

## SUMMARY.

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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.