



Palliative care case management in primary care settings: A nationwide survey



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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 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.

Setting: Primary 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 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.

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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.

1. 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 and 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 (Becker et al., 2010; Groot et al., 2005; 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 Vroomen 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.

2. Methods

2.1. 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

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