

**CHAPTER 9.
GENERAL DISCUSSION.**

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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 availa-

ble 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 cooperation 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 re-

spondents 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 (Sentinelc) 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 (Sentinelc) 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 (Sentinelc). 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.
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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 referers' 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.