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### Clinical, economic and methodological studies in elderly patients with dementia and their informal caregivers

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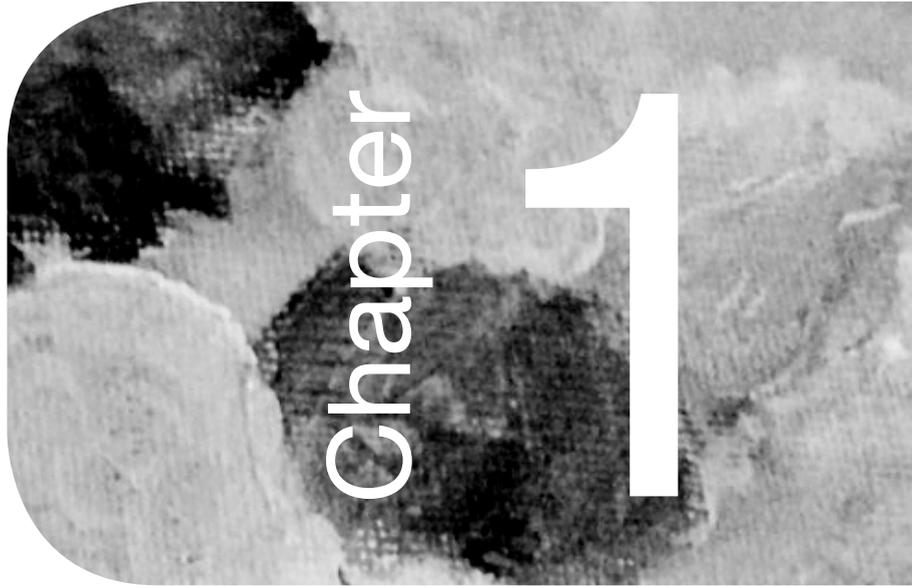
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## General Introduction

*"I am so well physically that I will live forever and my mind will be so useless I won't even die of stress because I probably won't even have the brains to realize what is happening."*

- My Great Aunt Joyce, fearing her future with dementia and the burden on her family and society.

Dementia is a chronic and devastating brain disorder marked by memory loss, cognitive impairment and behavioral lapses resulting in pronounced consequences for the people with dementia, their families and society (1). A recent systematic review estimated that there would be 48.1 million people with dementia in 2020 and approximately 90.3 million in 2040 (2). According to this review, in high-income countries the numbers of people with dementia will continue to grow, particularly among the oldest old, and the provision and financing of measures to meet their long-term care needs, including support for their informal caregivers, is already an increasingly important political issue (2,3). The OECD predicts that spending in high income countries on long-term care could possibly double or triple between now and 2050 given rising prices, more demand for quality and more responsive, patient-oriented social care systems (3,4). Standard and Poor's, a financial services company, considers global aging to be a significant threat to economic stability because sovereign debt could become unsustainable without changes to age-related public spending (3,5). These developments have made countries around the world evaluate how affordable and sustainable are their current levels of provision for long-term care taking into consideration the large projected increases in the numbers of older people with increasing care needs, coupled with a shrinking working age population (3,5).

### **The course of dementia**

Studies show that people age 65 and older survive an average of four to eight years after a diagnosis of dementia, although some may live as long as 20 years (6-12). In the Netherlands, approximately 260,000 people are currently living with a diagnosis of dementia and this number is expected to double by 2050 (13). Of these, approximately two-thirds live at home, while the remaining third resides in a nursing home or an accommodation linked to a nursing or residential care home (14,15). While living at home the majority of care is provided by informal caregivers. Eventually, most people are admitted in the last phase of their life and the majority of people with dementia die in a long-term care facility (LTCF) (16). Research shows that place of death is highly associated with perceived quality of life at the end of life (17). A survey conducted in the United States of family members of people who lived with chronic illnesses, such as dementia, reported a less favorable dying experience in institutionalized settings than at home with hospice services (17). Most people with dementia and care professionals prefer that people with dementia die at home (18-20). However, people with dementia have high and special care needs (21) [behavioural disturbances] making care at home challenging and in reality, it may be unrealistic to expect that this type of care can be provided at home until the end of their life (14,15,21). In the Netherlands, it is estimated that persons with dementia live two years on average in a LTCF (22).

### **Crisis and dementia**

The word crisis in dementia care is frequently mentioned in the literature, health policy and care practice, usually in the context of difficulty, danger or acute care needs, and not as a turning point of the disease, but it is rarely defined (22-24). The concept of crisis is included in many sets of quality indicators for dementia care (e.g. number of emergency consultations in dementia patients) (25). Budgets are reserved for crisis beds and crisis admissions. Recently, increased attention has been paid to crisis prevention aimed at both caregivers and patients. Examples of interventions to prevent avoidable crisis situations are the deployment of case managers or provision of psychosocial support (26-28).

### **Economic consequences of dementia**

Worldwide costs of dementia were estimated at US\$ 604 billion in 2010 (1,29). In high-income countries, informal care (45%) and formal social care (40%) make up the majority of costs, while the contribution of direct medical costs (15%) is smaller (1,29). In the Netherlands, more than five percent of the total health care budget is spent on dementia, and dementia related costs account for 24% of the total care costs for psychiatric disorders (30). It is estimated that approximately 53% of persons with dementia use home care (31). Around 5% of persons with dementia go to a day care facility three times a week (30). However, most care is provided by informal caregivers which has a large impact on these caregivers. Around 80 percent of caregivers feel overburdened or at high risk of being overburdened, and this is one of the major risk factors for institutionalization of persons with dementia (22,32). Moreover, informal caregivers of demented persons are at high risk to develop depressive or anxiety disorders (33,34).

### **Improving outcomes for persons with dementia and informal caregivers**

According to informal caregivers who look after people with dementia, the three most important forms of support they need are information and education, support from a case manager and daycare facilities (35). Although there is a wide variety of services available for community dwelling people with dementia and their informal caregivers, people often lack sufficient information regarding all available services that may address their care needs (36,37). Also, many experience insufficient alignment, management and continuity of care and support during the disease trajectory of their loved one with dementia (38-40). Developed countries across the world are creating policies in dementia care where there is an emphasis on care at home for dependent elderly people for as long as possible (41). It is essential that the various types of care and supporting disciplines involved in the management of people with dementia collaborate and support informal caregivers to provide optimal care at home for as long as possible because patients and caregivers prefer to live at home and there are less costs associated with living at home as compared to institutionalization. Case management has become key to many dementia care strategies in high income countries to keep people at home for as long as possible (41).

### **The rationale for case management**

Case management is defined as “a collaborative process in which a case manager assesses, plans, implements, coordinates, monitors and evaluates all options and services required to meet an individual’s health, social care, educational and employment needs, using communication and available resources to promote quality and cost effective outcomes” (42). It strives to provide pro-active care coordinated by a case manager, often a registered nurse or social worker, who is supported by a multidisciplinary team of health care professionals (e.g. general practitioner, psychologist, psychiatrist, geriatrician, elderly care physician or neurologist).

Several studies have evaluated costs and effects of case management in many different countries (43-47). However, reviews and meta-analyses have yielded inconsistent results regarding case management on patient and caregivers outcomes such as care satisfaction, institutionalization, hospitalization, caregiver burden, depression, and economic outcomes (43-49). A recent Cochrane review showed that the case management group was significantly less likely to be institutionalized than usual care groups at six months and at 18 months, but the results were less clear at one and two years. Quality of life, social support and satisfaction with the quality of care received from the perspective of the informal caregiver was better in the case management group than in the control group at 12 months, but there was no difference in quality of life for the person with dementia between the case management and the control group (41). In the early stages of dementia case management does not seem to have additional value as Jansen et al. found no differences in outcomes after one year (50).

A review which included both qualitative and quantitative studies looked at facilitators and barriers to successful case management implementation in the primary health care setting (49). Results indicated that high intensity case management was necessary and sufficient to produce positive clinical outcomes for patients and to optimize service use. The reviewers described high intensity case management as 1) a caseload of less than 50 patients per full-time equivalence, 2) regular meetings with the informal caregiver and the patient with at least 50% of these meetings being face to face, 3) education on health conditions, 4) close contact with family physicians, and 5) proactive and timely follow-up with patients during hospitalizations and short-term institutionalizations (49).

### **Case management in the Netherlands**

In the Netherlands, various models of case management are implemented. These differ with respect to how services are delivered and by whom, the training provided to its staff and the means of financing. In the COMPAS study (Case management of dementia patients and their caregivers), the two most prominent Dutch case management models, the intensive case management model and the linkage model, are compared with care in regions where there was no access to case management (control group) and with each other (51). The linkage model (LM) is a collaboration between multiple care providers (e.g. home care organizations, general practitioners, social care services) who were already providing health care services in the region and who then were given the

mandate to initiate case management services. After a formal diagnosis, persons with dementia are connected to a case manager who provides educational, emotional and practical support such as advice on disease-related issues and recommends supportive health and social services until time of nursing home admission or death of the patient. In general, caregivers are involved in this process whenever possible. Expert advice can be sought through multidisciplinary meetings held regularly with experts from the various collaborating organizations.

Case managers in the Intensive Case Management Model (ICMM) are appointed to one organization which is specialized in dementia care. They guide and support people with dementia for long periods of time mostly starting after diagnosis, and offer medical and psychosocial services from within their organization (52). The case manager, all registered nurses, works in collaboration with an 'in-home' multidisciplinary team to tailor care needs of the person with dementia and the informal caregiver (52).

The control group was recruited in areas without access to a case manager (53). In some cases, care may be monitored by a registered nurse working in the general practice in addition to the general practitioner. However, in these regions no central coordination of dementia care is provided by a specific health care professional which is in contrast with case management regions. Care is usually initiated by the patient, his /her informal caregiver or a health care provider involved in the care for the patient dependent on local service configuration. Access to home or respite care did not differ across regions.

### **Contents of thesis**

The main focus of this thesis is to evaluate the clinical and economic effects of case management for people with dementia and their informal caregivers in comparison with no access to case management. In addition, we attempted to understand what crisis is and how it can be approached within the care system. Also, we tried to identify characteristics associated with location of death in people with dementia. Finally, we tried to bring methods for economic evaluations further by investigating different strategies to impute missing cost and effect data.

The thesis consists of three parts;

The **first part** of this thesis explored important turning points in dementia care, i.e. crisis situations and location of death in dementia. A systematic review of the dementia literature was performed to identify crisis definitions and to propose a standardized definition for clinical practice and future research (Chapter 2). In Chapter 3, personal-level characteristics associated with location of death for persons who died of dementia in the Netherlands are identified using data from the 2006 Statistics Netherlands cause of death registry (54).

The **second part** of this thesis focuses on the evaluation of the costs and effects of case management in the Netherlands. The objectives of these chapters were:

1. to describe the design of the COMPAS study that compared two case management care models with no access to case management (Chapter 4).
2. to describe and compare the baseline characteristics of the persons with dementia and their informal caregivers included in the COMPAS study (Chapter 5).
3. to evaluate clinical effects for persons with dementia and their primary informal caregivers over two years between the two case management models and dyads without access to case management (Chapter 6).
4. to elaborate on the costs and cost-effectiveness of two groups receiving different forms of case management and a group with no access to case management for people with dementia and their informal caregiver (Chapter 7).

The objective of the **third part** of this thesis (Chapter 8) was to investigate which multiple imputation strategy was most appropriate to use for missing cost-effectiveness data in pragmatic randomized controlled trials (RCT). This study contributes importantly to the analysis of costs and cost-effectiveness of the current and future studies.

## **Chapter 1:** General Introduction

### *Part 1 Perspectives of dementia*

**Chapter 2:** Reviewing the definition of crisis in dementia care.

**Chapter 3:** The Dutch experience: People with dementia do not die in hospitals.

### *Part 2 The COMPAS study*

**Chapter 4:** Comparing Dutch Case management care models for people with dementia and their caregivers: The design of the COMPAS study.

**Chapter 5:** Two Dutch case-management models for dementia versus GP care: baseline results.

**Chapter 6:** Comparison of clinical outcomes in community dwelling patients with dementia and their informal caregivers with and without case management: two year results of the COMPAS study.

**Chapter 7:** The cost-effectiveness of two forms of case management compared to a control group for persons with dementia and their informal caregivers from a societal perspective.

### *Part 3 Methodological issues: multiple imputation in economic evaluations*

**Chapter 8:** Comparing Multiple Imputation strategies for zero-inflated cost data: which method works best?

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