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Summary in English

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

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”(1). It provides pro-active care coordinated by a case manager, often a registered nurse, who is supported by a multidisciplinary team of health care professionals (e.g. general practitioner, psychologist, psychiatrist, geriatrician, elderly care physician or neurologist). In dementia care, the case manager is often introduced after the diagnosis of dementia and remains with the family until institutionalization. Case managers are often confronted with different types of crisis situations and assist in decisions on what is best for the person with dementia and the informal caregiver. This thesis attempts to follow the path of the case manager by trying to understand what a crisis is, which characteristics are associated with location of death and what impact case management has on informal caregivers and persons with dementia.

In **Chapter 1** the progression of dementia, crisis, clinical and economic consequences of dementia and the need to improve outcomes for the persons with dementia and the informal caregivers are outlined. The rationale for case management and the use of case management in the Netherlands is also introduced as a possible solution to ameliorate outcomes. The outline of the thesis concludes chapter 1.

The **first part** of this thesis explores issues of dementia care using meta-data. We evaluated the construct of crisis using a systematic review and the personal-level characteristics associated with location of death in dementia through analysing the Dutch cause of death registry from Statistics Netherlands. In **Chapter 2** we defined crisis as “*a process where there is a stressor(s) that causes an imbalance requiring an immediate decision which leads to a desired outcome and therefore crisis resolution. If the crisis is not resolved, the cycle continues.*” We proposed an operational framework to standardize the definition of crisis based on the perspectives and key features from the literature. Figure 1 represents the full process of crisis in dementia. Dynamic proportions within circles represent the burden and time input for the different perspectives potentially involved. The proportions change to represent the individual situation in a crisis process. Stressor(s) can be psychological, medical, social or environmental change that causes a shift in an individual’s homeostasis. The imbalance represents the resulting state of fragility from the severe breakdown in homeostasis. Immediate decisions aim to regain homeostasis. Resolution equals equilibrium, otherwise the crisis is unresolved.

In **Chapter 3** we estimated, based on data from the Dutch registry of death certificates that of people who had dementia listed as a cause of death 707 (4%) persons died at home, 756 (4%) in a hospital and 16,351 (92%) in a LTCF (of which 14,692, (90%) in a nursing home and 1,659 (10%) in an elderly care home). Age, marital status, living status and income were all associated with place of death in this study. A year before death, over half of the population with dementia-related deaths were still living at home. Only 12% of the demented population was ever hospitalized the year before death, which is low compared to countries like the United States or the United Kingdom (2,3).

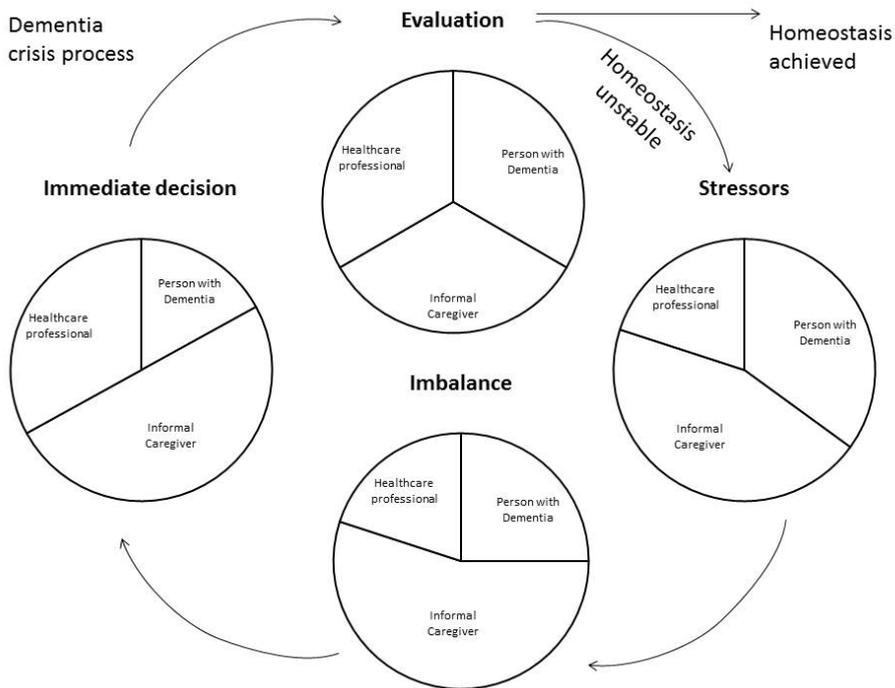


Figure 5 | Operational framework for crisis and retrieving a new equilibrium in dementia care.

In the **second part** of the thesis we followed informal caregivers and persons with dementia for two years to evaluate general health of the caregiver and neuropsychiatric symptoms of the person with dementia in addition to a large set of secondary outcomes to assess whether case management models versus no case management (control) models was associated with positive effects. In this two year study, we collected information on clinical outcomes in patients and caregivers, resource utilization data of patients and quality of life information from patients and informal caregivers to evaluate case management models versus no case management from a societal perspective.

In **Chapter 4** we described the design of the COMPAS study. The interventions were: case management provided within one care organization (intensive case management, ICMM), case management where multiple case management organizations are present within one region (Linkage model, LM), and a group with no access to case management (control). This was a prospective, observational, controlled, cohort study among persons with dementia and their primary informal caregiver in regions of the Netherlands with and without case management. Inclusion criteria for the study were: community-dwelling individuals with a dementia diagnosis who were not terminally-ill or anticipate admission to a nursing home within 6 months and with an informal caregiver who spoke fluent Dutch. Dyads of persons with dementia and their informal caregivers were to be followed for two years. The primary outcome measure was the Neuropsychiatric Inventory for the people

with dementia and the General Health Questionnaire for their caregivers. Secondary outcomes included: quality of life and needs assessment in both persons with dementia and caregivers, activity of daily living, competence of care, and number of crises. We planned to take a societal perspective to the economic evaluation using cost diaries.

In **Chapter 5**, we evaluated baseline characteristics of the people ($n= 521$ dyads) who were recruited into the COMPAS study and gave cross-sectional information on outcomes used in the study among groups as well as for the group as a whole. Mean age of persons with dementia was 80 years (range 54-97), and 55% were female. Mean age of informal caregivers was 65 (range 22-91), and 67% were female. Time in case management was 2.1 years (Interquartile range (IQR): 1.3-3.1) in the intensive case management model and 1.7 years (IQR:0.42-2.5) in the linkage model (Mann-Whitney $U=4.4$, $P<0.0001$). Persons with dementia in case management were more likely to be older, female, single, with lower education and had greater multi-morbidity than those in the control group ($n=521$). Median Neuropsychiatric Inventory (NPI) scores were 13 (IQR: 5 - 25) for intensive case management, 17 (IQR: 8 - 28) for linkage and 10.5 (IQR: 4.5 - 23.5) for the general practitioner model. Distribution of NPI scores was found to differ between the three models (Kruskal-Wallis $\chi^2 (2, 513) =7.146$, $p=0.03$). Despite overall significance of the Kruskal Wallis test, post-hoc comparisons using Mann-Whitney test and bonferroni correction for multiple testing did not show significant differences in the NPI score distributions between any pair of models. There were no differences in general health (GHQ-12) between informal caregivers with and without case management. Persons with dementia in case management appeared more vulnerable than those cared for only by a general practitioner, based on higher total NPI scores, increased age, living alone and presence of multi-morbidity.

In **Chapter 6** we investigated whether persons with dementia and their primary informal caregivers benefitted from either of the two case management models compared with dyads without access to case management. We found no differences in primary outcomes but secondary outcomes showed the possibility of positive effects of case management compared to no case management. Total, met and unmet care needs were less in the ICMM group compared to the control group. Total met needs were less in the LM group versus the control group. This indicates that the control group had more needs overall than the intensive case management group. Mean utility scores for the informal caregiver were 0.02 points per year higher in the ICMM more than the LM group (95%CI -0.01- -0.04, p -value=0.0012). In **Chapter 7**, the costs and cost-effectiveness of two different forms of case management and no access to case management for people with dementia and their informal caregiver were evaluated. We found that informal costs were lower in the intensive case management group compared to the linkage form of case management as well as compared to the control group. This study provides preliminary evidence that the IC model is cost-effective compared to groups without access to case management and the LM model. However, the findings should be interpreted with caution since this study was not a randomized controlled trial.

In the **third part** of the thesis, we evaluated different multiple imputation strategies and complete case analysis and found that in **Chapter 8** for all rates of missing data, multiple imputation strategies performed better than Complete Case Analysis (CCA). The results of the CCA, multiple imputation-predictive mean matching (MI-PMM) and the two-step MI were all influenced by the amount of missing data. With a larger amount of missing data, the Log MI-PMM deviated the least from the RA for the cost difference, cost standard error, Incremental Net Benefit and its standard error, and the probability that the co-prescribed heroin treatment was cost effective in comparison with methadone maintenance at a willingness to pay of 30,000 euros per QALY. Therefore, the Log MI-PMM is considered most appropriate to impute missing cost and effect data. However, when considering QALYs the MI-PMM performed best since it deviated the least from the Reference Analysis with increasing amounts of missing data.

CONCLUSION

The first part of the thesis reviewed the definition of crisis in the context of dementia care. A review of the literature in dementia care indicated that the definition of a crisis is idiosyncratic. Therefore, it is difficult to prevent or plan for all crises. We used an operational framework to compile types of crisis stressors and to consider recommendations from the crisis literature based on three different perspectives; namely, the person with dementia, the caregiver, and the healthcare providers. Based on data from Statistics Netherlands, we looked at personal-level characteristics associated with location of death for persons with dementia. Most people with dementia as one of the causes of death, died in a long care facility suggesting that most acute care in severely demented persons is handled within long-term care facilities. Presently, less people are admitted into long-term care facilities therefore, more people are expected to remain at home for the duration of the person's life. Considering our results, future studies should investigate whether this leads to an increase in people with dementia dying in hospital as a result of crisis situations at home in the final stages.

The second part of this thesis focussed on the COMPAS study. We found that there were no differences among the two case management groups, and persons with no case management in primary outcomes. The analysis of the secondary outcomes indicated positive effects in the Intensive Case management as compared to the other two groups. This warrants further research. The COMPAS study provided preliminary evidence that the ICMM is cost-effective compared to groups without access to case management and the LM. However, the findings should be interpreted with caution since this study was not a randomized controlled trial.

The objective of the **last part** of the thesis was to investigate which multiple imputation strategy was most appropriate to use for missing cost-effectiveness data in pragmatic randomized controlled trials (RCT). We recommend the use of the Log multiple-predictive mean matching with its ease to use and its reliable results related to increased amounts of missing data. Log MI-PMM also appears to perform well for zero-inflated data providing a constant is used in place of the zero in the data.

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