8	8	6.9	7.5	8.0	8.5	1.26
2.19. One or more contacts with the patient's informal support system takes place between one and eight weeks after the patient is deceased.							
(a) yes, to evaluate care and case management	7.3	8	6.1	7	7.3	7	1.18
(b) yes, to offer bereavement support	6.5	7	5.8	7.5	6.3	6.5	1.85
(c) yes, to evaluate and to offer bereavement support							
(d) no							
2.20. Within two weeks of the patient being deceased the case manager contacts the general practitioner and district nurse and other care professionals.							
(a) yes, to evaluate care and case management	6.8	7	6.8	8	6.6	7	1.24
(b) yes, to evaluate cooperation	6.6	7	6.8	8	6.8	7	1.29
(c) yes, to evaluate care and cooperation							
(d) no							

[2] For indication of agreement and high level of disagreement, the following symbols are used: * agreement is reached on importance of this element for successful implementation of case management in palliative care; ^ high level of disagreement is reached on importance of this element for successful implementation of case management in palliative care.

Table 3. Characteristics of structure of case management in palliative care[3]

		Ratings Palliative Care (n=16)		Ratings GPs and other physicians (n=8)		Ratings Other (n=10)	Ratings Total (n=34)
	mean	median	mean	median	mean	median	M.A.D.
3.1. The case manager works for:							
(a) a home care organisation	5.5	6.5	6.1	6	5.6	5	1.67
(b) a hospital^	3.9	4.0	2.8	2	4.9	5	2.09

(c) a hospice	4.4	5	4.6	5	3.6	4	1.67
(d) a residential care home	3.0	3	3.0	3	3.3	4	1.53
(e) a general practitioner or health care centre	4.3	5	5.4	5.5	4.1	5	1.88
(f) a specialised consultation team in palliative care	7.1	7.5	6.0	6	4.1	5	1.73
(g) a multidisciplinary support team	6.7	7	6.1	6.5	4.7	5	1.88
(h) a cooperative/network of palliative care providers	7.7	8	4.6	5	6.0	6	1.90
3.2. Referral to case management can be done by:							
(a) a home care organisation*	8.1	8	6.5	8	8.2	8.5	1.00
(b) a hospital*	8.1	8	7.5	8	8.5	9	0.79
(c) a hospice*	7.3	8	7.5	8	7.5	8.5	1.35
(d) a residential care home	7.2	8	7.1	8	7.3	8.5	1.45
(e) a general practitioner or health care centre*	8.4	8.5	7.6	8.5	8.0	9	0.91
(f) family/friends/the patient*	8.3	8	5.4	8	7.5	8.5	1.38
3.3. The case manager:							
(a) is part of a team of case managers	7.0	7	6.1	7.5	7.4	8	1.62
(b) is part of a multidisciplinary team	7.3	8	7.4	8	6.6	7.5	1.41
(c) other:							
3.4. The following disciplines are part of the multidisciplinary team or are otherwise available to the case manager for consultation:							
(a) a medical specialist^	6.6	7	4.4	3.5	6.3	7	2.03
(b) a general practitioner	7.6	8	7.5	8.5	7.3	8	1.36
(c) a psychologist	6.3	7	6.1	7	6.7	7.5	1.71
(d) a psychiatrist	4.4	4	3.0	2.5	4.7	5	1.61
(e) a spiritual counsellor	6.6	7	5.9	7	6.3	7	1.62
(f) a pharmacist^	4.3	4	5.0	5.5	5.3	5	2.03
(g) a physiotherapist	4.4	4.5	4.9	5.5	4.3	5	1.85
(h) a dietician	4.1	4	4.6	5	4.7	5	1.85
(i) a social worker	5.5	6	5.1	5.5	6.2	7	1.85
(j) an ethnicity consultant	4.9	5	4.9	5	4.0	5	1.82

	Ratings palliative care		Ratings physicians		Rating other		Ratings total
	mean	median	mean	median	mean	median	M.A.D.
(k) Centre for Youth and Family (knowledge centre for answers and advice on issues concerning upbringing, parenting, and growing up)	3.9	4	3.1	3	4.4	5	1.63
(l) when a case manager is part of a team of case managers only, arrangements for collaboration with other disciplines are made*	7.2	8	7.1	8	8.4	9	1.18
3.5. Case management is delivered:							
(a) as part of a larger/diverse range of tasks (e.g. consultation of nursing tasks, not combined with case management)	6.8	8	5.8	6	6.0	5.5	1.72
(b) by a case manager solely performing case management^	5.0	5.5	3.0	2.5	4.0	4.5	2.24
3.6. The case manager is one of the following:							
(a) nurse trained at level 4	4.1	3	4.6	4	3.1	4	1.81
(b) nurse trained at level 5	7.3	8	6.5	6.5	5.3	5	1.82
(c) nurse with further schooling in palliative care, oncology or another relevant field of specialist care	7.7	9	6.4	7	7.7	8.5	1.50
(d) nurse practitioner/clinical nurse specialist	5.9	6.5	6.3	7	7.4	7.5	1.68
(e) practice nurse in a general practice	4.3	4.5	5.5	6.5	4.7	5	1.97
(f) general practitioner^	4.8	5.5	6.5	8	4.4	5	2.12
(g) social worker	4.1	4	2.9	2	2.7	2	1.94
(h) other:							
3.7. Case management is for:							
(a) patients in need of palliative care (i.e. when there is no ongoing treatment aimed at curing disease or prolongation of life)^	5.8	5.5	3.6	2.5	3.2	3.5	2.09
(b) patients in need of palliative care or care aimed at prolongation of life (i.e. when there is no ongoing treatment aimed at curing disease)^	6.8	7.5	5.1	5	6.1	7	2.03

(c) patients with a life threatening decease (i.e. when care can be aimed at palliation, curing disease or prolongation of life or a combination of these aims)^	5.9	6	6.8	8	5.3	5	2.24
3.8. The case manager is accessible:							
(a) 24 hours a day, 7 days a week^	4.8	3.5	4.6	4	6.7	7	2.24
(b) office hours, 5 days a week, with a arrangement for times of crises	7.2	8	7.8	8	6.6	7.5	1.38
(c) office hours, 5 days a week^	5.9	6	4.4	4.5	3.7	4.5	2.03
(d) other:							
3.9. As a fundamental principle case management complements other care, it does not duplicate services or take over care of other providers. (yes / no)	8.5	9	6.6	8	6.0	6	1.34
3.10. The case manager engages in casefinding, for example by participating in team meetings in the local hospital. (yes / no)	7.4	7.5	5.4	5.5	7.2	7.5	1.62
3.11. The case manager identifies deficiencies in local care for patients in need of palliative care and discusses them with the regional coordinator of palliative care services.* (yes / no)	7.9	8	7.8	8	7.9	9	0.94

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[3] For indication of agreement and high level of disagreement, the following symbols are used: * agreement is reached on importance of this element for successful implementation of case management in palliative care; ^ high level of disagreement is reached on importance of this element for successful implementation of case management in palliative care.

SUMMARY.

Summary

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. Studies from the US showed positive results regarding case management, whilst studies from the UK showed mixed results. In Dutch healthcare 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. GPs function as gatekeepers to specialised forms of palliative care. Therefore, in the Netherlands, case management may be delivered differently and results may also differ from case management within other healthcare systems. To study the Dutch initiatives for case managers in primary palliative care, the CaPalCa study was set up. This thesis addresses the lacunae in research concerning primary palliative care case managers in the Netherlands by examining 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.

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

Chapter 2 reports on a set of aims and characteristics of case management in palliative care, as formulated by an expert panel. For this, a modified version of the RAND®/University of California at Los Angeles (UCLA) appropriateness method was used. A total of 46 health care professionals, researchers and policy makers participated. Nine out of ten aims of case management were met with agreement. The most important areas of disagreement were hands-on nursing care by the case manager, target group of case management, performance of other tasks besides case management and accessibility of the case manager. Research into the feasibility of different options and their effects on implementation could help health care planners to make informed decisions on the best way to deliver case management.

Chapter 3 describes how, and how often, case management is implemented in the Netherlands. Twenty initiatives for case management were identified in a nationwide survey among all palliative care networks in the Netherlands. Initiatives were mainly located in the most urban parts of the Netherlands, and the majority have been operational for less than five years. In all twenty initiatives the case managers were nurses. Support provided by case managers is supplemental to care by the GP and home-care nurse. Content of support was roughly the same in all initiatives. Differences between the various case management initiatives mostly regarded the organisation of care. A lack of uniformity in the description of interventions makes it difficult to compare interventions and to obtain insight into the usefulness of case management as a way of managing complex care processes. In describing the characteristics of case management in palliative care, an important first step is made in identifying effective elements of case management. Of the 20 initiatives identified in the nationwide survey, 13 were investigated in the evaluation described in part 2 and 3.

Part 2: What support is provided and to whom? (chapters 4 and 5)
Chapter 4 describes patients that are referred to a case manager. Case managers completed questionnaires for 687 patients; referrers completed 448 (65%). The majority (69%) of patients referred to a case manager had a combination of curative or life-prolonging, and palliative treatment aims. Almost all (96%) of those referred were cancer patients. The need for psychosocial support was frequently given as a reason for referral (66%) regardless of treatment aim. Case managers attract referrals before the patient is in the terminal stage of the disease, when discussions on the balance of treatment aims are still relevant and patients are still able to engage in discussions on preferred care. Reasons for referral cover all domains of palliative care, with an emphasis on psychosocial support, making it complementary to medical care provided in hospital and by primary care providers. However, those referred to a case manager are almost exclusively cancer patients. Future efforts to improve palliative care case management should focus on broadening the scope to include patients with diagnoses other than cancer.

Chapter 5 explores the support provided by case managers to patients and their informal carers. This prospective study followed cancer patients (n=662) receiving support from a palliative care case manager using registration forms filled out by the case manager after contact with the patient and/or informal carer. The number of contacts ranged from 1 to 36, with a median of 4 contacts. Contacts were mostly with the patient and informal carer together - a median of 2 contacts. The topics discussed at least once with most patients and/or informal carers were physical complaints (93.5% of patients/informal carers), life expectancy (79.5% of patients/informal carers), and psychological aspects of being ill (79.3% of patients/informal carers). Organisational characteristics explain the variability in data more than patient characteristics. Case managers provide support in a flexible manner, and support covered all domains of palliative care. Despite the generally agreed upon goal of palliative care providing patient centred care, our data suggests that the characteristics of the organisation are more important in predicting what topics are discussed between the case manager and the patients/informal carers than patient characteristics are. Thus, even though case managers provide support in a flexible manner this flexibility is ‘coloured’ by organisational characteristics.

Part 3: Does the case manager have added value? (chapters 6, 7 and 8)
In chapter 6, the experiences of bereaved informal carers are highlighted. The informal carer (n=178) completed a questionnaire two months after the patient had died. The number of healthcare professionals involved in the patients’ care was appropriate according to 90% of the informal carers. Care providers took time to listen to the informal carer and showed understanding of their feelings (respectively 78% and 76% of informal carers). However, 14% of informal carers did not receive sufficient information on the possibilities of care and support for people with a life threatening disease and their car-

ers from any of the care providers. This study suggests that concerns about adding another care provider should be no impediment to involving a case manager when needed, as long as the role of each care provider is explained clearly to patients and informal carers. Together, the primary care team and the case manager supported the large majority of the informal carers in all aspects investigated. At all times, support should be offered to informal carers as well as to the patient.

Chapter 7 reports on the appraisal of the GP and home-care nurse of the support provided by the case manager. GPs (n=168) and home-care nurses (n=125) completed a questionnaire after the patient's death. Of GPs, 46% rated the case manager as helpful in realising appropriate care for the patient, for home-care nurses this was 49%. Home-care nurses were more often positive on support provided by the case manager than GPs were. Whether or not the case manager was helpful in realising appropriate care was associated with tasks of the case manager, rather than patient characteristics or number of contacts with the case manager. The case manager did not hinder the process of care and had added value for patients, according to both GPs and home-care nurses. To further enhance cooperation, case managers should invest in contact with GPs and home-care nurses since a clear definition of roles and responsibilities and a development of trust follows from such contact.

Chapter 8 compares palliative care provided by the GP when a case manager is, or is not, involved in care. Questionnaire data were provided by GPs participating in two different studies: the Sentimelc study (280 cancer patients) and the CaPalCa study (167 cancer patients). The GP was more likely to know the preferred place of death (OR 7.06; CI 3.47-14.36), the place of death was more likely to be at the home (OR 2.16; CI 1.33-3.51) and less likely to be the hospital (OR 0.26; CI 0.13-0.52), and there were fewer hospitalisations in the last 30 days of life (none: OR 1.99; CI 1.12-3.56 and one: OR 0.54; CI 0.30-0.96), when cancer patients received additional support from a case manager, compared with patients receiving the standard GP care. The involvement of a case manager showed added value in addition to palliative care provided by the GP, even though the role of the case manager is 'only' advisory and he or she does not provide hands-on care or prescribe medication.

Conclusion

Chapter 9, the General Discussion, argues that case managers in palliative care should broaden their scope to include patients with diseases other than cancer. This could be done by working together with nurses specialised in the care of patients with other diseases, such as chronic heart failure and lung disease. To ensure timely referral to a case manager, the 'surprise question' ('Would I be surprised if this patient was to die in the next 6–12 months?') can be used. This may also enhance timely recognition of palliative care needs in patients with other diagnoses than cancer. Referral to a case manager is appropriate when the symptoms and problems of the patient and informal carer are complex. Besides specialised knowledge of palliative care, case managers should have skills that enable them to share knowledge and cooperate with generalist care providers where necessary. Furthermore, skills involve not only communication, but also the ability to engage with and teach others.

SAMENVATTING.

Samenvatting

Met de komst van verpleegkundigen gespecialiseerd in palliatieve zorg, die naast de huisarts en verpleegkundigen van de thuiszorg, thuiswonende patiënten bezoeken om te zorgen dat patiënten de juiste zorg ontvangen, is er een vorm van casemanagement in de eerstelijns palliatieve zorg ontstaan. Onderzoek uit de Verenigde Staten laat positieve resultaten zien voor casemanagement, terwijl onderzoek in het Verenigd Koninkrijk gemengde resultaten laat zien. In het Nederlandse zorgsysteem ligt een sterke nadruk op de eerstelijns zorg. De huisarts en wijkverpleegkundige zijn belangrijke zorgverleners voor de patiënt met palliatieve zorgbehoeften die thuis verblijft. Huisartsen fungeren als poortwachters naar gespecialiseerde palliatieve zorg. Daarom kan het zijn dat casemanagement in Nederland anders vorm krijgt en ook tot andere resultaten leidt dan in andere zorgsystemen. Om de initiatieven in Nederland op het gebied van casemanagement in de eerstelijns palliatieve zorg te onderzoeken, is het CaPalCa onderzoek opgezet. Dit proefschrift gaat in op hiaten in onderzoek naar de casemanagers in de eerstelijns palliatieve zorg door te onderzoeken: 1) wat casemanagement in de palliatieve zorg is, 2) welke ondersteuning of zorg wordt geboden aan wie, en 3) of de casemanager toegevoegde waarde heeft.

Deel 1: Wat is casemanagement in de palliatieve zorg? (hoofdstuk 2 en 3)

In hoofdstuk 2 worden doelen en kenmerken van casemanagement in de palliatieve zorg geformuleerd door een expert panel. Hiertoe is een aangepaste versie van de ‘RAND®/University of California at Los Angeles (UCLA) appropriateness method’ gebruikt. In totaal hebben 46 zorgprofessionals, beleidsmakers en onderzoekers hieraan meegewerkt. Er was overeenstemming over negen van de tien doelen van casemanagement. De belangrijkste verschillen van mening bestonden over of de casemanager ‘hands on’ verpleegkundige zorg verleent, wat de doelgroep van casemanagement is, het hebben van andere taken naast casemanagement, en bereikbaarheid van de casemanager. Onderzoek naar de haalbaarheid van de verschillende keuzes en gevolgen voor implementatie kan beleidsmakers helpen om geïnformeerde beslissingen te nemen over de beste manier om casemanagement toe te passen.

Hoofdstuk 3 beschrijft hoe en hoe vaak casemanagement wordt toegepast in Nederland. In een onderzoek onder alle palliatieve zorgnetwerken in Nederland werden twintig initiatieven voor casemanagement gevonden. Initiatieven bestonden vooral in en rond de Randstad en een meerderheid van de initiatieven was minder dan vijf jaar actief. In alle twintig initiatieven was de casemanager verpleegkundige. Ondersteuning door de casemanager wordt gegeven in aanvulling op zorg van de huisarts en wijkverpleegkundige. De inhoud van de ondersteuning was globaal genomen dezelfde in alle initiatieven. Verschillen bestonden vooral in de organisatie van de initiatieven. Een gebrek aan eenduidigheid in de beschrijving van interventies maakt het moeilijk om interventies te vergelijken en om inzicht te krijgen in het nut van casemanagement om complexe zorgprocessen te sturen. Door kenmerken van casemanagement in de palliatieve zorg te beschrijven wordt een belangrijke eerste stap gemaakt in het identificeren van effectieve elementen van casemanagement. Van de twintig initiatieven die zijn geïdentificeerd in Nederland, zijn er dertien onderzocht in het evaluatie onderzoek dat beschreven wordt in deel 2 en 3.

Deel 2: Welke ondersteuning wordt geboden en aan wie? (hoofdstuk 4 en 5)
Hoofdstuk 4 beschrijft patiënten die worden verwezen naar een casemanager. Casemanagers vulden een vragenlijst in met betrekking tot 687 patiënten, verwijzers vulden 448 (65%) vragenlijsten in. De meerderheid (69%) van patiënten die verwezen werden naar een casemanager hadden een combinatie van curatieve of levensverlengende behandeldoelen en palliatieve zorgdoelen. Bijna alle (96%) verwezen patiënten hadden kanker. Behoefte aan psychosociale ondersteuning werd vaak genoemd als reden voor verwijzing (66%), ongeacht het behandeldoel. Patiënten worden naar een casemanager verwezen voor het terminale stadium van de ziekte, wanneer gesprekken over de balans tussen verschillende behandeldoelen nog van belang zijn en patiënten hun voorkeur voor zorg nog kunnen aangeven. Redenen voor verwijzing naar de casemanager betreffen alle domeinen van de palliatieve zorg, met een nadruk op psychosociale ondersteuning, waardoor begeleiding aanvullend is op medische zorg in een ziekenhuis of door eerstelijns zorgverleners. Vooral patiënten met kanker worden verwezen naar een casemanager. Een verbeterpunt is dan ook het verbreden van de reikwijdte door patiënten met andere diagnoses dan kanker te includeren.

De ondersteuning door de casemanager aan patiënten en hun naasten wordt onderzocht in hoofdstuk 5. In een prospectief onderzoek werden patiënten met kanker gevolgd terwijl ze ondersteuning van een casemanager kregen, waarbij gebruik werd gemaakt van contact registratie formulieren die werden ingevuld door de casemanager na contact met de patiënt en/of naaste. Het aantal contacten varieerde van 1 tot 36, met een mediaan van 4 contacten. Contacten waren meestal met de patiënt en naaste samen (een mediaan van 2 contacten). De onderwerpen die minstens een keer met de meeste patiënt en naaste besproken werden waren: fysieke klachten (93,5% van de patiënten/naasten), levensverwachting (79.5%) van patiënten/naasten), en psychologische aspecten van ziek zijn (79.3%) van patiënten/naasten). Kenmerken van de organisatie verklaren meer in variatie van data dan kenmerken van patiënten. Casemanagers bieden flexibele ondersteuning en de ondersteuning betreft alle domeinen van de palliatieve zorg. Ondanks de algemeen geldende waarde dat palliatieve zorg de patiënt centraal stelt, wijzen onze data erop dat kenmerken van de organisatie belangrijker zijn in het voorspellen welke onderwerpen besproken worden tussen de casemanager en de patiënt/naaste dan kenmerken van de patiënt. Hoewel de casemanagers flexibel ondersteuning bieden, is deze flexibiliteit ‘gekleurd’ door kenmerken van de organisatie.

Deel 3: Heeft de casemanager toegevoegde waarde? (hoofdstuk 6, 7 en 8)
In hoofdstuk 6 worden de ervaringen van naasten besproken. De naaste (n=178) vulde een vragenlijst in twee maanden na overlijden van de patiënt. Het aantal zorgprofessionals dat betrokken was bij de patiënt, was goed volgens 90% van de naasten. Alle zorgverleners namen de tijd om te luisteren naar de naaste en toonden begrip voor de gevoelens van de naaste (respectievelijk 78% en 76% van de naasten). Echter, 14% van de naasten ontving van geen van de zorgverleners informatie over de mogelijkheden van zorg en opvang voor mensen met een levensbedreigende ziekte en hun naaste. Dit onderzoek duidt erop dat bezorgdheid over het toevoegen van een extra hulpverlener geen belemmering hoeft te zijn voor het betrekken van een casemanager indien nodig, zolang de rol van elk van de zorgverleners duidelijk wordt uitgelegd aan de patiënt en naaste. De huisarts, wijkverpleegkundige en casemanager samen ondersteunen de meerderheid van de naasten in alle onderzochte aspecten. Informatie dient altijd aangeboden te worden aan zowel de patiënt als de naaste.

De mening van de huisarts en wijkverpleegkundige over de ondersteuning door de casemanager komt aan bod in hoofdstuk 7. Huisartsen (n=168) en wijkverpleegkundigen (n=125) vulden een vragenlijst in na het overlijden van de patiënt. Van de huisartsen vond 46% dat de casemanager bijdroeg aan het realiseren van passende zorg voor de patiënt, van de wijkverpleegkundigen was dit 49%. Wijkverpleegkundigen waren positiever over de begeleiding door de casemanager dan de huisartsen. Of de casemanager al dan niet bijdroeg aan het realiseren van passende zorg hing samen met taken van de casemanager, meer dan met kenmerken van de patiënt of het aantal contacten met de casemanager. Het betrekken van de casemanager had geen ongewenste gevolgen voor het zorgproces en wel toegevoegde waarde voor de patiënt, volgens de huisartsen en wijkverpleegkundigen. Om de samenwerking te verbeteren moeten casemanagers investeren in contact met de huisartsen en wijkverpleegkundigen, aangezien uit contact duidelijkheid volgt over taakverdeling en verantwoordelijkheden en onderling vertrouwen groeit door contact.

In hoofdstuk 8 wordt palliatieve zorg door de huisarts onderzocht, wanneer wel of geen casemanager betrokken is bij de patiënt. Gegevens van vragenlijsten ingevuld door huisartsen die deelnamen aan twee verschillende studies werden vergeleken: het Sentimelc onderzoek (280 patiënten met kanker) en het CaPalCa onderzoek (167 patiënten met kanker). De huisarts was vaker op de hoogte van de gewenste plaats van overlijden (OR 7.06; CI 3.47-14.36), en de plaats van overlijden was vaker thuis (OR 2.16; CI 1.33-3.51) en minder vaak het ziekenhuis (OR 0.26; CI 0.13-0.52), en er waren minder opnames in het ziekenhuis in de laatste 30 dagen voor overlijden (geen: OR 1.99; CI 1.12-3.56 en één: OR 0.54; CI 0.30-0.96), wanneer een casemanager betrokken was bij de zorg dan wanneer dat niet zo was. Betrokkenheid van een casemanager had meerwaarde in aanvulling op palliatieve zorg door de huisarts, ondanks dat de casemanager alleen een adviserende rol heeft in de begeleiding en de casemanager geen 'hands on' zorg verleent of medicatie voorschrijft.

Conclusie

In hoofdstuk 9, getiteld 'General Discussion', wordt gesteld dat casemanagers hun reikwijdte moeten verbreden zodat ook patiënten met een andere diagnose dan kanker begeleid kunnen worden. Dit kan gedaan worden door samen te werken met bijvoorbeeld gespecialiseerd verpleegkundigen op het gebied van hartziekten, of longverpleegkundigen. Om tijdige verwijzing naar een casemanager te ondersteunen kan de 'surprise question' gesteld worden ('Zou ik verbaasd zijn wanneer deze patiënt overlijdt in de komende zes tot twaalf maanden'). Dit kan ook voor verbetering zorgen in het tijdig herkennen van palliatieve zorgbehoeften in patiënten met andere diagnoses dan kanker. Verwijzing van patiënten naar een casemanager is aan de orde bij complexe symptomen en problemen van de patiënt en/of naaste. Naast gespecialiseerde kennis op het gebied van palliatieve zorg, zouden casemanagers vaardigheden moeten hebben om, waar nodig, kennis te delen met en samen te werken met generalistische zorgverleners. Vaardigheden hebben niet alleen betrekking op communicatie, maar ook het vermogen om anderen te betrekken bij en onderwijzen in palliatieve zorg.

DANKWOORD.

Dankwoord

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> Want je kunt niets zeker weten en alles gaat voorbij
>
> Maar ik geloof in jou en mij.

ABOUT THE AUTHOR.
OVER DE AUTEUR.

About the author

Annicka van der Plas (1973) was born in Hengelo (Ov). In 1993 she finished secondary school and moved to Nijmegen to study Psychology at the Katholieke Universiteit Nijmegen (now called Radboud University). After graduation in 1999 she started working as a researcher on interventions for people who quit smoking during the nationwide media campaign ‘Dat Kan Ik Ook’, inviting people to quit smoking on Januari 1 2000, seizing the new millennium as an opportunity to attract extra attention. Also, she started an internship as a research assistant in the Pompekliniek, a clinic for detention under a hospital order. From January 2000 until September 2001 she worked there as an assistant summarising case files for treatment staff. Between 2002 and 2005 Annicka worked as a research-psychologist in projects in the field of (forensic) addiction care. From 2004 until 2009 she worked at Parnassia as a researcher on the implementation of Critical Time Intervention (CTI); is a time-limited, manual-guided case management approach intended to enhance continuity of care for mentally ill patients. For this project, she worked closely together with a community support team for patients with serious mental illness that are difficult to engage in services. In January 2010 Annicka started her PhD study at EMGO Institute for Health and Care Research (EMGO+), within the department of Public and Occupational Health, and as member of the Expertise Center for Palliative Care at VU University Medical Center. In 2012 and 2013 she was also involved in a focus group study on PaTz (palliative care at home, an adaptation of the Gold Standards Framework for Dutch healthcare), carried out by this department. She currently works as a researcher on several palliative care studies and as ‘kwartiermaker’ for the Palliative Care Consortium Noord Holland and Flevoland.

Over de auteur

Annicka van der Plas (1973) is geboren in Hengelo (Ov). In 1993 behaalde ze haar VWO diploma en verhuisde naar Nijmegen om daar psychologie te studeren aan de Katholieke Universiteit Nijmegen (inmiddels de Radboud Universiteit). Na haar afstuderen in 1999 begon ze haar loopbaan met een onderzoek naar interventies voor mensen die stoppen met roken in de ‘Dat Kan Ik Ook’ millennium campagne. Daarnaast begon ze in 1999 als onderzoeksassistent in een werkervaringsplaats bij de Pompekliniek, een TBS kliniek in Nijmegen. Tussen januari 2000 en september 2001 werkte ze in de Pompekliniek als assistent, waarbij ze samenvattingen maakte van de dossiers van strafrechtelijk onderzoek ten behoeve van de behandelstaf. Tussen 2002 en 2005 werkte Annicka als onderzoekspsycholoog op het gebied van (forensische) verslavingszorg.Van 2004 tot en met 2009 werkte ze bij Parnassia als onderzoeker aan de implementatie van de Critical Time Intervention (CTI); een gestructureerde interventie om patiënten met chronische psychiatrische stoornissen die moeilijk aan zorg te binden zijn in een periode van ongeveer 9 maanden toe te leiden naar passende zorg. In dit project werkte ze nauw samen met het team Openbare geestelijke Gezondheidszorg van de Parnassia Bavo Groep. In januari 2010 begon Annicka aan het promotie onderzoek bij het EMGO Instituut for Health and Care Research (EMGO+), bij de afdeling Sociale Geneeskunde, en als lid van van het Expertise Centrum voor palliatieve zorg van VU medisch centrum. In 2012 en 2013 was ze daarnaast ook betrokken bij onderzoek naar PaTz (palliatieve thuis zorg, een Nederlandse toepassing van het Gold Standards Framework), uitgevoerd door dezelfde onderzoeksgroep. Inmiddels is Annicka werkzaam als kwartiermaker voor het Consortium palliatieve zorg Noord Holland en Flevoland, en is ze betrokken bij diverse onderzoeken op het gebied van palliatieve zorg.

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