Network-based care for people with dementia: a complex transition

Anke Richters
Network-based care for people with dementia: a complex transition

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door

Anke Richters
geboren op 12 februari 1990
te Mill

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Network-based care for people with dementia: a complex transition

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Chapter 1

Introduction
INTRODUCTION

Over time, health care needs of populations change as a result of demographic and societal changes, incidences and prevalences of different types of diseases, environmental factors and health care policy. In order to meet the population’s needs, it is pivotal for health care systems to adapt to the changing needs of the population to be served. In middle and high income countries, the centre of gravity has shifted from single episodic diseases to high prevalence of chronic conditions with multiple increased severity episodes and multimorbidity, specifically among older persons. Meanwhile health care budgets have become and still are becoming more deficient. One of the major contemporary issues therefore is the challenge of achieving a high quality yet sustainable healthcare system that is capable of accommodating to the needs of such populations. Primary care is essential in achieving an effective and efficient healthcare system. It is usually the first contact of a patient with professional healthcare and functions as a gatekeeper and central hub that allows patients access to other health and social services and coordinates care.

Persons with dementia pose an illustrative example of the challenges posed on primary care as they form a population with progressive but very divergent disease courses, in many cases combined with other (chronic) conditions. As a result, their care needs are diverse and more often than not highly complex, involving various care providers.

Within the Dutch health care system (and similar systems such as those in Canada, Australia, UK, Germany), care is provided by three main domains: medical disciplines (e.g. general practice, geriatrics/elderly care), care disciplines (e.g. community nursing, case management), and social or welfare disciplines (e.g. social workers, respite care workers). The multitude of involved parties is further extended to the financial system underlying primary dementia care and the health care system. Various schemes with health care insurance companies and regional governments are in place to finance the different types of care.

Currently, various documents are available as guidelines for primary dementia care, both general (e.g. Zorgstandaard Dementie) and discipline-specific (e.g. NHG richtlijn dementie), as well as a national agreement for collaboration between the general practice and home care and elderly care physicians (LESA guideline on dementia). Despite their availability, conformity with these guidelines is low in many care professionals and even within the context of these guidelines, there is still a lot of space for organizations and individual professionals to arrange care in specific ways. Therefore, primary dementia care on a local level is the complex product of national, regional and local policies, and additionally of initiatives undertaken by the locally acting professionals and existing facilities. As a result, local care is highly variable and often suboptimal throughout the Netherlands. For instance, case management, playing a central role in primary dementia care, is offered in many shapes and forms throughout the Netherlands, with some forms yielding better outcomes than others. Commonly encountered shortcomings include fragmentation and lack of coordination between various care providers, lack of dementia-specific expertise and low levels of collaboration.

Several national and international attempts have been made to improve primary dementia care, with divergent results. For instance, initiatives have been undertaken to improve (early) diagnosis of dementia, to increase dementia-specific knowledge, and to organise casemanagement. When improvement efforts are undertaken without desired effects, this can have several possible explanations. Of course the improvement effort in itself may be marginally effective or even ineffective. An alternative explanation could be that there has not been used an appropriate implementation
strategy. Additionally, the research design applied to document effectiveness may have failed to capture the desired effect when it indeed did occur. This can happen because the research focuses on inappropriate outcomes, has a time span that does not fit the effects to be achieved, or has a design that does not allow for desired effects to be observed in full. Lastly, it should be taken into account that desired effects may be different for various stakeholders.

It is difficult to disentangle potential reasons why repeatedly dementia care improvement initiatives have not led to the health care system that satisfactorily meets the goals of most stakeholders (e.g. care providers, insurers, policymakers), including the patients with dementia and their caregivers. A general characteristic of the failing innovations however is that they did not sufficiently take into account the massive complexity of dementia care and its context within health care as a whole. This issue of complexity, which is also partly intertwined with the above mentioned reasons, is likely to play a major role in the problem of ineffective improvement efforts.

Complexity and Evidence-Based Health Care

Although shortcomings of primary dementia care may be identified rather easily, the solutions are hardly ever straightforward. Primary dementia care on its own can be represented as what is called a complex system, embedded in the even larger complex total health care infrastructure (see Box 1.1). When actions are undertaken in a complex system, the outcome will be dependent on the other conditions present or changing in the system as well as a stochastic factor. This makes the effects of initiatives to improve primary dementia care unpredictable to a certain extent and difficult to attribute to specific elements of interventions.

The complexity of the primary dementia care system underlines the necessity for the rigorous study of new programs. It is widely recognized and has been convincingly argued by Frenk et al., that "scientific evidence must be the guiding light in the design, implementation and evaluation of programs and policies". Earlier research evaluating interventions in primary dementia care have not yet led to the improvements needed to deal with the huge societal challenges ahead (e.g. aging, increasing single subject households, lack of health care professionals). In this complex system, it might be necessary to aim at a system-wide change, instead of focusing on improving only individual aspects of the system while leaving the rest unchanged.

Therefore, a network-based approach to primary dementia by the name of DementiaNet care has been developed. This approach incorporates several elements that have shown their value in the past, such as the integration of health and social services. The DementiaNet innovations is based on the following four principles: network-based care, clinical leadership, quality improvement cycles, and interprofessional education, both to increase dementia-specific expertise and to bridge the gaps between disciplines.

In order to study the effectiveness of primary dementia care innovations or policies such as DementiaNet, one first needs to set out the framework of the study, i.e. the research design. Historically, medical and health care research was primarily focused on questions regarding the effectiveness of single-component clinical interventions and thus relied on tools and methods grounded in linear models of cause and effect. Over decades, a shift has become apparent towards research in which the subject of study much more often is an initiatives or policy of greater complexity. However, the development of frameworks and approaches for research addressing these initiatives and policies is lagging behind. This causes researchers to still largely apply conservative research designs (i.e. randomized controlled trials) to more contemporary research questions. The Medical Research Council Frameworks for developing and evaluating complex interventions mark some milestones in proceeding towards more appropriate study designs, although much more is to gain in this area.
Systems, entities with interrelated and interdependent parts, can be categorized as simple, complicated, complex or chaotic systems. This depends on the number and level of parts in the system and their interrelatedness, resulting in how knowable and predictable they are. Complex systems are characterised by the following features:  

- Multiple components at various levels (e.g. numerous care professionals, organisations and governing structures involved in primary dementia care);
- Dynamic interrelations between components (e.g. behaviours of certain professionals influence behaviours of others);
- Adaptive abilities (e.g. the system is able to adjust behaviours in response to changes in health care policies);
- Stochasticity and uncertainty (e.g. actions and reactions of components are sometimes results of chance rather than a sum of factors in the system);
- Feedback mechanisms (e.g. adequate communication between professionals leading to fulfilling care provision and satisfaction, further stimulating adequate communication);
- Emergence of patterns (e.g. the emergence of communication patterns).

These characteristics lead to the fact that any input into the system results in an output that is not only dependent on the input but also on all other conditions present in the system. In addition, input often leads to changes the system itself, leaving the system in a permanent dynamic state.

**Aim of this thesis**

This thesis aims to introduce and evaluate the DementiaNet innovation as a potential answer to the above mentioned challenges to our health care system and to describe the study into the effectiveness of the DementiaNet innovation. Secondly, it aims to improve knowledge on the prerequisites for the rigorous studying of such innovations.

This thesis includes a plea for alternative study designs, such as the case study design, for which the DementiaNet study could be an illustrative example of strengths and limitations. Considerations for such designs are more elaborately discussed in the last part of this thesis.

Second, once an appropriate research design is defined, one needs to operationalize key variables in the analysis, and ensure sufficiently valid and reliable measurement instruments for those. The severity of dementia is often an indispensable variable in clinical research and primary care research alike. Dementia severity is not routinely assessed and registered in primary care. Yet, it is usually the informal caregiver who knows the patient best and has the most accurate indication of symptoms of the patient. Nevertheless, no measurement instruments exist that deliberately focuses on the knowledge and experiences of the informal caregiver to assess dementia severity. Therefore, in the first part this thesis describes work on an instrument – the IDEAL instrument which is modified for informal caregivers – to fill this gap. Furthermore, another measurement instrument – the informal caregiver perseverance time – is reviewed for its psychometric properties in order to assess its usability in primary dementia care research. This instrument goes beyond the measurement of just burden of the caregiver by incorporating the capacity to cope with the burden and might therefore be an interesting addition to existing instruments.

Together, these instruments and the case study design are applied in the effectiveness study of DementiaNet, which as mentioned earlier was devel-
oped as an answer to a large number of external challenges. Building on the literature that emphasizes the necessity of rigorous study designs to adequately evaluate programs and policies with high complexity\cite{16}, an evaluation study was conducted in conjunction with the implementation of the DementiaNet program.

The overall research questions addressed in this thesis are:

**Preparatory studies**
- What are the relevant psychometric properties of the IDEAL instrument for informal caregivers and the Perseverance time question in the setting of primary dementia care?

**Evaluation study of DementiaNet**
- What are the strengths and weaknesses of a multiple case study design to study programs such as DementiaNet?
- What is the effectiveness of DementiaNet and what further lessons can be drawn from this study?

**Outline of this thesis**
After this general introduction, Part 1 zooms in on some prerequisites for primary dementia care research, focusing on measurement instruments and research design. Chapter 2 provides background on the use of non-experimental research designs when evaluating complex programs or policies. In Chapter 3, the development and psychometric properties of the International Dementia Alliance Schedule for Informal Caregivers are described. Chapter 4 and 5 review the reliability and validity of the informal caregiver Perseverance time instrument. Part 2 discusses the work carried out in relation to the DementiaNet program, where the topics of Part 1 were put to work. Chapter 6 first describes the development and background of this program. Chapter 7 continues to outline the DementiaNet effectiveness study. Chapter 8 reports on the findings of this effectiveness study. In Chapter 9, the major findings of this thesis are summarized and discussed, with subsequent implications and recommendations for research, practice and policy.
1. Organization WH. The world health report 2008: Primary health care - now more than ever.


It was six men of Indostan,
To learning much inclined,
Who went to see the Elephant
(Though all of them were blind),
That each by observation
Might satisfy his mind.

Chapter 2

Quasi-experimental study designs: making a case for non-experimental designs in the spectrum

TO THE EDITOR:

In their contribution to the series on quasi-experimental studies, Frenk and Gómez-Dantés\(^1\) stated that “scientific evidence must be the guiding light in the design, implementation and evaluation of programs and policies,” and that “experiments and quasi-experiments do not stand in competition but can clearly enhance each other in generating causal knowledge.”

We would like to argue that their statement extends also to studies outside the scope of experimental and quasi-experimental designs, such as case study methodologies. Rather than trying to answer whether a program or policy works or not, these methods help to understand what works for whom under which circumstances. In many circumstances, the latter aspect provides vital information. When intervening in the setting of complex health care systems, there are several reasons to opt for such designs, which we will illustrate with an example.

In England, summary care records (SCRs) were introduced in 2007 in the context of the National Health Service.\(^2\) This is an illustrative example of a policy change that is complex in nature, with numerous stakeholders and various interdependent tasks required from multiple care professionals.

The investigators opted for a longitudinal mixed method case study instead of an experiment with control group. This study provided rich insight, not only into the implementation of the policy, but also into the impact it has on various scale outcomes as well as experiences from stakeholders. The report clearly shows how changes in a complex system such as health care may lead to impacts that were quite unpredicted in advance (e.g., longer consultation time instead of shorter) and why it is vital to take a broad scope to obtain a complete overview of impacts. Time trends in the quantitative results showed divergent levels of SCR use. Complementing these by qualitative results explaining these differences helped to identify factors to improve SCR chances for successful impact. In complex systems such as primary care, the information that reflects contextual factors on which successful implementation and effectiveness depend is essential. Studies such as these therefore provide very useful and meaningful evidence that may not be obtained through more conventional (quasi-) experimental designs.

Based on the progress the field has made in the evaluation of intervention in complex systems, we wholeheartedly agree with Greenhalgh et al. that a “debate on the applicability of the epidemiological hierarchy of evidence to studies of complex change in health care” is much desired.\(^3\) To conclude, when case study designs and other nonexperimental types of evaluation methods are precisely and rigorously designed and executed, they can yield highly valuable evidence that may carry much more relevance than experimental designs alone.

References

Chapter 3

The International Dementia Alliance Instrument for feasible and valid staging of individuals with dementia by informal caregivers

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The First approach'd the Elephant,
And happening to fall
Against his broad and sturdy side,
At once began to bawl:
"God bless me! but the Elephant
Is very like a wall!"
ABSTRACT

Objectives
To assess the feasibility and validity of the International Dementia Alliance (IDEAL) instrument for Informal Caregivers (IDEAL-IC), which is based on the IDEAL instrument for professionals (IDEAL-P), for staging individuals with dementia.

Design
Cross-sectional.

Setting
Memory clinic of a university hospital.

Participants
Informal caregivers of 73 community-dwelling elderly adults referred to a memory clinic and six geriatric registrars.

Measurements
Caregivers completed the IDEAL-IC; physicians completed the original IDEAL-P and the Clinical Dementia Rating sum of boxes (CDR-SB). Missing items and floor and ceiling effects were reviewed to assess feasibility. To test construct validity, a priori hypotheses were defined for expected correlations between IDEAL-IC, IDEAL-P, and CDR-SB scores.

Results
Seventy-three IDEAL-IC instruments were completed, 86% of which had no missing items. Three percent of all 730 individual items were missing. No floor or ceiling effects were detected. CDR scores were 0 in 7%, 0.5 in 33%, 1 in 27%, 2 in 10%, and unknown in 23%. IDEAL-IC scores correlated highly with IDEAL-P scores (correlation coefficient ($r$) = 0.70) and with CDR-SB scores ($r$ = 0.65) as expected; the difference between these two correlations was smaller than expected. Agreement between IDEAL-IC and IDEAL-P scores was 34% within a range of 1 point difference on 36-point scales, 57% within a range of two points, and 81% within a range of five points. Correlation between IDEAL-P and CDR-SB was very high ($r$ = 0.85).

Conclusion
Results of this study indicate good feasibility and high validity of staging dementia by informal caregivers using the IDEAL-IC.
BACKGROUND

Staging of dementia is an important step in care and research for people with dementia. Two problems can be encountered in this process: the scope and the person performing staging. Existing and commonly used staging instruments such as the Clinical Dementia Rating Scale (CDR) mainly focus on severity of cognitive and behavioral decline.\(^1\)\(^2\) This might be appropriate for clinical settings, but in primary care, an alternative approach that takes a broader perspective might be more relevant. For example, it is important to take the care needs and social system surrounding the individuals with dementia into account, together with the severity of the condition itself. This yields a more comprehensive reflection of the complexity of the disease's effect on the individual as a whole instead of merely the condition.

In societies in which healthcare organization is changed to increase empowerment of individuals with dementia and informal caregivers to enhance autonomy and cost-effectiveness, informal caregivers will increasingly become the persons with most valid and detailed information to stage dementia and progression of the person they care for. In contrast, physician, who first must obtain this information with tests or from the individual with dementia and informal caregivers to complete the available staging instruments, rather than informal caregivers doing so directly.\(^3\)\(^4\)

The rating by the informal caregiver most accurately takes the care recipient's social context into account. Also, using informal caregivers' information by letting them complete the staging instrument pre-empts the extensive care recipient–professional contact and thus is less laborious and more easily applicable in nonclinical settings. Furthermore, it would facilitate the combination of collecting staging information together with self-reported outcomes in research.\(^5\)

The International Dementia Alliance (IDEAL) study group recently developed the professionally directed IDEAL staging instrument.\(^6\) An important advantage of this instrument for professionals is that it focuses on the individual with his or her context as a whole, taking into account informal and formal care needs. The purpose of this instrument is to determine dementia stage from a broad perspective, including the individual's social context, and to monitor dementia progression, including evaluation of interventions in regular care and dementia research settings. Application opportunities of this instrument would increase substantially if informal caregivers could use it in addition to healthcare professionals.

Therefore, the aim of this study was to transform the original IDEAL instrument for professionals (IDEAL-P) into a version suitable for completion by informal caregivers (IDEAL-IC) and to evaluate the feasibility and construct validity of the IDEAL-IC to determine the complexity of individuals with dementia.
Chapter 3 — The International Dementia Alliance Instrument for feasible and valid staging of individuals with dementia by informal caregivers

METHODS

Study Design
The psychometric properties of the IDEAL-IC were investigated in a cross-sectional study performed in accordance with the COSMIN taxonomy and guidelines. The medical ethical committee of Radboud University Medical Center (CMO Arnhem-Nijmegen) stated that no formal evaluation by a medical ethical committee was necessary according to Dutch law and that written informed consent was not required (Reference 2015–2053).

Original Instrument for Professionals: IDEAL-P
The IDEAL-P measures a construct called “complexity of the individual with dementia,” which has been described as “the severity of symptoms and related disease burden for the patient and caregiver and the dementia-related need for healthcare services and informal care.” This means that not merely the disease is staged, but also disease severity within the context of the individual and its effect on formal and informal care needs. This construct is measured using a formative model in which the construct is the result of the items, called causal indicators.

The instrument and its development and validation have been described in further detail elsewhere. In short, the IDEAL-P is a 10-item instrument with seven dimensions (activities of daily living, physical health, cognitive functioning, behavioral symptoms, social support, nonprofessional care (two items), professional care (three items)). Each item has anchors (reference points) and is rated on a 6-point scale from 0 to 5. Scores per dimension are the score of the item for dimensions with one item and the average of the item scores for dimensions with multiple items. The sum score is the sum of the seven dimension scores and ranges from 0 to 35, with higher scores indicating disease progression. In sum, the IDEAL-P had adequate face, content, and construct validity and reliability; was easy to use without prior extensive training; and was usable in clinical practice.

Transformation for Completion by Informal Caregivers: IDEAL-IC
To make the IDEAL instrument suitable for completion by informal caregivers, the original Dutch IDEAL-P was modified into the IDEAL-IC. Jargon was replaced with language understandable to laymen. Additional information was provided in the IDEAL-IC version for activities of daily living, physical health, cognitive functioning, social support, behavioral symptoms, and caregiver distress to explain the items, including examples for the extreme anchors. The modified version was piloted for ease of understanding in a group of five informal caregivers and revised accordingly by rephrasing. Item content, scoring options, and calculation of sum scores of the IDEAL-IC remained identical to those of the original IDEAL.

Participants
Informal caregivers of consecutive individuals visiting the outpatient memory clinic of Radboud university medical center for diagnostic examination of dementia from February to June 2015 were recruited for this study. Appointments were made with one of the six registrars in geriatric medicine who recruited participants for this study. Data collection continued until at least 50 complete cases were obtained.

Data Collection
During the memory clinic visit, the physician asked the informal caregiver of the care recipient to fill out the questionnaire. They completed a questionnaire that gathered information about demographic characteristics of the care recipient and themselves and the IDEAL-IC. The physicians were instructed to complete the IDEAL-P and the CDR independently of the outcomes of the IDEAL-IC.
Chapter 3 — The International Dementia Alliance Instrument for feasible and valid staging of individuals with dementia by informal caregivers

The CDR was used because it is the best-evidenced staging instrument for dementia, which consists of six items with five scoring options per item. It yields a global score (0, 0.5, 1, 2, 3) that uses single item scores based on an algorithm and a sum of boxes score (CDR-SB), which is the sum of each score on the individual items. In this study, the CDR-SB was used for analyses, because this is considered to be a more detailed quantification than the overall score and provides more information in individuals with mild dementia, who make up a large proportion of the target population. The CDR-SB has shown adequate reliability and validity. The global CDR score is used to describe the study population.

Analyses

Feasibility was assessed based on the percentage of completed instruments with no missing values. Floor and ceiling effects were considered to be present if more than 15% of respondents achieved the lowest or highest possible score.

Testing of a priori defined hypotheses was performed to assess construct validity of the IDEAL-IC. To assess linear relations, the sum scores for the IDEAL-P, IDEAL-IC and CDR-SOB were calculated, and then Pearson correlation coefficients (r) with 95% confidence intervals were calculated between these scores. No sum score was calculated when one of the items was missing for the particular instrument. Strength of correlation coefficients was interpreted according to the following cut-off values: less than 0.1, trivial; 0.1 to 0.3, small; 0.3 to 0.5, moderate; 0.5 to 0.7, high; 0.7 to 0.9, very high; greater than 0.9, nearly perfect.

The following hypotheses were established a priori: the correlation between the IDEAL-IC and the IDEAL-P is high to very high, and relative agreement (<5 points difference in score) should be greater than 75%; IDEAL-IC scores correlate moderately to highly with CDR-SB scores; correlation between the IDEAL-IC and IDEAL-P is higher than correlation between the IDEAL-IC and the CDR-SB, with a difference of at least 0.1; and correlation between the IDEAL-P and the CDR-SB is very high and should reproduce the correlation found in the original article on the development of the IDEAL-P. All formulated hypotheses were expected to have a positive direction.

Agreement between IDEAL-IC and IDEAL-P was measured using the limits of agreement (LoA). The differences between professional and informal caregiver scores were plotted in a Bland–Altman plot against the mean score of each pair. LoA were calculated using the mean difference per instrument (d) and the standard deviation (SD) of the mean difference (LoA = d ± 1.96*SD_d), indicating the values between which 95% of all differences fall. The agreement within a less-than-1-, less-than-2-, and less-than-5-point difference in score was calculated as a proportion of all observations.

Correlations between single items of the IDEAL-IC and IDEAL-P were also calculated using Spearman correlation (because these data are ordinally distributed). Subgroup analyses were performed on correlations between the sum scores of IDEAL-IC and IDEAL-P to see whether there were differences between groups of informal caregivers based on their relationship to the care recipient (spouse vs other).
Chapter 3 — The International Dementia Alliance Instrument for feasible and valid staging of individuals with dementia by informal caregivers

RESULTS

Care Recipients and Informal Caregivers
In total, 73 informal caregivers were included in the study. In 11 cases, the physician was unable to complete the questionnaire for practical or logistic reasons or time constraints. Characteristic of care recipients and informal caregivers are shown in Table 3.1. Global CDR scores were 0 (no dementia) in 6.9% of cases, 0.5 in 32.9%, 1 in 27.4%, 2 in 9.6%, and unknown in 23.3%. Care recipients had mean scores standard deviation of 4.5 ± 3.7 on the CDR-SB and 10.3 ± 5.5 on the IDEAL-P.

Table 3.1 — Care Recipient and Caregiver (N=73) Characteristics

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<tr>
<th>Care recipient</th>
<th>Value</th>
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<tr>
<td>Female, n (%)</td>
<td>32 (43.8)</td>
</tr>
<tr>
<td>Age, mean ± SD</td>
<td>74.2 ± 9.8</td>
</tr>
<tr>
<td>Clinical Dementia Rating global score, n (%)</td>
<td></td>
</tr>
<tr>
<td>0 (no dementia)</td>
<td>5 (6.9)</td>
</tr>
<tr>
<td>0.5 (very mild dementia)</td>
<td>24 (32.9)</td>
</tr>
<tr>
<td>1 (mild dementia)</td>
<td>20 (27.4)</td>
</tr>
<tr>
<td>2 (moderate dementia)</td>
<td>7 (9.6)</td>
</tr>
<tr>
<td>Unknown</td>
<td>17 (23.3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, n (%)</td>
<td>49 (68.1)</td>
</tr>
<tr>
<td>Age, mean ± SD</td>
<td>62.7 ± 14.8</td>
</tr>
<tr>
<td>Living with care recipient, n (%)</td>
<td>39 (54.2)</td>
</tr>
<tr>
<td>Relation to care recipient, n (%)</td>
<td></td>
</tr>
<tr>
<td>Partner</td>
<td>41 (56.2)</td>
</tr>
<tr>
<td>Child or child in law</td>
<td>25 (34.3)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (9.6)</td>
</tr>
</tbody>
</table>

SD = standard deviation.

Feasibility
Of 73 completed, 63 (86.3%) IDEAL-IC instruments had no missing values. Of all single items (total 730; 10 per instrument), missing values were reported on 3.0%. Six items had no missing values at all; missing values were reported only on care domains. None of the informal caregivers reported the lowest or highest possible score, indicating that there were no floor or ceiling effects.

Validity
Correlation between the IDEAL-P and the IDEAL-IC was very high ($r = 0.70, 95\% CI = 0.52–0.81; n = 52$), confirming the first hypothesis. The Bland–Altman plot (Figure 3.1) shows the agreement between IDEAL-IC and IDEAL-P sum scores. The LoA were 8.9 and 8.9 on the 36-point scales. Relative agreement with a maximal difference of one point between scores of professionals and informal caregivers was found in 34% of the observations, two points in 57%, and five points in 81%. The correlation between the IDEAL-IC and CDR-SB was high ($r = 0.65, 95\% CI = 0.45–0.79; n = 50$), confirming the second hypothesis. The second correlation was higher than the first one mentioned above but with a difference of only 0.05, so the third hypothesis was not satisfied. Correlation between IDEAL-P and CDR-SB was very high ($r = 0.84, 95\% CI = 0.73–0.90; n = 58$), confirming the high correlation found earlier and supporting the construct validity of the original IDEAL-P.

Scores on individual items of the professional version and the informal caregiver version correlated highly ($\rho$ between 0.50–0.70), except for the item social support ($\rho=0.33$).

There was no statistically significant difference in correlation between IDEAL-IC and IDEAL-P scores between informal caregivers who were care recipient spouses ($r = 0.56$) and other informal caregivers ($r = 0.72$; difference $P = .37$).
DISCUSSION

This study demonstrated good feasibility and validity of the adapted version of the IDEAL instrument to facilitate staging of dementia by informal caregivers. No floor or ceiling effects were found, and high correlations of scores from staging by informal caregivers with those from professionals indicate high validity.

Feasibility was shown to be high, with 87% of the IDEAL-IC having no missing values and no floor or ceiling effects observed. The overall percentage of individual missing items was very low. All missing items concerned items related to care, and most of the missing values were on the item about type of dementia-related care. The selection of the population might explain this; some individuals visiting the memory clinic were still in the diagnostic process and had not received a formal diagnosis of dementia. The fact that the majority of the observations with missing values on this item were obtained from care recipients with low IDEAL-P and CDR-SB scores might suggest that the informal caregivers regarded the dementia-specific item as inapplicable.

The construct validity of the IDEAL-IC was very good. The sum scores on the IDEAL-IC and the original IDEAL-P correlated very highly with each other. Adequate agreement between scores of informal caregivers and professionals were achieved. The negligible systematic difference shows that informal caregivers do not systematically score lower or higher on this instrument than do professionals, indicating that staging by either one would result in comparable outcomes. Correlation between the IDEAL-IC and the CDR-SB was also high. The difference between these two correlations was in the hypothesized direction but slightly lower than expected. The sum scores of the IDEAL-IC and the CDR-SB show more overlap than
expected because multiple items overlap on content, but the IDEAL-IC still provides additional information on the care recipient’s care needs on the individual items. In the article on the development of the IDEAL instrument, a high correlation with the CDR was found. The current study confirmed this with the CDR-SB, supporting the validity of the original instrument.

This study has strengths and limitations. The first strength is that modification of the IDEAL was first piloted in the target group to ensure readability and comprehensibility. Furthermore, informal caregivers were included to test each hypothesis on at least 50 observations to ensure sufficient power for reliable estimates as stated by the COSMIN group. Additionally, adequate distributions over the range of possible scores were realized, increasing external validity of the study results. No statistical difference was found based on subgroups of informal caregivers, which should be interpreted as indicative rather than confirmative because of lower statistical power, but point estimates of the correlations suggest that partners and non-partners were adequate at staging the care recipient because each subgroup confirmed the hypothesized correlation between IDEAL-IC and IDEAL-P scores. A possible limitation of the study is that some care recipients had not received a formal diagnosis of dementia. (For five persons, it was concluded that they did not have dementia.) Most visited the memory clinic for treatment management, but some visited to receive a diagnostic examination. Nevertheless, agreement between professionals and informal caregivers were adequate along the whole range of IDEAL scores, showing that staging by informal caregivers is also valid in this subgroup.

Seven (9.6%) care recipients had global CDR scores of 2, and none were classified with a CDR score of 3, resulting in a population with mostly mild dementia. Nevertheless, the population represented individuals targeted within primary care because the majority of individuals with a CDR score of 3 have been institutionalized. It would be of interest to investigate whether these conclusions are also applicable in individuals with more severe dementia.

The IDEAL-P and IDEAL-IC are intentionally short, easy-to-use tools that do not require prior training and can be used for various purposes in research and care settings. The IDEAL-IC has the added benefit of the possibility of obtaining this information independent of a care professional or trained researcher. This is particularly useful when information is needed on community-dwelling individuals with dementia, because they may have less extensive contact with care professionals. An additional strength is that the rating by the informal caregiver most accurately takes the care recipient’s social context into account. Moreover, the IDEAL-IC might be cost effective, which Western societies with high healthcare expenditures and middle and low income countries would profit from.

The construct to be measured using the IDEAL is not merely the individual’s disease severity, but also the total complexity of the individuals as reflected by disease manifestations, the system surrounding the individual, and care needs. This is an innovative approach to staging individuals with dementia in terms of the aspects considered in the staging process. Staging by informal caregivers is novel in the context of dementia and has great advantages over staging by physicians. Making use of the information that is already at hand for informal caregivers pre-empts availability of a physician with information about the care recipient and direct contact between them. Therefore, further evaluation of psychometric properties of both versions of the IDEAL is worthwhile. In line with the COSMIN guidelines, after assessment of validity, the next step would be to investigate the reliability of the instruments. If application in longitudinal or evaluative settings is desirable, then assessment of responsiveness is advised.
Chapter 3 — The International Dementia Alliance Instrument for feasible and valid staging of individuals with dementia by informal caregivers

Conclusion
The adapted version of the IDEAL instrument for informal caregivers has good feasibility and concurrent and construct validity. It is an easy, valid method for staging individuals with dementia by informal caregivers in clinical practice and research.

Acknowledgements
The authors wish to thank the informal caregivers and physicians for participating in this study.

References
Chapter 4

Perseverance time of informal caregivers for institutionalized elderly: construct validity and test-retest reliability of a single-question instrument

TO THE EDITOR:

Because both the relative proportion of elderly and longevity in Western populations are steadily increasing, while health care resources remain limited, societal dependency on informal care will grow. The impact of providing informal care should be taken into account when designing research or policy regarding structure and provision of health care services. Currently, most studies monitoring the effect of providing care on the informal caregiver use instruments focusing on the burden of caregiving. Yet, the capacity of caregivers to cope with a specific burden varies greatly, for instance as a result of the caregiver’s age, health, or social context. Consequently, although the burden of caregiving might be similar, it might result in different impact on caregivers with different coping capacities.

For studies evaluating effects of interventions for patients or caregivers, it is useful to be able to assess how long caregivers can maintain the informal care situation. Although this is only partially explained by the perceived burden of it, most instruments still solely address this aspect and leave out the capacity to cope. In contrast, a recently introduced instrument called Perseverance time integrates the aspect of perceived burden with the caregiver’s capacity to cope with the burden. This instrument includes 1 question by which the informal caregiver is asked to indicate the time he or she will be able to continue providing care under a hypothetically stable situation with 6 ordered answering categories (<1 week; 1 week–1 month; 1–6 months; 6 months–1 year; 1–2 years; >2 years). This new instrument is interesting to use as a caregiver-reported outcome, as it is short, simple, and intuitive and might pose added value over existing instruments because of the more comprehensive underlying construct. Validation steps thus far have shown positive results, but have been restricted to the population of informal caregivers for community-dwelling patients with dementia. Because informal care for institutionalized elderly often differs with respect to tasks and degree of involvement, this instrument might function differently in this group of informal caregivers. Therefore, we assessed the construct validity and test-retest reliability of the Perseverance time instrument in a population of informal caregivers for elderly nursing home residents with psycho-geriatric and somatic indications.

We made use of data from an earlier study among informal caregivers of a single nursing home in the Netherlands. This study used Perseverance time with 5 answering categories, in which the lowest 2 categories were merged. Data were obtained from 104 informal caregivers using a paper questionnaire, which was completed twice with a median interval of 7 days (Q1–Q3 = 2–9 days). For the current study, construct validity was assessed with a hypothesis-testing approach by means of Spearman correlations between Perseverance time categories and related measures, including care-related quality of life in terms of well-being (CarerQol-7D tariff and CarerQol visual analog scale [VAS]), subjective burden of informal care (Self-Rated Burden), and care situation (VAS score) from the first measurement. As these are related but different constructs, we expected correlations to be of moderate strength. Test-retest reliability was assessed in those respondents who were still caring for one of the residents (7 excluded) and reported no change in care situation (17 excluded), by calculating Cohen weighted kappa between both measurements. This statistic describes the reliability between the 2 measurements in terms of agreement, in which disagreement in adjacent categories is penalized less than disagreement in categories farther apart by applying linearly increasing weights to disagreement.

The characteristics of informal caregivers are described in Table 4.1, together with the Perseverance time scores. Perseverance time scores at first measurement correlated moderately with CarerQol-7D, CarerQol-VAS, SRB, and care situation VAS scores in expected directions, with Spearman coefficients of 0.44, 0.36, −0.27, and 0.43, respectively (all P < .02). Linear weighted kappa was 0.61 (95% confidence interval 0.46–0.75). The maximum obtain-
able linear weighted kappa was 0.68, given the observed marginal frequencies. Thus, the observed kappa was 90% of the maximum possible kappa.

These results indicate adequate construct validity and test-reliability of the Perseverance time instrument in informal caregivers of elderly nursing home residents. Researchers can use these findings to support their choice regarding the suitability of the Perseverance time instrument in studies within similar populations. It should, however, be kept in mind that, although the sample size provides sufficient power according to COSMIN guidelines, the study sample was limited to informal caregivers from a single nursing home.

The Perseverance time instrument is a useful addition to existing instruments because it takes into account not only the burden of informal care, but also the ability of the informal caregiver to cope with this burden. In addition, it is an easy-to-use instrument, as it is a single question combined with intuitive interpretation. Given the current and previous findings, this instrument seems promising for use in research setting. For future research, it would be worthwhile to consider more subpopulations of informal caregivers and to assess other aspects of this instrument’s psychometric properties. If current findings are confirmed, Perseverance time could additionally be a useful screening instrument in clinical practice, for example for early detection of crises and timely intervention.

Acknowledgments
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---

Table 4.1 — Characteristics of care recipient and caregiver (n=104)

<table>
<thead>
<tr>
<th>Care recipient</th>
<th>Distribution of characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y, mean (SD)</td>
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<td>Female, %</td>
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<table>
<thead>
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<th>Distribution of characteristics</th>
</tr>
</thead>
<tbody>
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<td>Female, %</td>
<td>75</td>
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<table>
<thead>
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<th>Relationship to care recipient, %</th>
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</thead>
<tbody>
<tr>
<td>Child</td>
</tr>
<tr>
<td>Partner</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perseverance time, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 month</td>
</tr>
<tr>
<td>1 – 6 months</td>
</tr>
<tr>
<td>6 months – 1 year</td>
</tr>
<tr>
<td>1 – 2 years</td>
</tr>
<tr>
<td>&gt;2 years</td>
</tr>
</tbody>
</table>
Chapter 4 — Perseverance time of informal caregivers for institutionalized elderly: construct validity and test-retest reliability of a single-question instrument

References


7. Cohen J. Weighted kappa: nominal scale agreement with provision for scaled disagreement or partial credit. Psychol Bull 1968;70(4).

Chapter 5

Perseverance time of informal caregivers for people with dementia: construct validity, responsiveness and predictive validity


The Third approach'd the animal,
And happening to take
The squirming trunk within his hands,
Thus boldly up and spake:
"I see," —quoth he— "the Elephant
Is very like a snake!"
ABSTRACT

Background
Informal care is essential for many people with dementia (PwD), but it often results in a considerable burden for the caregiver. The perseverance time instrument integrates the aspect of perceived burden with the caregiver’s capacity to cope with the burden, in contrast to most available instruments, which measure solely the burden of caregiving. The aim of this study was to extend insight into psychometric properties of the perseverance time instrument, specifically the construct validity, responsiveness, and predictive validity, within the population of informal caregivers for PwD.

Methods
Data from two studies among informal caregivers of community-dwelling PwD in the Netherlands were used. The first study included 198 caregivers from a single region in the Netherlands and lasted 1 year. The second was a cross-sectional nationwide study with 166 caregivers for PwD. Questionnaires of both studies included questions regarding demographics and informal care, perseverance time, and other informal caregiver outcomes (Caregiver Strain Index, Self-rated Burden scale, Care-related Quality of Life instrument, and visual analogue scale health scores). Construct validity and responsiveness were assessed using a hypothesis-testing approach. The predictive validity of demographic characteristics and perseverance time for living situation after 1 year (living at home, institutionalized, or deceased) was assessed with multivariable multinomial regression.

Results
All but one of the hypotheses regarding construct validity were met. Three of five hypotheses regarding responsiveness were met. Perseverance time scores at baseline were associated with living situation after 1 year (p<0.01), unlike age, sex, and relationship with PwD. Perseverance time strongly increased predictive power for living situation after 1 year (c-index between 0.671 and 0.775) in addition to demographic characteristics.

Conclusions
This study supports previous findings regarding the construct validity of the perseverance time instrument and adds new evidence of good construct validity, responsiveness, and predictive validity. The predictive power of perseverance time scores for living situation exceeds the predictive power of other burden measures and indicates informal care as an important factor for maintaining the patient at home.
BACKGROUND

Informal care, which is nonprofessional care provided by people from a person’s social environment, is a large and crucial part of all necessary care for people with dementia (PwD), and it is usually provided by a partner or child. As in most other developed countries, the vast majority of Dutch PwD live at home, evidencing the great demand for informal care. As the number of PwD is projected to rise substantially and demands on health care resources increase, it is becoming increasingly important to maintain adequate informal care to uphold quality care for community-dwelling PwD.

Hence, it is of utmost importance that those willing and able to provide informal care for a loved one with dementia can maintain the care situation for as long as possible. However, providing this care often comes with a considerable burden. Their ability to maintain their caregiver role depends on their perceived burden as well as on their capacity to cope with this burden. This means that the burden of care has to be acceptable, given the physical, emotional, social, and financial capacities of the informal caregiver. Although the balance between burden and capacity to cope is crucial for maintaining informal care, the majority of informal care instruments assess solely the burden of care, from either an objective (hours spent on care) or a subjective (perceived burden) perspective.

The recently introduced perseverance time instrument integrates the aspects of perceived burden and ability to cope, and thus potentially provides valuable information to health care professionals and researchers about caregivers’ ability to maintain informal care. This instrument consists of one question that asks the informal caregiver to indicate the time she or he will be able to continue providing care under a hypothetically stable situation. Although earlier validation steps have been carried out and shown to have promising results (construct validity has been tested in a single population), more information is desirable before widespread application. For example, the instrument has not been thoroughly assessed for responsiveness and predictive validity. Therefore, the aim of this study was to extend construct validity assessment to a broader population and to investigate the responsiveness and predictive validity.
Chapter 5 — Perseverance time of informal caregivers for people with dementia: construct validity, responsiveness and predictive validity

METHODS

Data
Individual participant data of two questionnaire studies were used. The first dataset was derived from a longitudinal study (study A) of 198 informal caregivers of community-dwelling PwD, with paper questionnaires sent to their home addresses at baseline and after 1 year to be completed independently. Informal caregivers were approached through a regional assessment agency with a registry of diagnosed PwD. This study was specifically set up to validate the perseverance time instrument. The second dataset was obtained from a cross-sectional study (study B) in which an online questionnaire, also to be completed independently, was sent to a sample representative of adults in the Netherlands in terms of age and sex. A total of 1244 informal caregivers responded, 166 of whom reported providing informal care to a community-dwelling PwD and were selected for the present research. The subsequent selection of dementia informal caregivers is not necessarily representative of dementia informal caregivers in the Netherlands. We cannot analyze the selection mechanisms at play, because no information on the nonresponders is available, either for the whole group or for the subgroups of people who provided informal care for a PwD. However, no specific selection was applied by the researchers. Recruitment of informal caregivers for study A took place between September 2007 and March 2008, after which the caregivers were included in longitudinal data collection, and data collection of study B took place in October 2010.

 Measures
Demographic characteristics of caregivers and PwD they cared for included age, sex, relationship (child, partner, or other), and duration of informal care. In addition, the questionnaires included various measures of caregiver outcomes. Perseverance time measures the time for which a caregiver will be able to continue providing care if the caregiving situation remains as it currently is, and it includes six ordered answering categories: <1 week, 1 week–1 month, 1–6 months, 6 months–1 year, 1–2 years, and >2 years. The Care-related Quality of Life (CareQol) instrument measures care-related quality of life and consists of the CareQol-7D and the CarerQol-visual analogue scale (VAS). The CarerQol-7D comprises two positive and five negative dimensions of care-related burden to which caregivers can respond regarding their experience with the level score “no,” “some,” or “a lot.” A summary score reflecting care-related quality of life can be obtained by applying a tariff derived from the Dutch general population to each scoring option. The CarerQol-VAS is a score tallied using a VAS representing caregiver’s general level of happiness (range 0–100, where higher scores reflect greater happiness). The Self-rated Burden scale (SRB) is an overall assessment of care burden with a single VAS (range 0–100, where higher scores indicate higher burden). The Caregiver Strain Index (CSI) assesses the caregiver’s negative caregiving experiences with 13 propositions to which the caregiver can indicate if the statements apply to their situation (yes/no; score range 0–13, where higher scores indicate higher burden). The objective burden was quantified as the average of hours per week spent on providing informal care, which is the sum of multiple informal care tasks (e.g., personal care, instrumental activities of daily living tasks, health care visits). Two additional VAS scores were included for the overall perceived health of the informal caregiver and of the PwD as rated by the caregiver (range from 0 for “worst imaginable health” to 10 for “best imaginable health”).

Statistical analysis
For analysis of construct validity, data from study A (baseline data) and study B were analyzed both separately and conjointly using a meta-analytic approach. To assess construct validity of perseverance time (i.e., the degree to which scores are consistent with hypotheses), we employed a hypothesis-testing approach with correlations between perseverance time and the other instruments. Hypotheses were constructed on the basis of the
Chapter 5 — Perseverance time of informal caregivers for people with dementia: construct validity, responsiveness and predictive validity

The notion that perseverance time is an integral reflection of perceived burden of care and capacity to cope with this burden. CarerQol-7D, CSI, and SRB (all measuring subjective burden) were expected to be at least moderately to highly related with perseverance time. The measure of objective burden (less closely related) and CarerQol-VAS (a more general assessment of happiness) were both expected to be slightly more weakly associated. Health of the informal caregiver was thought to be related to the capacity to cope with burden and was thus expected to be associated. Health of the PwD was expected to be unrelated to the capacity to cope with the burden of the informal caregiver, because it is believed that this aspect relies mainly on intrinsic factors of the informal caregiver. Furthermore, health of the PwD is largely suboptimal in this patient group because it concerns elderly people who have dementia but often also comorbidities. It is expected that these health deficits may be partially associated with actual informal care tasks, which are only partially associated with perceived burden of the informal caregiver. Because this indirect association with only one aspect of the perseverance time construct, we expected negligible correlation between health of the PwD with perseverance time. Together, this resulted in the following hypothesized Spearman's correlations, using the guidelines for strength described by Hopkins:\textsuperscript{14} CarerQol-7D tariff (positive, moderate/strong correlation), CarerQol-VAS (positive, moderate), SRB (negative, moderate/strong), CSI (negative, moderate/strong), objective burden (negative, moderate), and VAS scores on health of informal caregiver (positive, weak/moderate) and health of PwD (no correlation). Random effects meta-correlations allowing for heterogeneity between both studies were calculated in the pooled dataset.\textsuperscript{15}

Responsiveness (also referred to as longitudinal validity)—that is, the degree to which changes in scores over time are consistent with hypotheses—\textsuperscript{16} was assessed within study A. For informal caregivers who were included in both baseline and follow-up questionnaires (n = 74)\textsuperscript{5}, changes in scores over time were calculated. Hypotheses regarded correlations of 1-year change in perseverance time with CarerQol-VAS score, SRB, CSI, caregiver health VAS score, and objective informal care burden, and correlations were expected to be weak to moderate.

Predictive validity of baseline perseverance time regarding living situation of PwD (living at home, institutionalized, or deceased) after 1 year was assessed by means of three multinomial models. The lower three categories of perseverance time (<1 week, 1 week–1 month, and 1–6 months) were combined in these models because these were too few in number to separately provide sufficient power for the analysis (n = 0, n = 12, and n = 29, respectively). First, basic characteristics (age, sex, and relationship of informal caregiver and PwD) were selected as explanatory variables for living situation of PwD after 1 year. Second, a model was constructed with only perseverance time as an explanatory variable. Third, variables in these models were combined to assess the added value of perseverance time over basic characteristics. Last, SRB, CSI, and CarerQol-7D scores were added iteratively, instead of perseverance time, to the basic characteristics to compare the added predictive value of perseverance time relative to other burden measures. Predictive validity of these models was assessed through pairwise c-statistics between each couple of outcome categories and compared between models.\textsuperscript{17} Analyses were conducted in SAS version 9.2 (SAS Institute, Cary, NC, USA) and R 3.1.1 (packages meta and nnet; R Foundation for Statistical Computing, Vienna, Austria) software.
RESULTS

Study populations
The characteristics of the study populations are shown in Table 5.1. In both populations, the majority of informal caregivers were women. In study B, informal caregivers were more often children of PwD, whereas study A included mostly partners, hence the higher average age and higher proportion living with PwD.

Construct validity and responsiveness
In study A, correlations were moderate to strong and statistically significant between perseverance time score and CarerQol-7D and CarerQol-VAS, SRB, and CSI (Table 5.2), and correlations were weak with objective burden and informal caregiver VAS health score. There was no significant correlation with PwD VAS health score. Data from study B showed similar results, except for correlation with informal caregiver VAS health score (not significant). Meta-correlations showed no relevant differences between both study populations, except for a significantly higher correlation with SRB in study A. All hypotheses were met, except for informal caregiver VAS health score, which was lower than expected.

Change scores for perseverance time over 1 year of follow-up showed significant correlations only with the change scores on CarerQol-VAS, SRB, and CSI, and not with objective burden and VAS health scores of PwD and informal caregivers (Table 5.2). The observed correlations were weak to moderate.

Predictive validity
Overall, 37% of PwD still lived at home 1 year after baseline measurement, 41% were institutionalized, and 21% were deceased. Proportions still living at home increased considerably over the increasing categories of perseverance time at baseline, from 8% for the answer category less than 1 month to 51% for the answer category more than 2 years (p<0.001). The opposite was true for institutionalization, ranging from 67% in the lowest category to 30% in the highest.

The multivariable multinomial model without perseverance time showed that none of the basic characteristics were statistically associated with higher risk of either institutionalization or death, nor did any show strong effect estimates (Table 5.3). They jointly yielded very limited predictive value for living situation, as indicated by the pairwise c-indices (0.611–0.639). In contrast, perseverance time alone was significantly associated with higher risk of both institutionalization and death. When perseverance time was added to the model with basic characteristics, only perseverance time was statistically associated with higher risk of institutionalization and death and strongly increased predictive value (c-indices 0.671–0.775). When perseverance time was replaced with CSI, SRB, or CarerQol-7D, none of these measures yielded as great an increase in predictive value as perseverance time (highest c-indices obtained by CSI 0.62–0.73).
Table 5.1 — Characteristics of informal caregivers and persons with dementia

<table>
<thead>
<tr>
<th></th>
<th>Study A N=198</th>
<th>Study B N=166</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver</strong></td>
<td></td>
<td></td>
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<tr>
<td>Gender, female, %</td>
<td>67</td>
<td>55</td>
</tr>
<tr>
<td>Age, years, mean (SD)</td>
<td>66.6 (12.9)</td>
<td>49.5 (14.4)</td>
</tr>
<tr>
<td>Resides with person with dementia, %</td>
<td>59</td>
<td>17</td>
</tr>
<tr>
<td>Duration of informal caregiving, years</td>
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<tr>
<td>0</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>27%</td>
<td>Median (IQR):</td>
</tr>
<tr>
<td>2</td>
<td>28%</td>
<td>3 (1-5)</td>
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<tr>
<td>3</td>
<td>18%</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td>5 or more</td>
<td>15%</td>
<td></td>
</tr>
<tr>
<td>Informal care in hours/week, median (IQR)</td>
<td>20 (8-50)</td>
<td>8 (5-18)</td>
</tr>
<tr>
<td>Relationship with person with dementia, %</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse or partner</td>
<td>55</td>
<td>7</td>
</tr>
<tr>
<td>Child</td>
<td>37</td>
<td>54</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>40</td>
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<tr>
<td>Perseverance time, %</td>
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<tr>
<td>Less than 1 month</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
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<td>11</td>
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<td>13</td>
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<td>More than a year, less than 2 years</td>
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<td>13</td>
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<td>More than 2 years</td>
<td>40</td>
<td>54</td>
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<td>CarerQol-7D tariff, mean (SD)</td>
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<td>75.2 (28.4)</td>
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<td>CarerQol-VAS, mean (SD)</td>
<td>6.4 (1.8)</td>
<td>7.0 (1.7)</td>
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<td>CSI, median (IQR)</td>
<td>8 (6-10)</td>
<td>5 (2-7)</td>
</tr>
<tr>
<td>SRB, mean (SD)</td>
<td>6.0 (2.2)</td>
<td>4.8 (2.3)</td>
</tr>
<tr>
<td>Health VAS score, mean (SD)</td>
<td>7.3 (1.6)</td>
<td>7.3 (1.7)</td>
</tr>
</tbody>
</table>

**Person with dementia**

|                     |               |               |
| Gender, female, %   | 53            | 73            |
| Age, years, mean (SD) | 81.3 (6.6)   | 76.6 (17.8)  |
| Health VAS score, mean (SD) | 5.8 (1.9) | 5.4 (2.8)    |

CarerQol-7D score ranges from 0 to 100, with higher scores indicating favorable situation; CarerQol-VAS score ranges from 0 to 10, with higher scores indicating favorable situation; CSI score ranges from 0 to 18, with lower scores indicating favorable situation; SRB score ranges from 0 to 10, with lower scores indicating favorable situation; and VAS health score ranges from 0 to 10, with higher scores indicating favorable situation. The category “Other” in relationship includes other family members, friends, neighbors and acquaintances. Abbreviations: CarerQol Care-related Quality of Life instrument, CSI Caregiver Strain Index, SRB Self-Rated Burden scale, VAS Visual Analogue Scale

**DISCUSSION**

The results of this study with multiple datasets and comprehensive assessment in a longitudinal setting support previous findings regarding the construct validity of the perseverance time instrument. The present study adds new evidence of good construct, responsiveness, and predictive validity. The results show adequate construct validity based on two separate study populations of informal caregivers for PwD as well as a pooled population of community-dwelling PwD. Moreover, we found moderate to good responsiveness. Analyses also showed considerably higher predictive value by perseverance time of living situation after 1 year than for basic characteristics such as age, sex, and relationship, as well as other burden measures, indicating high predictive validity.

Construct validity was assessed by testing hypotheses regarding correlations between perseverance time and other related constructs, based on the assumption that perseverance time incorporates subjective burden and capacity to cope with the burden. Earlier findings regarding the construct validity were promising. This study adds to the evidence of high construct validity by supporting these previous findings in a new study. Furthermore, we were able to pool data from two previous studies, resulting in a more divergent population, with one of the study populations selected from among the general population. Although both populations concerned informal caregivers of community-dwelling PwD, characteristics showed that the care situation was slightly more burdensome in study A than in study B, possibly resulting from selection source (registry of formal help for dementia), and the relationship and residence with the PwD were also differently distributed. In general, the partner is the primary informal caregiver for the PwD and is usually of older age, like the PwD. The fact that study B used an online questionnaire to recruit informal caregivers may have resulted in selection...
of more informal caregivers who were younger, because these individuals are more likely to regularly use computers and take part in online questionnaires. This is indeed supported by the difference in informal caregiver characteristics between study A and study B, with study B consisting of, on average, younger informal caregivers, with a smaller proportion being the PwD’s partner. This provides more importance to the analysis performed regarding construct validity. Nevertheless, despite the divergence between both study populations, construct validity was equally well upheld in both studies, indicating a wide range of application opportunities. Study B was initiated in a sample representative of the adult population in the Netherlands in terms of age and sex. Owing to the selection of only informal caregivers for PwD among those who responded, the resulting study population might not be representative of all adult informal caregivers for PwD in the Netherlands. However, the major characteristics that may be relevant for this particular study population are well described in this study. Furthermore, unlike studies with prevalence estimates, for instance, the exact representativeness of the study population is less relevant for a validation study, because it is highly unlikely that the instrument will function differently in slightly different populations of informal caregivers for PwD. study B, with study B consisting of, on average, younger informal caregivers, with a smaller proportion being the PwD’s partner. This provides more importance to the analysis performed regarding construct validity. Nevertheless, despite the divergence between both study populations, construct validity was equally well upheld in both studies, indicating a wide range of application opportunities. Study B was initiated in a sample representative of the adult population in the Netherlands in terms of age and sex. Owing to the selection of only informal caregivers for PwD among those who responded, the resulting study population might not be representative of all adult informal caregivers for PwD in the Netherlands. However, the major characteristics that may be relevant for this particular study population are well described in this study. Furthermore, unlike studies with prevalence estimates, for instance, the exact representativeness of the study population is less relevant for a validation study, because it is highly unlikely that the instrument will function differently in slightly different populations of informal caregivers for PwD.

The responsiveness of the perseverance time instrument had not been assessed before. Because application of this instrument is especially suitable in a research setting of a progressive disease, it is particularly useful to know whether the instrument accurately reflects changes over time, such as in the setting of use of the instrument or the longitudinal effects of determinants. Our results show that constructs that are theoretically the furthest from perseverance time indeed were not significantly correlated to change scores for perseverance time. This was in line with our expectations because there is already an expected deviation among scores as constructs only partially overlap. When looking at change scores, this deviation was expected to become even larger because different but related constructs do not necessarily change in the same direction and the same magnitude over time within a person. The fact that change in perseverance time significantly correlated with the subjective burden measures of CSI and SRB as well as the CarerQol-VAS indicates that perseverance time is sensitive to changes over time, supporting its use in longitudinal settings. It must be kept in mind that statistical power to show significant correlations in this analysis was impaired by the fact that there were only 74 observations, and the majority of informal caregivers reported no change in perseverance time, resulting in little dispersion on which to base correlation.

In an earlier study using the same data, researchers looked at the percentages of informal caregivers who anticipated the perseverance time correctly by considering whether the patient still lived at home after 1 year. This gave some first indications of predictive validity, which was further complemented in the present study by employing more sophisticated methods. First, the alternatives to the situation of living at home (i.e., being institutionalized or deceased) were separated by employing multinomial models because perseverance time may be differently associated with each of these alternatives. Second, we did not dichotomize indicated perseverance time as being more or less than 1 year, but instead kept separate answer categories in the analyses. Last, we additionally provided insight in the predictive value of
perseverance time for predicting the three separate outcomes by calculating pairwise c-statistics.

Our results show that a longer indicated perseverance time was associated with higher risk of both institutionalization and death of PwD after 1 year. This indicates that perseverance time predicted institutionalization and death. Interestingly, it showed that this single-question instrument had high accuracy in predicting PwD who still lived at home after 1 year and those who were institutionalized or deceased. This was even the case in addition to known characteristics (age and sex of PwD and informal caregiver and their relationship), unlike other perceived burden measures. This indicates that the perseverance time instrument indeed measures a construct that transcends perceived burden. We have now assessed the predictive value of perseverance time scores for the events of institutionalization and death to underscore the predictive validity of the instrument as such. Additional studies are required to assess the added value of other potentially useful predictors for these events, such as severity of dementia. Which other predictors are relevant is largely dependent on the setting of the research or, as in the case of the present study, which information is readily available.

On the basis of the present and previous findings, it is clear that the perseverance time instrument validly reflects the construct to be measured (i.e., an integration of burden of informal care with the capacity to cope with the burden). This short and easy-to-use instrument therefore constitutes a strong and valuable tool in care and research on informal caregiving for PwD. However, because validity is dependent on aspects such as setting and population, and not a characteristic belonging to the instrument itself, further validation in other caregiving settings and populations is recommended.

**Conclusions**

The results of this study with multiple datasets and comprehensive assessment in a longitudinal setting support previous findings regarding the construct validity of the perseverance time instrument. This study adds new evidence of good construct validity, responsiveness, and predictive validity. The predictive power of perseverance time scores for living situation exceeds the predictive power of other burden measures and indicates informal care as an important factor for maintaining the patient at home.

<table>
<thead>
<tr>
<th>Table 5.2 — Correlation of Perseverance time with related measures for assessment of construct validity and responsiveness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Construct validity</strong></td>
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<tr>
<td></td>
</tr>
<tr>
<td>CSI</td>
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<tr>
<td>SRB</td>
</tr>
<tr>
<td>CarerQol-7D</td>
</tr>
<tr>
<td>CarerQol-VAS</td>
</tr>
<tr>
<td>Objective burden</td>
</tr>
<tr>
<td>Health VAS (IC)</td>
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<tr>
<td>Health VAS (PwD)</td>
</tr>
</tbody>
</table>

**Abbreviations:** CarerQol Care-related Quality of Life instrument, VAS Visual Analogue Scale, IC Informal Caregiver, PwD Person with Dementia, SRB Self-Rated Burden, CSI Caregiver Strain Index, N/A Not Applicable, because these measures were not included in the follow-up measurement

\(\ast\) Correlations between actual scores

\(\ast\) Correlations between change scores over time. Change in perseverance time was used as a positive or negative difference in number of ordered answering categories between follow-up and baseline. Change in other scores is used as continuous difference between follow-up and baseline

\(p < 0.05; \ast p < 0.01\)
Table 5.3 — Multivariable multinomial regression models to assess predictive validity of Perseverance time (data from study A)

<table>
<thead>
<tr>
<th>Basic characteristics</th>
<th>OR institutionalization</th>
<th>OR deceased</th>
<th>Perseverance time</th>
<th>OR institutionalization</th>
<th>OR deceased</th>
<th>Basic characteristics and Perseverance time</th>
<th>OR institutionalization</th>
<th>OR deceased</th>
</tr>
</thead>
<tbody>
<tr>
<td>PwD sex</td>
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<td></td>
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<tr>
<td>Male</td>
<td>Reference</td>
<td>Reference</td>
<td>-</td>
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<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
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<tr>
<td>Female</td>
<td>0.76 (0.31-1.91)</td>
<td>1.29 (0.42-3.99)</td>
<td>-</td>
<td>-</td>
<td>0.79 (0.30-2.09)</td>
<td>1.28 (0.41-4.03)</td>
<td></td>
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<tr>
<td>Informal caregiver sex</td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
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<td>Reference</td>
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<tr>
<td>Female</td>
<td>0.93 (0.38-2.29)</td>
<td>0.66 (0.28-2.09)</td>
<td>-</td>
<td>-</td>
<td>1.01 (0.39-2.65)</td>
<td>0.71 (0.22-2.33)</td>
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<tr>
<td>PwD age</td>
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<td></td>
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<tr>
<td>Per year</td>
<td>1.05 (0.99-1.12)</td>
<td>1.06 (0.97-1.15)</td>
<td>-</td>
<td>-</td>
<td>1.03 (0.96-1.10)</td>
<td>1.04 (0.96-1.13)</td>
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<tr>
<td>Informal caregiver age</td>
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<tr>
<td>Per year</td>
<td>0.98 (0.93-1.04)</td>
<td>0.97 (0.91-1.04)</td>
<td>-</td>
<td>-</td>
<td>0.99 (0.94-1.05)</td>
<td>0.97 (0.92-1.05)</td>
<td></td>
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<tr>
<td>Relationship with PwD</td>
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<tr>
<td>Partner</td>
<td>Reference</td>
<td>Reference</td>
<td>-</td>
<td>-</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
<td>Reference</td>
</tr>
<tr>
<td>Child</td>
<td>1.19 (0.25-5.74)</td>
<td>0.66 (0.09-4.61)</td>
<td>-</td>
<td>-</td>
<td>2.39 (0.43-13.18)</td>
<td>1.06 (0.14-8.21)</td>
<td></td>
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<tr>
<td>Other</td>
<td>1.22 (0.27-5.53)</td>
<td>0.55 (0.06-4.88)</td>
<td>-</td>
<td>-</td>
<td>2.40 (0.45-12.02)</td>
<td>0.80 (0.09-7.49)</td>
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<tr>
<td>Perseverance time</td>
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<tr>
<td>&lt;6 months</td>
<td>-</td>
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<td>Reference</td>
<td>Reference</td>
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<td>Reference</td>
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<tr>
<td>6-12 months</td>
<td>-</td>
<td>-</td>
<td>0.37 (0.54-0.72)</td>
<td>0.28 (0.89-1.52)</td>
<td>0.16 (0.84-0.68)</td>
<td>0.32 (0.08-1.36)</td>
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<tr>
<td>1-2 years</td>
<td>-</td>
<td>-</td>
<td>0.13 (0.04-0.43)</td>
<td>0.12 (0.03-0.59)</td>
<td>0.08 (0.02-0.31)</td>
<td>0.12 (0.03-0.56)</td>
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<tr>
<td>&gt;2 years</td>
<td>-</td>
<td>-</td>
<td>0.15 (0.03-0.29)</td>
<td>0.09 (0.04-0.55)</td>
<td>0.06 (0.02-0.21)</td>
<td>0.14 (0.04-0.54)</td>
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<tr>
<td>C-index</td>
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<tr>
<td>Home vs. institutionalization</td>
<td>0.639</td>
<td>0.689</td>
<td>0.775</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home vs. deceased</td>
<td>0.611</td>
<td>0.659</td>
<td>0.717</td>
<td></td>
<td></td>
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<tr>
<td>institutionalization vs. deceased</td>
<td>0.631</td>
<td>0.571</td>
<td>0.672</td>
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PwD: Person with Dementia; OR: odds ratio
References


Chapter 6

Triple aim improvement for individuals, services and society in dementia care: The DementiaNet collaborative care approach

ABSTRACT

Background
A redesigning of primary care is required to meet dementia patients' needs. In the Netherlands, current dementia care still falls short in areas including ad hoc collaboration, lack of feedback on quality to professionals involved, and insufficient implementation of established multidisciplinary guidelines.

Objective
DementiaNet is a collaborative care approach, which aims to reduce the burden of the disease on individuals, healthcare services and society via network-based care that encourages collaboration, enhances knowledge and skills and stimulates quality improvement cycles.

Material and methods
DementiaNet was developed to support primary care networks through implementation of five core processes: network-based care, clinical leadership, quality improvement cycles, interprofessional practice-based training and communication support tools, following a stepwise tailor-made approach. Alongside this, a mixed method study was designed to evaluate innovation and effectiveness.

Results
Currently, 18 networks have been formed. These vary in quality of care and strength of collaboration due to local circumstances. Initial activities and goals of each network also vary, ranging from acquaintance to shared care plans. Ongoing research will identify barriers, facilitators and merits of the approach in increasing quality of care and ultimately improving outcomes for patient, carer, health service and society.

Conclusion
Initial results show that clinical practice varies and the DementiaNet approach can lead to quality improvement. Complexity and variety of local care requires complex interventions and evaluation methods that account for this in order to safeguard the value for practice. Strict methodology lessens external validity.
BRIEF INTRODUCTION

The number of elderly people with cognitive problems who are still living at home is likely to increase. As a result, primary healthcare professionals will be increasingly required to manage and optimize treatment for dementia patients. This underlines the need to improve dementia care within primary care. We developed the DementiaNet collaborative care approach, which includes a gradual reorganization of care towards high-quality, network-based dementia care. The development, implementation, initial experiences and study design are described to evaluate the possible merits of this approach.

SHORTCOMINGS OF CURRENT DEMENTIA CARE

Although many initiatives have recently been designed, collaborative dementia care is still fragmented and far from optimal due to lack of disease-specific expertise and training and limited communication between healthcare professionals. A collaborative approach could be especially important for dementia patients as manifestation of the disease is often complex and complicated by comorbidities, while loss of mental autonomy and disease awareness are specific for this disease, and determine specific care needs. Dementia patients have to cope, not only with dementia, but also with other chronic health and welfare problems. In a large Scottish study, 95% of all dementia patients also had relevant concurrent diseases. Yet, collaboration between healthcare professionals is mainly scheduled ad hoc rather than structurally. This was also apparent in a Dutch study into the effectiveness of post-diagnosis dementia care of memory clinics versus general practitioners conducted in nine memory clinics. In both study arms, the care process was relatively unstructured. Furthermore, care was insufficiently personalized and structured without formal assessment of individual problems and priorities or taking the individual context into account. Personalization should also address informal carers, who are often faced with a high burden. Another limitation to current practice includes the lack of long-term monitoring of symptoms, signs, quality of life, caregiver burden, and feedback on quality of care and cost-effectiveness. To tackle these shortcomings, the DementiaNet approach aims to reduce the burden of the disease for all involved in dementia care, including healthcare professionals, patients and their informal caregivers (quality of life, perseverance time), and societal (cost-effectiveness) impact.
DEVELOPMENT OF DEMENTIANET

DementiaNet functions as an overarching umbrella that facilitates the organization, implementation and maintenance of primary care networks, which are in direct connection with secondary care facilities for dementia. It was designed to support these networks to become an independent, sustainable and interprofessional collaborative, in which members can provide better quality of care and achieve higher effectiveness. Primary care for dementia patients in the Netherlands is characterized by complex social and financial developments. Due to the high societal and economic impact of dementia, the Dutch Government, as many others, aims for high-quality and affordable dementia care. Between 2005 and 2016 changes were instigated through the financing of four successive national dementia and elderly care improvement programs. This created a nationwide regional network structure, deployment of dementia case managers and dissemination of multidisciplinary guidelines; however, incomplete implementation and lack of structural finance caused large variation in the acceptance and adherence to the new guidelines and regulations in clinical practice. Additionally, in 2015, the Dutch Government introduced radical reforms in the financial structure of primary healthcare, resulting in shifting responsibilities for welfare and care from national and regional levels to local governments at municipality level. Responsibility for welfare was transferred to local authorities. General practitioners (GP) act as gatekeepers for medical care and community nurses (CN) determine the amount of nursing care required. Case management is not yet structurally financed; therefore, funding varies between regions and case managers are not available for all dementia patients. This new financial arrangement has created much insecurity for healthcare professionals and institutes, as well as for patients and their carers in primary care practice. The DementiaNet approach was designed taking this healthcare complexity, shifting roles and variety in clinical practice into account. A stepwise, tailor-made and bottom-up approach was chosen. Various stakeholders were consulted in designing DementiaNet. Primary care professionals and representatives of elderly and dementia patients were interviewed on their experiences, barriers and facilitators in dementia care. The theoretical framework underlying DementiaNet includes collaborative network theories, such as the conceptual framework of partnership collaboration, which emphasizes the importance of addressing shared ambitions, mutual gains and relationship dynamics between network participants. We also applied best practice models on quality improvement, including the Improvement Model/Plan-Do-Check-Act (PDCA) and Breakthrough Series Collaborative, and evidence from previously implemented collaboration models, e.g. the ParkinsonNet and Healthy Aging Brain Care model. Finally, experiences from previous primary care network projects were used. For example, as the presence of active clinical leaders emerged as the key to successful implementation, clinical leadership was added as a central theme of DementiaNet.
CENTRAL THEMES

The DementiaNet approach consists of the following five central themes. These core themes form the basis for all DementiaNet networks, as the starting point for a stepwise, tailor-made approach.

**Network-based care**
Each DementiaNet represents a local interprofessional team that includes healthcare professionals from medical, care and social domains e.g. GPs, CNs, dementia case managers (CM), and welfare professionals (WP). A CM supports community-dwelling individuals with dementia and their caregivers during the care process, from the prediagnostic phase to nursing home admission. The CM regularly visits patients at home and coordinates medical and social care. The WPs support patients and carers with participation in the community. They also visit patients at home and organize activities in the community, such as day care activities. Together, these professionals form a network in a local neighborhood, which is characterized by the catchment area of the GP practice. Recent research findings about interprofessional collaboration in primary care support the importance of a team vision, shared goals, formal quality processes, information systems and shared team spirit; therefore, development of collaboration and communication skills including all these aspects and jointly sharing responsibility for improvement of dementia care are key issues.

**Clinical leadership**
In the primary care setting, organizational and personal barriers can hamper collaborative team efforts, for example, lack of trust, absence of shared goals and lack of opportunities to meet. Strong clinical team leadership is important to facilitate low-level redesigning of work, and achieve quality and efficiency improvements; therefore, in each local DementiaNet network, at least one network participant is recruited to lead connection and quality catalysis. This network leader or network connector, must be able to connect the different professionals and stimulate collaboration. As this is a new role for many professionals, we developed a leadership program to provide support to these primary care clinical professionals.

**Quality improvement cycles**
DementiaNet network members are stimulated to use practical tools to enhance quality improvement of dementia care. The process of quality improvement begins with data acquisition to facilitate feedback reports on performance measurements. An online questionnaire is distributed to the network participants. This questionnaire consists of multiple validated instruments, such as team skills, attitudes towards healthcare teams, prerequisites for collaboration and knowledge about dementia. Furthermore, data on quality of care are gathered including a concise set of quality indicators derived from the Dutch multidisciplinary guidelines for dementia care. Benchmarking provides members with insights into their own quality compared to the average quality of care of all participating networks. The network is then encouraged to discuss quality feedback, select a problem for focus, formulate goals and design an action plan, according to the PDCA cycle. This tailor-made approach stimulates a sense of urgency and ownership amongst network members towards improved care.

**Interprofessional practice-based training and learning**
Based on the feedback on quality of local dementia care and the action plan, we support the organization of practice-based interdisciplinary training on topics selected by the network participants. In these training sessions, examples from daily clinical practice are taken, in which complex cases are discussed to ensure integration of knowledge and practice. Teamwork can also be the focus of training sessions, as team competency is important for collaboration, although frequently lacking as healthcare professionals are often not actively taught to cooperate.
Communication
Successful collaboration in practice depends on clear and effective communication between the key disciplinary groups; therefore, communication tools are provided. For example, an electronic communication tool for healthcare professionals and informal caregivers to discuss patient cases and coordinate actions. Additionally, an online community will enable interprofessional communication and networking between different local platforms, and secondarily, more specialized dementia expertise.

STEPWISE DEVELOPMENT OF A DEMENTIANET NETWORK

DementiaNet networks are formed via a stepwise approach. The program for each network is tailored to the members’ own needs and priorities. This tailor-made approach requires the guidance of each DementiaNet team in applying the central themes. Various steps to support the network are undertaken over a 2-year period. As a wide variety of dementia care practice exists between regions, the DementiaNet approach must be adapted to local settings and needs. In some networks, team members already collaborate. Hence, these networks obviously require a different approach than those in which team members have never worked together before. In general, the following three steps are undertaken to form a network and enhance performance:

Step 1: Recruitment of network leaders.
The DementiaNet team organizes training sessions comprised of interprofessional workshops that address the DementiaNet themes. DementiaNet is also promoted in various local, regional and national healthcare meetings and through printed and online publications to encourage professionals to start a network.

Step 2: Network leader forms local network.
If a potential network leader is interested to join the program, the network leader and DementiaNet coordinator assess the local situation together. Detailed insight into actual dementia healthcare provision in that specific community is crucial to optimize connection to other related healthcare initiatives. If the potential network leader can organize a group of interested professionals, preferably from medical, care and social services, the DementiaNet coordinator meets with this potential team to provide information about DementiaNet and gauge support. This step usually takes 3–6 months
and requires the commitment of the potential network leader; it is a first test of the leadership of this individual’s competencies. So far 18 network leaders have succeeded in establishing a DementiaNet network, 10 are still in the process of organizing the network and 17 healthcare professionals were not able to engage other professionals to jointly start a network.

**Step 3: Implementation of the DementiaNet program.**
This step encompasses the implementation of the central themes, according to an action plan with: monitoring of team performance, annual self-assessment of quality of care in the local network and interprofessional and practice-based education to enhance expertise.

Network leaders also join a leadership support program based on the UK National Health Service (NHS) healthcare leadership model. This provides individual coaching and group session workshops to improve personal leadership skills. Regular meetings facilitate long-lasting collaboration and help develop a collaborative view on healthcare through open discussion of task coordination and responsibilities and conflicts of interests. Prerequisites for collaboration and reflections on team performance results are also discussed in local network meetings. During the 2-year program all network members attend interprofessional training workshops, often twice a year. Network members select training topics themselves, for example on recognition of cognitive decline, dementia diagnosis, complex behavioral problems and shared decision making.

**SCIENTIFIC EVALUATION**

An evaluation study provides insight into the possible merits of DementiaNet. The longitudinal mixed methods multiple case study design is in line with evaluation methods used for complex interventions. All DementiaNet networks serve as a case in this study and are followed over time. Quantitative data are collected at baseline and annually and qualitative data are collected throughout the course of the study to gain in-depth knowledge on processes and experiences of people involved i.e. care professionals, patients and informal caregivers. The evaluation study commenced at the start of the first network in January 2015 and will be concluded in the second half of 2017.

From the concept of evidence-based healthcare it follows that local resources should be invested in those programs that have been studied and found to be effective. Regarding novel health care delivery systems, this is of great importance, as innovations occur in complex environments with numerous stakeholders and external influences that make the effects difficult to predict. This high level of complexity also applies to DementiaNet, emphasizing the need for a mixed methods design, especially as the approach is tailored to each network. In addition, innovations such as DementiaNet, are impossible to evaluate before implementation, and so implementation and evaluation occur simultaneously. For this, data are gathered from multiple sources for each network. Firstly, each network is rated on their network-based maturity, based on yearly structured interviews with the network leader(s). The rating is performed based on a Dutch model, The Primary Care Maturity Model, in which the level of network-based functioning is rated as one of four levels on eight domains. Secondly, online questionnaires are completed by network members on instruments, such as team skills and attitude towards dementia. Each network is also requested
to complete a set of quality indicators of care, as described, including indicators related to diagnostics in primary care settings, involvement of case management, geriatric assessment, care plan, polypharmacy check, and emergency consultations. Lastly, paper-based questionnaires are sent to informal caregivers of patients within the network, including instruments to measure quality of life,25-26 caregiver burden,27-29 satisfaction with care,30 and health services utilization. In addition to these data sources, in-depth interviews with care professionals in the networks, as well as informal caregivers and patients are performed to gain more insight into experiences with the DementiaNet approach, identify other possible merits or challenges and to find opportunities to enhance the DementiaNet approach to fit each situation better. We use semi-structured interviews which are transcribed verbatim and subsequently coded independently by two trained researchers after which consensus is obtained to ultimately lead to overarching lessons. Quantitative and qualitative data sources will be combined to reflect on our hypothesis. We hypothesize that network maturity level will change differently for each network, depending on varying baseline situation and improvement actions. We expect that quality of care, as measured by the quality indicators, will be associated with the network maturity and will increase if the network maturity has increased. We also measure informal caregiver reported outcomes; however, we realize that the timeframe of the current evaluation study might be too short to indicate significant effect, especially as these outcomes are indirectly influenced by the organization of networks. From the data, trends are examined over time by means of growth models. Not only are measurements within each network investigated but data between different networks are compared to identify improvement patterns. This is facilitated by natural contrasts between networks, as each baseline level differs and will vary in development during the 2-year course. Qualitative data enables us to explain findings and patterns. Additionally, specific elements of the approach are assessed for effectiveness, including the DementiaNet leadership program and communication between GPs and CNs, as key players within the networks.

INITIAL EXPERIENCES AND RESULTS

The first generation of DementiaNet currently includes 18 networks, distributed throughout the Netherlands. These networks are comprised of an average of 10 care professionals, and range from 5 to 22. The most frequently represented disciplines are GPs, CNs, CMs, and practice nurses. Other disciplines include allied health care professionals, such as physiotherapists and occupational therapists, and welfare professionals. In five networks, volunteers, interested groups or carers of dementia patients participate as team members. In total, the healthcare professionals in these networks provided care for over 278 community-dwelling dementia patients at baseline. As expected, the networks varied considerably regarding their situation on enrolment. Some networks had already worked together intensively for a long time and had already established reasonable levels of collaboration and communication. Of the networks six worked together in a program for complex elderly patients before they entered the DementiaNet program. Contrary, the majority of health care professionals were still focused on getting to know each other and formulating agreements on sharing responsibilities in care processes. This variety between networks is also reflected in the quality indicators, which show a large heterogeneity and indicate that improvements are still needed in several domains.

In general, the PDCA method to design quality improvement cycles is appreciated by healthcare professionals, as it requires them to focus on one or two specific aims at one time, for which they can draw up a concrete action plan. Since these cycles are based on each network’s own goals and priorities, a wide variety of improvement targets were defined, including: improvement of collaborative skills, increase knowledge on management of behavioral changes, implementation of shared care plans for all professionals involved, enhancement of diagnostic expertise in the general practice, and optimization of the format of multidisciplinary team meetings.
With DementiaNet, we aim to work towards high-quality, network-based care. These networks are organized on a local level, including healthcare professionals from medical, care and social disciplines. Based on theory, literature and experiences, we designed a stepwise approach to increase the quality of dementia care, including multiple elements on quality improvement, interprofessional learning and collaboration, and clinical leadership. So far, our initial experiences and results confirm the effectiveness of this DementiaNet design, as a tailor-made integrated care innovation, directly built on the differences and needs in clinical dementia practice. Although, initially, we aim to enhance dementia care, the basics of DementiaNet are general and might also, therefore, serve as a model to increase quality of healthcare for other populations, for example, frail elderly and patients that require palliative care.

More patients with dementia will live at home for longer periods of time, which highlights the need to improve dementia care within primary care. DementiaNet improves local collaboration amongst primary healthcare professionals to provide care for community-dwelling elderly with dementia and their informal careers. Our mission is to deliver added value for patients, caregivers, healthcare services and society, by realizing an innovative, cost-effective change in care processes, finely tuned for local, collaborating professionals. We engage patients and carers, and start from their perspectives, which we adopt in line with network and system-based methodologies. As many themes and activities are generally applicable, the DementiaNet approach might also serve as a model towards enhanced collaboration and quality improvement for other populations.
References


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Chapter 7

Evaluation of DementiaNet, a network-based primary care innovation for community-dwelling patients with dementia: protocol for a longitudinal mixed methods multiple case study

Chapter 7 — Evaluation of DementiaNet, a network-based primary care innovation for community-dwelling patients with dementia: protocol for a longitudinal mixed methods multiple case study

ABSTRACT

Introduction
Primary healthcare professionals will increasingly be required to manage and optimise their treatment for patients with dementia. With DementiaNet, we aim to reduce the burden of dementia on healthcare services and society through implementation and facilitation of integrated network-based care with increased dementia expertise. DementiaNet is designed as a step-wise approach including clinical leadership, quality improvement cycles and interprofessional training, which are tailor-made to the local context. For example, the composition of the network and improvement goals are tailored to the local context and availability. Here, we describe the linked evaluation study which aims to provide insight in effectiveness, process and mechanism of the DementiaNet approach through an innovative evaluation design.

Methods and analysis
We designed a longitudinal, mixed methods, multiple case study. Study population consists of two levels: (i) local DementiaNet networks of primary care professionals and (ii) patients and informal caregivers who receive care from these networks. At the start and after 12 and 24 months, quantitative data are collected for each network on: level of network maturity, quality of care indicators and outcomes reported by informal caregivers of dementia patients. We assess changes in networks over time and the association with quality of care and informal caregiver-reported outcomes. Throughout the study, logs about each network are registered. Additionally, semi-structured interviews with network members and informal caregivers will provide insight in experiences and opinions regarding effects and mechanisms through which changes in quantitative outcomes are effectuated. Rich narratives will be constructed about the development of the local networks using collected data.

Ethics and dissemination
The study protocol was reviewed by the local medical ethics committee; formal judgement was not required (protocol number: 2015–2053). The findings of this study will be disseminated through peer-reviewed publications, conference presentations and presentations for healthcare professionals where appropriate.
Strengths and limitations of this study

— Primary care innovations are not always subjected to the right rigorous evaluation, especially if their complexity is at odds with the conceptual assumptions of the randomised controlled experiment. This evaluation study adds to evidence-based healthcare, by employing research methods that help to understand whether DementiaNet is effective or not and focuses on why, how and in which context certain outcomes can be expected. Therefore, comprehensive data collection is designed with quantitative and qualitative methods.

— The knowledge resulting from this longitudinal multiple case study emanates from theoretical generalisability rather than statistical generalisability, and may have great importance in allocating healthcare resources in such a way that patients benefit most.

— Quality indicators of care were derived based on widely supported primary care guidelines and were developed specifically for the current study to fit the innovation. Hence, these have not been employed in research before. Indicators’ face validity has been established and will be reviewed for feasibility and reliability before final data analyses.

— The time span of the current evaluation study is likely too short to result in impacts on informal caregiver-reported outcomes; however, it may provide important data for further evaluation of DementiaNet with extended follow-up.

INTRODUCTION

Healthcare needs of elderly are characterised by high prevalence of chronic conditions, multimorbidity and strong heterogeneity between individuals and over time. As a result, numerous health and social caregivers are involved in care for this population. Additionally, over the last years, care systems and services have changed with a shift from long-term residential care facilities towards increased community-based care for elderly, resulting in increased requirements for primary care. Despite many initiatives, care arrangements are still suboptimally designed to deal with the complexity of care, that is, the large number of different available services, the involvement of many different professionals and the accompanying lack of certainty and agreement about the best treatment plan. This has led to a lack of integration, coordination and continuity. Possible explanations might be the facts that, in general, new guidelines are not fully taken up in clinical daily practice and are not adapted to each other, and improvement strategies merely target only parts of the system or aim at regional instead of local systems.

Community-dwelling patients with dementia present an illustrative example of the challenges that are posed on complex chronic primary care. First, much diversity exists in care needs since both the manifestation of dementia and the patients’ social contexts are multiform. Second, many different primary care professionals are involved from different health and social disciplines to provide care for patients with dementia. This urges the need for a high level of collaboration, as clinical practice is still mainly characterised by ad hoc collaboration. Hence, reorganisation of primary care is needed, in a way that is innovative, effective, scalable and also cost-effective. An overview of usual care is provided in Box 7.2.

Education alone is insufficient to improve primary dementia care. Also, interventions targeted at improving case management, a crucial factor in
primary dementia care, show limited improvements on outcomes such as caregiver burden or care needs and quality of life. Another UK-based analysis showed disappointing results from efforts on dementia recognition, diagnosis and management. In contrast, innovations aimed at a more comprehensive system, such as the PRISMA model for integrated service delivery system for frail older people in Canada, were positively evaluated on several relevant outcomes such as functional decline rate and unmet care needs. Another intervention study that targets dementia management in primary care as a whole, the Delphi study in Germany, shows promising preliminary results (on general practitioner attitude and caregiver burden), but is yet to publish the overall results.

Both the necessity and possibility for improvement in primary care for patients with dementia are evident, which led to the development of DementiaNet. This innovation aims at network-based care for community-dwelling patients with dementia, following a stepwise, tailor-made approach. The innovation is integrated with a parallel running evaluation study which aims to assess implementation of DementiaNet in primary care, and to assess the merits and harms of this approach.

DementiaNet is complex in nature, as it alters a services delivery system with many different players involved and many external factors potentially influencing the pathways through which effects can be accomplished. The evaluation study, thus, has to fit the complexity of the healthcare innovation. In contrast to most medical and healthcare research where the influence of context is minimised, this is of particular interest in the evaluation of complex innovations. Therefore, research should not solely be aimed to answer the question of ‘does it work?’, but should prioritise on how and why does it work. Therefore, the current evaluation study aims to answer the following questions: what are the merits and drawbacks of the DementiaNet approach; how are these achieved and which factors influence these processes? This paper describes the innovative methods used for the evaluation of DementiaNet along with background on these methods.

**Usual care for patients with dementia in the Netherlands:**
Dementia care in the Netherlands is characterised by practice variation among regions. The most important characteristics and common shortcomings are:

- Key players in primary dementia care are general practitioners, practice nurses, case managers, district nurses;
- Originally focused on acute episodes of single diseases instead of chronic multimorbidity patients;
- Care is fragmented with professionals working in their own domain, with limited interprofessional communication and ad hoc collaboration;
- Many professionals do not know each other, are unfamiliar with each others’ disciplines, responsibilities and competencies;
- There is little adherence to guidelines;
- Knowledge about dementia diagnosis and management is often insufficient.

**Care with the DementiaNet innovation:**
The DementiaNet innovation aims to promote a shift, addressing these limitations, towards integrated dementia care through:

- Network-based care with high levels of collaboration;
- A network leader to stimulate and coordinate the network;
- Care improvement through quality improvement cycles with tailor-made goals and improvement plan to fit the situation of each individual network;
- High dementia-specific expertise through interprofessional training and practice-based learning.
DementiaNet Innovation

With DementiaNet we work towards high-quality, network-based care, which is organised on a local level with professionals from medical, care and social disciplines. DementiaNet aims to optimise care processes and outcomes, both from a perspective of community-dwelling patients with dementia and their informal caregivers, as well as from care professionals’ perspective. This is pursued through multidisciplinary network-based care with a high level of collaboration. A tailor-made approach is employed to ensure fit to the large practice variation as seen in daily clinical practice. DementiaNet encompasses the transition towards network-based care through practice facilitation. These clinical networks are designed in primary care, and include professionals from multiple disciplines and from varying organisations. Hence, these networks include collaborations between individuals and organisations across institutional and professional boundaries. These clinical networks thereby ensure quality of and access to care for patients, including those who require coordination of care across a range of settings. This is pursued through formation of networks of primary care professionals who jointly and locally provide care to a number of patients with dementia, desirably including at least one professional of the medical (eg, general practitioner), care (eg, community nurses or case managers) and welfare (eg, social workers) discipline. Inclusion of health-care professionals is adapted to local sources and needs. As a consequence, each network in the programme is different from another in terms of size, represented disciplines and starting level of collaboration and care. A baseline data collection assessment takes place to map the starting position of the network. This includes measurements regarding network members and their backgrounds as well as the quality of care in their network. Feedback of the findings in the baseline data collection is then provided to the networks. Local network meetings are scheduled which start by making several actions to improve dementia care. These goals and actions are part of the quality improvement cycle, which are tailor-made to each networks’ specific situation. Tailoring the approach to fit their local diversity is key in this innovation.

Each network will employ four key components that are central to the approach of DementiaNet. Primarily, it relies on network-based care. The professionals in the network generally share a caseload of patients, the majority of whom have multiple professionals involved, requiring structured and organised collaboration to ensure continuity in care.

Second, the network leaders take up a central role in the process. Their task is to connect all professionals in the network and to stimulate and facilitate collaboration and improvement actions. Specifically, there is a leadership support programme for network leaders to help them take up this role.

Third, networks work through quality improvement cycles (Plan-Do-Check-Act (PDCA)). This means that at the beginning of each PDCA cycle, a comprehensive assessment is performed to get an overview of the quality of care and their network characteristics. The network jointly identifies improvement goals based on this measurement and their own experiences. A plan is drawn up with specific actions, tasks and a timeframe to achieve their goals. At the end of the yearly cycle, another assessment is performed to evaluate improvement and to identify new goals.

The last key element has a facilitating function. Interprofessional training and practice-based learning are used to increase knowledge and competencies. The contents of these training and coaching sessions are tailored to each network’s own goals, as they have different starting levels and different improvement goals. Preferably, the training topics are linked to the quality
improvement cycles. Also team training sessions are applied to increase team coherence, with sufficient team working skills, attitudes and competencies in the individuals involved in the team. Furthermore, professionals from different networks can take part in other sessions that were planned for these groups together, to be able to learn from each other and from best practices. More detailed information on the development of the DementiaNet innovation are described elsewhere.17

**Study design and population**

The evaluation study is designed as a longitudinal, mixed methods, multiple case study.18 Each participating network serves as a case in this study. Networks will be followed over time. Quantitative data will be collected at baseline and after every 12 months, with a maximum of three measurements within the current study period (January 2015–July 2017). Qualitative data will be collected throughout the course of the innovation programme to gain in-depth knowledge on processes and experiences of involved persons (ie, care professionals, patients and informal caregivers). Triangulation of quantitative and qualitative data will be used to strengthen insight in patterns.

The study population consists of two levels. The first level includes the local DementiaNet networks participating in the DementiaNet programme. The second level includes patients and informal caregivers who receive care from care professionals in these local networks.

**Data collection**

We will collect data from multiple sources to describe the networks and to measure outcomes. First, for each network, data will be documented by the research team regarding the number and discipline of professionals involved. Log documents will be kept for each network with information on the process of network formation and actions taken before enrolment of networks into the programme, as well as specifics that may influence the way their network develops and is able to execute the quality improvement cycles. Of this log, a narrative is to be constructed about each network. Additionally, a yearly online questionnaire will be distributed among network members, including instruments including their attitude towards healthcare teams19 and dementia,20 their perceived team skills21 and enabling factors for collaboration.22

The following data will be collected to assess the effects of the DementiaNet innovation on care processes and outcomes (Figure 7.1):

![Figure 7.1 — Overview of data collection for the evaluation of the DementiaNet innovation.](image-url)

<table>
<thead>
<tr>
<th>Network characteristics and narrative ¹</th>
<th>Quality of care ¹</th>
<th>Informal caregiver outcomes ¹</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Network maturity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Person-focused care</td>
<td>1. Casemanager</td>
<td>— Patient quality of life (QoL)</td>
</tr>
<tr>
<td>2. Population-focused care</td>
<td>2. Diagnosis in primary care</td>
<td>— Informal caregiver quality of life (QoL)</td>
</tr>
<tr>
<td></td>
<td>3. Diagnosis communicated</td>
<td>— Satisfaction with care (QoL)</td>
</tr>
<tr>
<td></td>
<td>4. Recent multidisciplinary meeting</td>
<td>— Empowerment in care (QoL)</td>
</tr>
<tr>
<td></td>
<td>5. Goals of patient and informal caregiver discussed</td>
<td>— Care consumption of institutionalizations</td>
</tr>
<tr>
<td></td>
<td>6. Recent care plan</td>
<td>— Behavioral symptoms of dementia (QoL)</td>
</tr>
<tr>
<td></td>
<td>7. Recent care plan with informal caregiver</td>
<td>— Objective informal care burden</td>
</tr>
<tr>
<td></td>
<td>8. Psychosocial intervention for behavioural problems</td>
<td>— Care-related quality of life (QoL)</td>
</tr>
<tr>
<td></td>
<td>9. Antipsychotic drugs for behavioural problems</td>
<td>— Perseverance time with care situation (QoL)</td>
</tr>
<tr>
<td></td>
<td>10. Recent systematic geriatric assessment</td>
<td>— Complexity of dementia patient (QoL)</td>
</tr>
<tr>
<td></td>
<td>11. Recent pharmacotherapeutic meeting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12. Number of emergency consultations</td>
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</tr>
<tr>
<td></td>
<td>13. Recent diagnostic work-up for memory problem patients</td>
<td></td>
</tr>
</tbody>
</table>

| **In-depth interviews ²**             |                  |                               |
| 1. Casemanager                        |                  |                               |
| 2. Diagnosis in primary care          |                  |                               |
| 3. Diagnosis communicated             |                  |                               |
| 4. Recent multidisciplinary meeting   |                  |                               |
| 5. Goals of patient and informal caregiver discussed |                  |                               |
| 6. Recent care plan                   |                  |                               |
| 7. Recent care plan with informal caregiver |                  |                               |
| 8. Psychosocial intervention for behavioural problems |                  |                               |
| 9. Antipsychotic drugs for behavioural problems |                  |                               |
| 10. Recent systematic geriatric assessment |                  |                               |
| 11. Recent pharmacotherapeutic meeting |                  |                               |
| 12. Number of emergency consultations |                  |                               |
| 13. Recent diagnostic work-up for memory problem patients |                  |                               |

¹ Continuous collection of data; ² Data collected at and after 12 and 24 months; ³ Data collected at one time point in a selected number of networks. References for the informal caregiver outcome instruments.27–46
Network maturity

Network maturity is defined as the level at which the care professionals operate as a network. To assess the starting level and changes over time, we will use a model for integrated primary care called the ‘Primary Care Maturity Model’, which includes eight items in three domains: (i) person-focused care, population-focused care; (ii) clinical integration, professional integration, organisational integration, system integration and (iii) functional integration, and normative integration. Each item is rated on four defined levels, ranging from (1) ad hoc, through (2) defined, and (3) controlled, to (4) synchronised. By summing the scores on the eight domains, a global maturity score will be derived for each network for each measurement point, reflecting their network maturity at each time.

The rating of network maturity will be based on information obtained directly from the networks by means of interviews. Structured interviews with the network’s leader(s) will be held at each measurement point (baseline and after every 12 months) by an independent researcher. An interview guide is developed based on the content of the Primary Care Maturity Model in such a way that sufficient information is obtained on each of the eight items to be scored. This approach is chosen in order to allow a certain degree of flexibility to each networks composition and context, while still targeting the specific topics to be scored. Interviews are recorded on audio tape and stored until the end of the evaluation study. At that point, another independent and blinded researcher, who is unfamiliar with the study design and networks in the programme, will be instructed to rate the eight aspects of the Primary Care Maturity Model based on the information in the interview, to obtain the global network maturity score.

Quality of care indicators

Quality of dementia care will be assessed by means of quality indicators. The quality indicators will be reported on by the local networks through a registration file. A composite score will be constructed of the indicator scores of the final quality indicators to obtain a single overall score reflecting the network’s quality of care.

This set of quality indicators was developed by an expert panel consisting of a geriatrician, general practitioner, community nurse/researcher, primary care researcher, epidemiologist and geriatric researcher prior to the current study to fit this particular evaluation. As it regards an innovative services delivery approach, it therefore requires different indicators than have already been developed for primary care settings. First, a framework was drafted with the basic concepts of the DementiaNet innovation, which were translated into criteria and subsequently operationalised into indicators that care should meet. These were checked to comply with relevant current guidelines and agreements regarding primary dementia care. Consensus on 13 final indicators was reached after multiple meetings in which relevance and feasibility of indicators were reviewed, as well as the comprehensiveness of the total set. This set was tested for face validity, acceptability and perceived feasibility in a pilot survey among 18 primary care professionals and showed good results on every aspect.

As these indicators have not been used before, they will be subjected to additional assessment based on the baseline data before the actual analysis of the data. Assessment will ensure the use of only reliable indicators, for instance, taking into account missingness, floor and ceiling effects and coherence with definitions. Therefore, the final set of indicators used in actual data analysis is expected to be more concise.
Informal caregiver-reported outcomes
Data on informal caregiver-reported outcomes will be gathered through paper-and-pencil questionnaires. Patients will be informed about the project and associated evaluation study through a letter from their general practitioner. This letter includes an answering card in which they can indicate whether they are interested in participation in an informal caregiver questionnaire. If so, the research team will contact them to obtain consent from informal caregiver and the patient where possible, and the postal address to send them the questionnaire. The informal caregiver questionnaire consists of demographic questions about the patient and informal caregiver, as well as validated instruments on several outcomes (Figure 7.1).

Experiences and perspectives
In conjunction with the quantitative evaluation, a qualitative approach will be employed. For this part of the evaluation study, we will use semi-structured interviews with both care professionals in the networks as well as patients and informal caregivers. These data will provide insight in experiences and complex processes influencing potential results to be examined in the quantitative part. Interviews will be held by a trained researcher, starting after the first year of the project. By purposive sampling of participants, we aim to include relevant perspectives from different disciplines of care professionals, as well as patients and their informal caregivers originating from different networks.

Analysis
It is expected that this innovation has effects on multiple levels which may vary. Also, it is expected that the networks have different starting levels and divergent progression rates. Hence, the study considers both within and between network analyses, as follows.

Within each network, all data sources will be conjoined in order to identify any changes resulting from the DementiaNet innovation. We will look for patterns in trends over time in quantitative measures and we look for possible explanations for trends in activities carried out by the networks and their improvement goals. More specifically, we will look into associations that follow from a hypothesised pathway of effects, where we expect that network maturity will increase over time, and will be associated with quality of care as measured by the quality indicators. Potentially, an increase in patient-reported outcomes will eventually follow the increases in quality of care. This will be analysed by using mixed effects growth models to account for repeated measures and clustering of data within networks.

As the course of this innovation will proceed differently in each network, there will be a natural contrast between different networks with regard to the maturation into networks and the subsequent approach to care. Given the fact that these aspects will be also monitored over time within each network, this will allow for cross-case comparisons. This approach has been used previously, for example, on an integrated services delivery system in primary care for elderly, in which they monitored the degree of implementation of integrated services in a quantitative manner. In outcome evaluation studies, such a quantification of implementation can be used as a measure of ‘dosage’ of the intervention to be able to look for dose-response patterns to strengthen plausibility of found patterns.

By comparing cases (ie, cross-case comparison) on the extent these have matured into a coordinated network and how much improvement efforts have been made and output (ie, trends in quality of care and informal caregiver-reported outcomes), it will be possible to increase plausibility of causality to attribute changes to the DementiaNet innovation similar to a dose-response manner.

Furthermore, the qualitative data from the semi-structured interviews will be used to explore experiences of professionals and patients and informal caregivers with the DementiaNet innovation. A thematic analysis will be
used to analyse the verbatim transcripts of the semi-structured interviews. The analysis will be partly guided by a predetermined framework of potential experiences and perceived benefits based on the development of the innovation. We will remain open to discovering unanticipated nuances and topics in the data. First, transcripts will be independently coded by two trained researchers. Subsequently, both coding schemes will be jointly reviewed to reach consensus about most appropriate coding. After that, codes will be categorised and major themes will be identified by the same two researchers. Lastly, both researchers will independently draw overall findings from the codes in each category, after which a consensus round will be applied to these findings. Qualitative data analysis will be performed in Atlas.ti software.

The findings from these qualitative data will be conjointly used with the quantitative findings in the interpretation phase of the study in multiple manners: a) through triangulation, to corroborate findings and provide a stronger basis for conclusions, b) the qualitative findings will be used to augment quantitative findings, c) the qualitative findings will be used to identify unexpected and/or unintended effects that are not covered by the quantitative data.

**DISCUSSION**

DementiaNet is an innovation that aims to tackle the current shortcomings in primary care for patients with dementia by effectuating a transition from ad hoc collaboration towards more integrated network-based care with increased dementia expertise. With the current evaluation study, we aim to provide insight in implementation of the DementiaNet innovation and its merits and harms by means of a longitudinal, mixed methods, multiple case study. Here, we will also take DementiaNet as an example of a complex intervention to elaborate further on the viewpoint that rigorous evaluation of these types of innovations in health services systems is essential and which considerations should be taken into account when designing such an evaluation study, to ensure adequate capturing of the complexity while achieving high external validity.

**Rationale of the study**

Unlike clinical treatments, innovations in health services and primary care are not always subjected to rigorous evaluation. Such evaluation studies add to evidence-based healthcare, which is essential in order to distinguish innovations that change healthcare organisations for the better, from those that lack beneficial effects. Such knowledge has great importance in allocating healthcare resources to spread innovations and ensure actual implementation.

Innovations in health services systems are often complex in terms of multiple components that interact, the number of involved professionals, the extent to which they have to alter their behaviours and the flexibility and tailoring necessary to fit the situation in which it is implemented, which is particularly the case in the DementiaNet innovation. In such complex innovations, it is often difficult to accurately predict to what extent and through
which pathways the intervention may affect outcomes, and how the context in which it is implemented influences these pathways. In other words, it is hardly possible to predict if and how healthcare innovations will lead to the intended outcomes. Many examples exist of previous efforts in healthcare innovations that seemed promising but did not induce the desired changes, or even worsened outcomes or expenses. For instance, interventions aimed at reduction of emergency admissions have failed to produce the desired outcomes or even produced counterproductive outcomes because several aspects had been ignored, such as alternative explanations, regression to the mean and supply-induced demand. The degree of uncertainty in effective pathways through which interventions work and therefore the results they lead to, increases with a higher degree of complexity of healthcare change. In general, but especially in times of limited resources, it is of invaluable importance to evaluate innovations in healthcare services to know which ones are worth adopting and investing in.

**Study design**

From the viewpoint that evaluation is indispensable, one inevitable choice is the optimal study design. From the perspective of traditional scientific (statistical) generalisation, the highest form of evidence for efficacy of interventions comes from randomised clinical trials (RCTs). The key methodological components of an RCT are the use of a control group and random assignment to groups to balance distribution of potential confounders, to allow for causal inferences. These components ensure high internal validity, but often limit external validity. However, several differences are encountered between the evaluation of relatively simple (medical) interventions and of complex healthcare innovations. For instance, the nature and complexity of health services innovations often cause assumptions underlying the RCT design to not be upheld, therefore compromising internal validity of RCTs and thus advocating the use of alternative study designs. The most often violated assumption is the assumption of context independence, but the assumption of equipoise may not apply if preference for the intervention over usual care exists.

The DementiaNet innovation is complex on multiple aspects, according to definitions from the Medical Research Council (MRC): it consists of multiple interacting components; healthcare professionals have to alter their behaviours considerably and multiple organisational levels are targeted. Additionally, the innovation is tailored to the specific situation of each local network, which has been recognised as a logical fit for complex interventions to be adapted to local contexts rather than completely standardised. Logically, the context in which the intervention is implemented is of great influence and therefore of interest to the evaluation. This will be taken into account by constructing narratives of each network with specific attention to their context and by looking for patterns in different contextual factors that may account for different trends in outcomes.

For these reasons, we designed the evaluation study as a longitudinal multiple case study. The unit of analysis is the individual network participating in the DementiaNet project. This makes it impossible to set up a comparable control unit, as these networks do not exist yet without the innovation. Additionally, necessary investment in data collection was not endorsed by professionals if participation in the project was not ensured. In case studies, the context is explicitly taken into account as part of the evaluation, in contrast to experimental designs which employ the opposite approach by controlling the context as much as possible. Therefore, a multiple case study is found very suitable for this type of evaluation. In a multiple case study, each case can be seen as a single experiment. Hence, a multiple case study may then be considered the equivalent to multiple experiments. Under this assumption, generalising from case studies can be equivalent to generalising from experiments. Inferences are drawn both from within-case changes over time and cross-case comparison. The longitudinal multiple case study design allows for the addition of this latter approach, thereby providing the potential to replicate findings and identify patterns, which increases explanatory power and generalisability of findings.
Although there is a certain selection underlying the participating networks in the evaluation study, we believe that the results will extrapolate to other locations as well. This is assumed because the innovation is not specific to this innovators and early adopters group, but is applicable to every network as it is strongly tailor-made to the specific needs of every network. We will evaluate the suitability for networks that start at higher and lower levels of collaboration and quality, leading to higher external validity.

Each network is enrolled into the evaluation study as a case on starting in the project. Hence, the evaluation study commences at the same time as the implementation of the innovation. This timing allows for the most optimal within-case comparison between the situation right before implementation started and during increasing levels of implementation within the network. This outweighs the fact that effects take time to develop and thus may not come to full fruition within the timeframe of the study in our opinion as it strongly increases the validity of inferences to be drawn from this evaluation.

*Expectations*

Successful transition towards network care will be evidenced by an increase in the rating of network maturity. It is expected that this is not the case in all networks, as some probably fail to succeed in transitioning after the starting initiative to take part in the innovation, for instance, because of organisational problems or because network leaders are unable to fulfil their role. Moreover, it is expected that rating of network maturity is associated with the score on quality of care as measured by indicators. Hence, we expect that quality of care scores will increase along with network maturity, although possibly with a considerable delay. It is not hypothesised that informal caregiver-reported outcomes will already be affected by the DementiaNet innovation in a way that is timely and strong enough to be picked up by this evaluation study. However, as it is an extension of the hypothesised pathway and the ultimate goal of many health services innovations, we do consider the inclusion of these outcomes relevant to incorporate the patient and informal caregiver’s perspective to expand on in further studies.

We expect that the mixed methods design provide us with insight in how the innovation actually was implemented in each network, how it worked and which contextual aspects influenced this. Furthermore, we expect information on which aspects of the innovation are most effective in which circumstances. Possibly, the innovation and future implementation can be improved with this information. Next to highly valuable data for effective and efficient network-based care for chronic conditions in older populations, starting with dementia care, this study may yield important methodological data on the value of a multiple case study analysis for other complex interventions as well.
References


18. Yin RK. Enhancing the quality of case studies in health services research. Health Serv Res 1999;34(4 Pt 2).


The Sixth no sooner had begun
About the beast to grope,
Then, seizing on the swinging tail
That fell within his scope,
"I see," —quoth he,— "the Elephant
Is very like a rope!"

Chapter 8

Longitudinal multiple case study on effectiveness of network-based dementia care towards more integration, quality of care, and collaboration in primary care

Under review
ABSTRACT

Introduction
This study aimed to provide insight into the merits of DementiaNet as a network-based primary care innovation for community-dwelling dementia patients.

Methods
Longitudinal mixed methods multiple case study including 13 networks of primary care professionals as cases. Data collection comprised continuously-kept logs; yearly network maturity score (range 0-24), yearly quality of care assessment (quality indicators, 0-100), and in-depth interviews.

Results
Networks consisted of median 9 professionals (range 5-22) covering medical, care and welfare disciplines. Average yearly increase was 2.03 (95%-CI:1.20-2.96) on network maturity and 8.45 (95%-CI:2.80-14.69) on quality indicator score. High primary care practice involvement and strong leadership proved essential in the transition towards more mature networks with better quality of care.

Discussion
Progress towards a more mature network favored quality of care improvements. DementiaNet appears to be an effective model to realize a transition towards network-based care, enhance multidisciplinary collaboration, and improve quality of dementia care.

INTRODUCTION

Chronic conditions like dementia pose a great challenge to health care systems. Primary care for community-dwelling dementia patients is multifaceted, especially in later stages of the disease, in which dementia affects many aspects of the lives of patients and their informal caregivers. Medical issues fall under the responsibility of the primary care physician, but many patients also require other forms of care and support such as home care, nursing care, and temporary involvement of occupational or physiotherapists. Subsequently, patients often require case management to ensure continuity and availability of services and thus primary care professionals are increasingly urged to work in a multidisciplinary manner.

The primary care system in the Netherlands (Box 8.1) is adapting to major policy changes, such as widespread closing of homes for the aged, a move towards a participatory society with incentives to stay at home longer, and stimulation of market mechanisms in health care. This trend, which is met in many other high-income countries, resulted in fragmentation of care, lack of expertise on dementia and multimorbidity among primary care professionals, and unintended variation in health care between regions.

National and international efforts to improve dementia care have shown some promising results\(^2\)\(^3\), but much room for improvement remains. Interventions targeting specific suboptimal aspects of the care system so far lacked effectiveness because they did not comprehensively improve the integration and continuity of dementia care.\(^4\)\(^5\) Therefore, it is likely that the health care system itself requires adaptation, and that improvement of the individual components is not effective in improving dementia care.
This insight led to the development of DementiaNet. DementiaNet is an innovative primary dementia care approach that targets the transition towards network-based primary care by forming networks of primary care professionals. It embodies a complex health care innovation, given the multiple interacting components of the program, the required behavioral changes of professionals, and the high degree of flexibility required to adapt to different local circumstances. The implementation context is also highly complex, as it involves many different stakeholders (e.g., care professionals, municipalities, insurers, government). This high degree of complexity results in unpredictability of the consequences such a program induces and warrants an appropriate perspective on evaluation. Hence, instead of asking whether an intervention works, researchers should aim to identify if and how it contributes to reshaping a system in favorable ways. In order to gain insight into such effects and to facilitate evidence-based primary care, an evaluation study ran parallel to the DementiaNet program. Therefore, this study aimed to answer the following questions: what are the merits and drawbacks of the DementiaNet approach; how are these achieved; and which factors influence these processes? Consequently, given said complexity, an innovative study design for its evaluation was advocated.

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**Box 8.1 — Primary care for community-dwelling dementia patients in the Netherlands**

- Community-dwelling dementia patients receive care from multiple care professionals, including medical disciplines (primary care physician, elderly care physician), care disciplines (community nurse, case managers), and social disciplines (social workers, respite care workers).

- All Dutch inhabitants are registered at a primary care practice in close vicinity to where they live. Primary care physician referral is needed for specialist care. Indications to obtain home care are provided by municipalities or district nursing organizations.

- All Dutch inhabitants are obliged to have health care insurance and are free to choose between various private health care insurance companies. Primary care, home care and nursing care are part of insurance and are paid for directly by private health care insurance companies. The organization and financing of social care is the responsibility of municipalities. Case management is paid for by insurance companies, and exists in multiple formats and may be independent or part of home care organizations.

- Several national guidelines and documents are available on primary dementia care arrangements in the Netherlands, including guidelines for the primary care practice, a national standard for multidisciplinary dementia care, and agreements describing collaboration between the primary care practice and home care and elderly care physicians. Despite availability, uptake of and compliance with these documents is low in practice. In addition, guidelines leave ample opportunity for individual professionals to arrange care in various ways.

- Dementia care on a local level is determined by national, regional and local policies, and additionally by initiatives undertaken by the acting professionals and existing facilities. As a result, local care is highly variable throughout the Netherlands.
METHODS

DementiaNet networks
DementiaNet encompasses a transition towards high quality, network-based care organized at a local level. The program’s key strategy is practice facilitation, a promising approach to supporting primary care redesign where trained facilitators support primary care practice. Multidisciplinary networks are formed of primary care professionals, desirably including at least one professional of the medical (e.g. primary care physician), care (e.g. community nurses) and welfare (i.e. social workers and case managers) discipline, which jointly provide care to a number of dementia patients. Inclusion of professionals is defined by the networks themselves and tailored to local sources and needs. As a consequence, each network is different in terms of size, represented disciplines, and starting level of collaboration and quality of care.

The DementiaNet program consists of fixed and tailored elements. The following four key components were applied in each network. Firstly, a transition towards network-based care was initiated, aimed at structural instead of ad hoc collaboration. Secondly, one or two professionals in each network took on the role of network leader and were supported in this leadership role via individual and group coaching. This coaching enabled them to stimulate and facilitate multidisciplinary collaboration and improvement actions. Thirdly, networks followed the Plan-Do-Check-Act method for quality improvement based on jointly identified improvement goals. Fourth, interprofessional training and practice-based learning were used to increase knowledge and competencies on dementia care and multidisciplinary collaboration. Since each network and their context varied, various aspects of DementiaNet were tailored to the local setting and needs, including the actual improvement goals and plan, and extent of leadership coaching.

The enrollment of networks in the DementiaNet innovation program was aimed at early adopters. Through various media, the start of the program was announced and motivated primary care professionals were invited to initiate the formation of a local network.

Study design
Following extensive scrutiny of research designs to fit DementiaNet as an innovation embedded in complex health care setting, a longitudinal mixed methods multiple case study was chosen (further elaborated in study protocol). Each of the DementiaNet networks served as a case for a period of up to 24 months. This design fits the description of comparative case studies, where qualitative and quantitative data were collected from multiple sources and integration of both types of data was performed to leverage the strengths of both. Through joint interpretation, new insights could be drawn, beyond the information gained from the separate sources.

Data collection
Multiple sources of data were collected for all networks: logs were kept continuously for network narratives, quantitative data was collected at baseline and yearly and qualitative data after 12 months.

Network narratives
A log on each network was kept with characteristics of the network and members, including the number of professionals and disciplines involved. Also, data was collected on the formation of the network and change efforts, with information on process and actions undertaken before enrolment; on collaboration at baseline and changes over time; on improvement goals, actions and achievements as part of quality improvement; and any specifics that may influence development over time.
Network maturity
As part of yearly assessments, structured interviews were held with the network leaders with topics based on the Rainbow Model of Integrated Care to assess network maturity. The global network maturity score (range 0-24) was derived by rating 8 items (population-based care, person-focused care, clinical integration, professional integration, organizational integration, system integration, functional integration and normative integration) on a scale with predefined levels (score 0-3). Rating was performed independently by two researchers (AR, TK), after which consensus was reached on each item. Higher scores indicate higher maturity.

Quality of care indicators
Prior to the study, an expert panel developed a set of 13 quality indicators (QIs) based on available dementia care guidelines and agreements, which was pilot-tested by primary care professionals for feasibility, relevance, and comprehensiveness. Prior to analysis, baseline scores on the initial set of QIs were reviewed for appropriateness, taking into account feedback from the networks, missingness, floor and ceiling effects, and coherence with definitions. This led to a final, more concise set of six QIs: proportion of patients with (1) involvement of case management; (2) dementia diagnosis in primary care setting; (3) recent geriatric assessment; (4) recent consideration during a multidisciplinary meeting; (5) recent polypharmacy check; and (6) average number of emergency consultations per year.

Data on these QIs included all shared dementia patients of each network and were collected yearly via a registration document, which was completed by a network member based on information as registered in electronic patient files. Sum score were constructed by averaging scores on each of these indicators, yielding a total score between 0 and 100, with higher scores indicating better quality of care.

Experiences and perspectives
Semi-structured interviews were held with professionals to obtain insight into experiences with and perspectives on DementiaNet, until data saturation was achieved. A purposive sample of professionals (n=9) from networks that had been participating for at least one year were invited for interviews, securing input from multiple networks and different disciplines. A trained qualitative researcher (IM) performed the interviews using a topic list and did a member check after the interviews.

Analyses
Quantitative analyses were performed in R (package lme4). Interview transcript analysis was performed in Atlas.ti.

Quantitative analysis
Quantitative data were used to assess overall changes in network maturity and QI scores over time by means of calculating differences and mixed regression models to account for repeated measures (random intercepts per network, fixed effect for time). Association of network maturity with QI scores was also assessed.

Qualitative analysis
Logs were processed into narratives of each network by three researchers (AR, MN, MP). Transcripts from the semi-structured interviews were independently coded by two trained researchers (AR, IM), after which both coding schemes were jointly reviewed to reach consensus. Subsequently, codes were categorized to identify major themes. Quotes belonging to each major theme were independently reviewed by the two researchers to draw overall findings per theme, after which a consensus round yielded the overall findings.
Integration
Trends on network maturity and QI scores of each individual network were jointly considered with the narrative of that particular network, in order to identify possible explanations for (lack of) change. Cross-case comparison of networks was performed to identify patterns. First, networks with similarity in specific aspects of quantitative data were identified and compared based on the narratives to explain patterns. Second, networks were grouped based on common characteristics to explore the influence on trends in quantitative measures. Additionally, findings of quantitative analysis in combination with narratives were compared to the findings from the semi-structured interviews to identify convergence or divergence among topics and to identify how these complement each other. The integration step was carried out by four researchers (AR, MN, MP, MvdM) based on consensus and verified by the other authors.

RESULTS

DementiaNet networks
Seventeen networks started in the DementiaNet program between January 2015 and June 2016. Four of them ceased active participation within the first year. Reasons were either related to lack of intrinsic motivation (e.g. participation was initiated by local government) or lack of time, resulting in insufficient momentum for a transition process. Hence, results refer to 13 networks. The median number of professionals in the networks was 9 (range 5-22). The composition regarding disciplines varied, with primary care physicians, practice nurses, case managers, and community nurses being most represented. Eleven networks included professionals from medical, care, and welfare disciplines. All networks were followed for at least one year, and six for 2 years, resulting in total in 19 yearly evaluations. A detailed description of each network’s characteristics and proceedings is described in Table 8.1.

Network maturity and quality of care
The individual network trajectories in network maturity and QI scores over time are shown in Figures 8.1A and 8.1B. In total, 19 yearly evaluations were completed with network maturity scores, of which 16 showed improvement and 13 increased more than 2 points. The networks completed 18 evaluations with QI scores, of which 14 showed improvement with 10 evaluations resulting in an increase of over 5 points. Improvements in network maturity were accompanied by an increase in QI scores in 13 of 15 cycles (Figure 8.1C). The regression model with network maturity as dependent variable showed an estimated increase of 2.03 (95% CI 1.20-2.96) in network maturity per year in the networks. The regression model with QI scores as dependent variable showed an average increase of 8.45 (95% CI 2.80-14.69) per year in the networks. When extending the latter model by including the network maturity score as a time-varying predictor, the QI scores indicated to be positively associated with network maturity (2.11; 95% CI 0.89-3.33).
### Table 8.1 — Characteristics and narrative summaries of the primary care networks in the DementiaNet program

<table>
<thead>
<tr>
<th>Network</th>
<th>Composition at start</th>
<th>Collaboration</th>
<th>Network leaders</th>
<th>Catchment area</th>
<th>Caseload of patients (start; yr 1; yr 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1 CM; 2 CN; 1 GS; 1 PCP; 1 PH. (total: 6)</td>
<td>Existing collaboration</td>
<td>CM, PCP</td>
<td>Small</td>
<td>13; 17; 22</td>
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<tr>
<td></td>
<td><strong>Narrative summary</strong></td>
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<td></td>
<td>Started as a compact network where a lot of structures were already in place. It could be considered a best practice network from the start. They already participated in an elderly program and had a very well functioning multidisciplinary meeting and high levels of collaboration at start. With highly dedicated network leaders and all the relevant professionals present in the network, improvement plans were carried out well. A care map was constructed defining everyone's role in dealing with signals of cognitive decline.</td>
<td>In the second year, more insight was obtained in everyone's care tasks to improve efficiency by removing doubly executed tasks and identifying gaps. Even though collaboration was already high and structured at start, bonds between the professionals were strengthened over the two years of participation by yearly evaluation of their collaboration.</td>
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<td>B</td>
<td>2 CM; 3 CN; 1 OT; 3 POP; 1 PT; 2 WF; 1 other. (total: 13)</td>
<td>Existing collaboration</td>
<td>CM, CN</td>
<td>Large</td>
<td>19; 16; unknown</td>
</tr>
<tr>
<td></td>
<td><strong>Narrative summary</strong></td>
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<td>In this neighborhood, a collaboration of several professionals was already in place. They decided to enroll in the DementiaNet program to get support in improving integrated care. They were mainly interested in improvements on a neighborhood-level instead of improving care for individual patients. A social care map was introduced.</td>
<td>With lack of a strong position of the network leader, improvements were less prominent than potentially could have been. Also, considerable changes to the network took place, with two out of three PCPs leaving and the primary network leader changing jobs.</td>
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<td>C</td>
<td>1 CM; 9 CN; 2 GS; 3 MM; 1 PCP; 1 PN; 3 WF; 1 other. (total: 22)</td>
<td>Existing collaboration</td>
<td>PCP, PN</td>
<td>Large</td>
<td>35; 25; 30</td>
</tr>
<tr>
<td></td>
<td><strong>Narrative summary</strong></td>
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<tr>
<td></td>
<td>A rather large network of care professionals for dementia was already established for several years, after the municipality and several care professionals actively recruited care professionals to work together. After several years, the municipality could not provide support anymore. Therefore, the network enrolled in the DementiaNet program to get support and guidance in improving care and to get training and education. The first year went well, with sufficient meetings and training, resulting in concrete agreements on care on cognitive decline detection.</td>
<td>During the second year, some personal struggles caused interprofessional frictions among network members, with not everyone getting along and feeling included, but this was resolved. A multidisciplinary meeting was introduced and agreements were made. Additional training on geriatric assessment topic took place.</td>
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<td>D</td>
<td>1 CM; 4 CN; 1 MM; 2 PCP; 2 WF. (total: 18)</td>
<td>New collaboration with unacquainted members</td>
<td>2 CNs</td>
<td>Large</td>
<td>15; 12; 9</td>
</tr>
<tr>
<td></td>
<td><strong>Narrative summary</strong></td>
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<td></td>
<td>The initiative to participate came from a home care organization. The DementiaNet team helped to get the group of PCPs on board; several other disciplines joined. During the first year, the network focused on implementation of a scan of the informal care network of each patient; however, most of the actions to be undertaken were dependent on the network leaders, as other network members took a passive role in the process, resulting in suboptimal improvement actions. Educational sessions on dementia content were also held. A start was made with ICT communication tools.</td>
<td>The main effort of the second year was to move forward with the uptake of the ICT tool, which eventually proceeded steadily after some technical difficulties. Training sessions were evaluated positively and many involved professionals participated. However, enthusiasm of the network leaders who were the driving force decreased, due to lack of activity from other members in the first year. During the second year, the PCP was succeeded by a new one, taking some time in getting all care processes on track. Also, both network leaders were absent for some time due to personal reasons. While some other parties remained in the network, they were represented by new members.</td>
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</table>
### Chapter 8 — Longitudinal multiple case study on effectiveness of network-based dementia care towards more integration, quality of care, and collaboration in primary care

**Table 8.1 — Characteristics and narrative summaries of the primary care networks in the DementiaNet program**

<table>
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<tr>
<th>Network</th>
<th>Composition at start</th>
<th>Collaboration</th>
<th>Network leaders</th>
<th>Catchment area</th>
<th>Caseload of patients (start; yr 1; yr 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>E</td>
<td>1 CM; 2 CN; 2 GS; 2 PCP; 1 PN. (total: 8)</td>
<td>Relatively new collaboration</td>
<td>CM, PN</td>
<td>Small</td>
<td>7; 9; 13</td>
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<tr>
<td></td>
<td>Improvement of multidisciplinary meeting (year 1); improvement of signaling cognitive decline (year 1); increase expertise for dealing with problematic behavior (year 2)</td>
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<td>The network formation was initiated by the network leaders who were aware of the fact that two of the PCPs they worked with had difficulties in caring for dementia patients, which they experienced as well. They worked together on a patient-basis before without being a formal network. They started of small, but with the most important players involved. During the first year, their efforts in the context of the program lead to slowly but steadily accomplishing the first improvement goals, but mostly resulted in being more acquainted with each other and more and better communication between them, specifically between the case manager and PCPs. The actions have also lead to a better overview of the population.</td>
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<td></td>
<td>During the second year, the actions aiming to improve their new goals revealed many differences in vision on better care. This resulted that most actions had to first be aimed at solving those discrepancies and less on improving actual care.</td>
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<tr>
<td>F</td>
<td>1 CM; 1 CN; 2 PCP; 2 PN; 1 other. (total: 7)</td>
<td>Relatively new collaboration</td>
<td>CM, PN</td>
<td>Large</td>
<td>12; 21; 31</td>
</tr>
<tr>
<td></td>
<td>Improvement of multidisciplinary meeting (year 1); increasing expertise in diagnostics (year 1); increasing expertise on dementia (year 2); improving collaboration (year 2)</td>
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<td></td>
<td>Before start, the members of this compact network already shared patients but no formal collaboration existed beyond ad hoc interactions. However, they felt there was a lot of room for improvement, as they did not feel fully competent on all aspects. Also, a new PCP had just taken over the involved practice, covering many elderly patients. Support in tackling some issues was wanted. Over the first year, several trainings were held and improvement goals were considered to be achieved. Moreover, the network leaders were much more confident in their role, as viewed by themselves and others.</td>
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<td></td>
<td>During the second year, the PCPs were better equipped and confident in diagnostics, and numbers of new diagnoses further increased. Next to training on the new topics of the improvement goals, they also initiated meetings for other disciplines (e.g. occupational therapists) to explain what they can offer in the care path of dementia patients, to become more acquainted with all involved professionals and thus enhance collaboration on a patient-level. The network composition was stable and the network showed to be capable of fairly independent improvement initiatives.</td>
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<tr>
<td>G</td>
<td>7 CN; 1 OT; 1 PT. (total: 9)</td>
<td>New collaboration with unacquainted members</td>
<td>2 CNs</td>
<td>Large</td>
<td>4; 5</td>
</tr>
<tr>
<td></td>
<td>Dealing with early signals of cognitive decline (year 1); introduction of multidisciplinary care plans (year 1)</td>
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<tr>
<td></td>
<td>This network was initiated by the local team of community nurses. They shared patients with a number of PCPs but could not get them on board of the network prior to participation in the program. An occupational therapist and physiotherapist were interested in joining the network. The plan was to improve collaboration with PCPs and case managers first, and have them join the network later.</td>
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<td></td>
<td>The community nurses often pick up signals of cognitive decline and suspect dementia, but there are no agreements on how to communicate these signals with the PCP and how to make sure the patient is evaluated. Training was given to the network, which managed to get case managers involved. It improved the collaboration between community nurses and case managers, but the network was unable to get PCPs involved. Training on multidisciplinary care plans did not take place because the network could not arrange a time for it.</td>
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</table>
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</tr>
</thead>
<tbody>
<tr>
<td>Improvement goals (per year)</td>
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<tr>
<td>H</td>
<td>1 CM; 2 CN; 2 PCP; 1 WF. (total: 6)</td>
<td>Existing collaboration</td>
<td>CN, PCP</td>
<td>Small</td>
<td>28; 28</td>
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<td>Right after initial enrollment in the program, the network leader became absent due to personal reasons and could not return. Therefore, actual start took place a year later, even though it remained unclear who formally took over the role as network leader. It is a very concise network of people who had already worked together for many years but only included the core disciplines (PCP, CN, and CM). In the year between the first attempt at enrollment and actual enrollment, they successfully included welfare workers in their multidisciplinary meetings.</td>
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<tr>
<td>I</td>
<td>1 CM; 6 CN; 1 OT; 2 PCP; 4 WF; 2 other. (total: 16)</td>
<td>New collaboration</td>
<td>CN</td>
<td>Large</td>
<td>28; 25</td>
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<tr>
<td>Obtaining overview on “who does what” regarding dementia care to identify doubling and gaps (year 1)</td>
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<tr>
<td>For this network, the DementiaNet practice facilitators were contacted by a third (national) party with the intention to make this neighborhood ‘dementia-friendly’. The program team contacted multiple care professionals in this area with a shared patient caseload and eventually a network was formed.</td>
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<tr>
<td>J</td>
<td>1 CM; 1 CN; 1 MM; 1 PCP; 1 PN. (total: 5)</td>
<td>New collaboration with unacquainted members</td>
<td>CN</td>
<td>Small</td>
<td>18; 16</td>
</tr>
<tr>
<td>Obtaining overview on “who does what” regarding dementia care (year 1); improvement of diagnostic process (year 1)</td>
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<tr>
<td>A community nurse undertook the initiative to set up a local network, which was quickly formed. This was a compact network with only key players in dementia care, yet they were unacquainted with each other at enrollment in the program.</td>
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</tr>
<tr>
<td>K</td>
<td>2 CM; 2 CN; 1 MM; 1 OT; 1 PT; 2 WF; 3 other. (total: 12)</td>
<td>New collaboration with unacquainted members</td>
<td>OT, WF</td>
<td>Small</td>
<td>8; 11</td>
</tr>
<tr>
<td>Social care map (year 1); increasing dementia expertise (year 1)</td>
<td></td>
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<td>Initiative to participate came from a manager of a home care organization. A meeting was set up with the care professionals and after they expressed interest, other interested professionals were found from the primary care practice, day care and welfare. At enrollment, they were mostly unacquainted with each other.</td>
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<tr>
<td>Their focus was to get to know each other and to get more insight into each other’s roles and tasks. This was highly stimulated by the network leader who showed to be skilled in connecting people. Interprofessional training further stimulated this and simultaneously increased expertise on complex care situations. Agreements were set out for patient care between involved professionals. It is a stable and compact network and attracted other interested professionals during the year.</td>
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</table>
### Characteristics and narrative summaries of the primary care networks in the DementiaNet program

<table>
<thead>
<tr>
<th>Network</th>
<th>Composition at start</th>
<th>Collaboration</th>
<th>Network leaders</th>
<th>Catchment area</th>
<th>Caseload of patients (start; yr 1; yr 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>L</td>
<td>1 CM; 8 CN; 2 PCP. (total: 11)</td>
<td>New collaboration</td>
<td>CM, CN</td>
<td>Small</td>
<td>22; 30</td>
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<tr>
<td></td>
<td><strong>Narrative summary</strong></td>
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<tr>
<td></td>
<td>Introduction of multidisciplinary meetings (year 1); geriatric assessment (year 1)</td>
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<tr>
<td></td>
<td>Case manager initiated the formation of a network, by talking to several professionals in the area; primary care physician and home care joined. This network operates in a small village with only one home care organization, resulting in much overview. All key players are present in the network and highly involved; network leaders are enthusiastic and capable of undertaking action.</td>
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<td>They have implemented several initiatives on their own to move forward with the network, such as a comprehensive approach to formulating a vision and tackling possible discrepancies among network members. Improvement of multidisciplinary meetings was successful. They also worked on a shared vision towards care, enhancing the connection between different professionals. They also followed training on geriatric assessments and implemented this in practice. During this year, a manager of the home care organization joined the network.</td>
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<tr>
<td>M</td>
<td>1 CM; 4 CN; 1 GS; 1 PCP; 1 PN; 1 WF. (total: 9)</td>
<td>New collaboration</td>
<td>PN</td>
<td>Small</td>
<td>11; 16</td>
</tr>
<tr>
<td></td>
<td><strong>Narrative summary</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Working agreements (year 1); improvement of communication (year 1); improvement of expertise (year 1)</td>
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<tr>
<td></td>
<td>Primary care physician was interested in the program; practice nurse took on the role as network leader. Home care, an elderly care physician and case manager responded positively to the request to join.</td>
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<td></td>
<td>The connection with elderly care physician and case manager needed some improvement and all professionals felt they could benefit from formulating working agreements regarding dementia care. After that, they focused on improvement of communication, of which the introduction of joint multidisciplinary care plans was one aspect. Educational sessions on problematic behavior and diagnostics were arranged. The network is stable with no changes.</td>
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</table>

**Catchment area:** area from which the network attracts its patient population, defined by geographical size and population distribution and density; large = more than approximately 5,000 persons. PCP = primary care physician; PN = practice nurse; CM = case manager; CN = community nurse; GS = geriatric specialist; OT = occupational therapist; PT = physiotherapist; MM = management or municipality; WF = welfare worker.
Experiences with Dementianet program

Collaboration
In general, care professionals perceived that participation in the DementiaNet program resulted in shorter communication channels, higher acquaintance with each other's disciplines as well as personally, increased overview of local professionals and easier access to other disciplines, such as occupational therapists and physiotherapists.

Care processes
Perceived impacts of DementiaNet on care were: increased and more active monitoring of individual dementia patients as well as at population level of older patients in a network, introduction and improvement of multidisciplinary meetings, increased expertise in diagnostics subsequently resulting in more and earlier diagnoses, a shift towards diagnostics in primary care instead of unnecessary referral to expert clinics, increased person-centered care regarding care needs of patients and informal caregivers, and better coordination of different care services.

Benefits for professionals and patients
Perceived benefits for professionals included more awareness about dementia in general and feeling more competent to care for people with dementia. Regarding the network collaboration, professionals experienced a more profound feeling of shared goals and visions, easier and more efficient collaboration among involved care professionals, and improved coordination of care. Care professionals reported no disadvantages and felt that patients and their informal caregivers gained benefit from better-timed and more efficient processes regarding the diagnosis.

Contextual factors
Conditions that enhanced collaboration included a sufficient size of the shared caseload, practice-based learning that transcends the boundaries of individual disciplines and networks, concrete agreements about communication and working in close proximity to other professionals, preferably in the same building. Factors to stimulate continuity of care were integration of services from different disciplines by means of multidisciplinary meetings and multidisciplinary care plans, and short communication channels between all involved care professionals (i.e. by shared infrastructure to exchange information). The presence of active and capable network leaders seemed to play a key role in achieving actual improvement goals.

Integration
Joint interpretation of the multiple data sources led to the identification of several patterns (Table 8.2). Although most networks increased in network maturity, patterns showed that those networks that started with professionals who were already acquainted with each other to some extent, were more likely to increase on QI scores. Unacquainted networks were more likely to choose improvement goals focusing on initiating their network and collaboration, whereas more acquainted networks were already able to work collaboratively on actual care processes.

The primary care practice of the primary care physicians (PCP) was identified as an essential element of successful network-based care. Patterns showed that networks with highly involved PCPs performed better than those without or with only little involvement. Especially, those networks in which leadership was assigned to staff working at the primary care practice (i.e. PCP or practice nurse) improved. These findings were also confirmed in the two best performing practices, in which primary care practice involvement seemed to play a central role in their success.
Leadership in general was an important prerequisite for success. Networks that experienced problems with leadership and those without competent leaders showed no or only minor improvements. Furthermore, lack of accurate leadership was possibly one of the factors leading to decreases in QI scores and network maturity, along with not having all key disciplines involved in the network and interpersonal problems among network members.

The area in which networks operated seemed to influence the magnitude of improvement. The catchment area sizes seemed to be related to network sizes: larger areas, on average, showed higher numbers of involved professionals, likely as a result of higher numbers of care providers operating in those catchment areas. This increases the complexity of collaboration and also decreases the shared caseload between several professionals in the networks. Networks from smaller catchment areas displayed increased progression of network maturity and QI scores.
Figure 8.1 — Network maturity and quality of care trajectories

A: trajectories over time in network maturity
Letters indicate the networks and correspond with the letters in Table 8.1.

B: trajectories over time in quality indicator scores
Letters indicate the networks and correspond with the letters in Table 8.1.
Figure 8.1 — Network maturity and quality of care trajectories

Table 8.2 — Inferences from joint interpretation of data sources

Patterns prompted by quantitative findings

Networks starting at low quality of care
- Of the six networks with the lowest QI scores at start, three showed very large increases over the first year (E, H, L) and three had only minor increases (B, D, K).
- Several factors may explain differences between these two groups. Most importantly, the three successful networks are characterized by active participation of primary care practice: the PCPs are highly involved as team members and have an active role in the improvement plans, and network leaders all work as part of the primary care practice. Also, the successful networks are relatively small and more rural compared to the less successful networks.

Network maturity as prerequisite to increase quality of care
- Networks J, K and M started as (fully) new collaboration and showed considerable increase in network maturity.
- Network J and K started as a fully new network. Hence, improvement actions were primarily aimed at getting to know each other in person as well as each other’s professions, tasks, competences and preferences.
- Network M started as a relatively new network with acquainted members. Improvement goals were aimed on process agreements and communication.
- In all networks, network maturity increased, yet, no considerable improvements were reached on QI scores. Hence, this indicates that a certain level of network maturity is required as prerequisite to enable networks to collaborate in improving care processes and thereby improving quality of care.

Declining quality of care
- Some networks (D, E, G) showed decreased QI scores after quality improvement cycles.
- Network G showed a substantial increase in QI scores over the first year, but decreased over the second. In this network, divergent visions on good care caused problems in interpersonal relationships. In addition, both network leaders had been absent for part of the second year, which resulted in delays for improvement actions.
- Network E started without several key players, but with the intention to involve a primary care practice along the way. This was deemed unsuccessful due to several reasons: the geographical area was large including multiple different primary care practices; PCPs showed no interest to collaborate or join as network members; and inability to improve care processes without involvement of relevant primary care practices. Hence, attention was largely aimed at initiating overall collaboration as a network, instead of working as a team on patient-level processes.
- Network H showed minor increase in the first year, but decreased to the starting level during the second year. Although advancements were accomplished during the second year, this was not reflected in the QI score. The primary improvement goal was the implementation of an online communication tool (not reflected in the QI scores). Other improvement goals received little attention and network leadership was suboptimal (one of two leaders was replaced and both felt less motivated because of little actions undertaken by other network members).

Table: Differences in network maturity and quality indicator scores per year

Letters indicate the networks and correspond with the letters in Table 8.1.
Patterns prompted by network characteristics

<table>
<thead>
<tr>
<th>Strength of leadership</th>
<th>Improvement goals vary with level of collaboration</th>
<th>Catchment areas</th>
</tr>
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<tbody>
<tr>
<td>Three networks (B, C, D) were identified based on the fact that leadership was observed to be suboptimal, with absent leaders, insufficient time investment to adequately lead improvement actions, no acceptance of the leadership role other network members, or leaders were not assertive enough for improvement plans to proceed.</td>
<td>Four networks (A, B, C, H) were characterized as existing collaborations. This corresponded with high network maturity at start.</td>
<td>Networks were categorized as having either a small or large catchment area, depending on the size of the population (i.e. geographical area and population density) in the area they operate in. High density areas (often urban) are particularly characterized by a high variety in services available with numerous care providers (e.g. multiple home care organizations), increasing the number of professionals working in those geographical areas, decreasing the number of shared patients and an increased presence of competition, which all might complicate actual collaboration.</td>
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<tr>
<td>Indeed, networks with suboptimal leadership were not among those that displayed strong progression either on network maturity or QI scores.</td>
<td>Hence, improvement cycles were not aimed at increased acquaintanceship but mainly focused on increasing dementia-specific care processes and expertise (i.e. cognitive decline, problematic behavior in patients and dementia-friendly society).</td>
<td>Networks in large catchment areas (B, C, D, F, G, I) had higher average size of the networks. This also reflects more complex collaborations within the networks.</td>
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<tr>
<td>Networks with leaders from the primary care practice seemed to be more successful than those with other leaders.</td>
<td>Notably, improvement goals of those networks that just started collaboration and networks with lower network maturity scores at start were more often aimed at initiation or organization of collaborations, to meet each other and work together in the setting of primary dementia care.</td>
<td>With the exception of network F, the networks with the large catchment areas showed considerably less improvement, both on network maturity as on QI scores.</td>
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Unsuccessful networks

- The common denominator of the four networks that ceased participation within the first year is that no sufficient momentum was created to form a network. Overall, a necessary level of commitment and motivation was not reached before enrollment in the program in these networks.
- In one case, the network was initiated by a local government, although the participating healthcare professionals were not very motivated.
- In another network, there were problems with the primary care practice staff (the core of this network), and they felt like priority should be given to keeping up with regular work instead of investing in new initiatives.

Patterns prompted by success of networks

<table>
<thead>
<tr>
<th>Best practices</th>
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<tr>
<td>Two networks can be described as “best practices”. Network A was already at an exceptionally high level, both on network maturity and QI scores. Network F was a newly started collaboration and hence started rather low, but proceeded to high scores during the course of the program.</td>
<td>In network A, several elements have been identified making this network state of the art. First of all, they started as a tight group of professionals that have worked together for a long period. The fact that they were situated in a rather small village resulted in a limited number of professionals operating in the area, so they basically work together for all dementia patients in the area resulting in a sufficient shared caseload. Strong PCP leadership and a long mutual history, ensure high levels of acquaintanceship and trust among these professionals, as well as highly structured care processes. Explicit agreements have been laid out for many processes (e.g. diagnosis and assessments). Furthermore, they have a well-structured multidisciplinary meeting to discuss each patient, which is a central aspect, with active involvement of patients and informal caregivers. The meeting results in (adjustment of) a multidisciplinary care plan, which is available to all professionals in an online infrastructure, including informal caregivers. This ensures continuity and stimulates collaboration to a great extent.</td>
<td>Network F already had the preconditions for a mature network at enrollment, such as acquaintanceship and a history together, but had not gotten around to defining their network and the processes, partly due to lack of knowledge and leadership. Upon starting in the DementiaNet program, both needs were addressed at the very start. This network was then capable of defining a collaborative structure and simultaneously working on specific care processes, resulting in a high increase in both network maturity and quality of care scores over both years. Their major focus points were the disciplinary meeting and diagnosis.</td>
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<td>Characteristics that both networks have in common are the highly involved primary care practice, network leader(s) working in the primary care practice, and strongly basing collaboration and coordination on highly structured and frequent multidisciplinary meetings at fixed time points as the main way to communicate about individual patients.</td>
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DISCUSSION

Seventeen networks were successfully established of whom 13 accomplished one or more active years in this program. Overall, this multiple case study showed an increase in both network maturity and quality of care during the course of the program. Also, a positive association was indicated between network maturity and quality of care scores. Collaboration, communication, and coordination of care improved according to healthcare professionals in the networks, and DementiaNet enabled them to beneficially impact care. Importantly, prerequisites for successful transition towards more mature and integrated networks were identified.

These findings indicate that most networks have successfully transitioned towards a more mature and integrated network. The estimated overall effect in network maturity per year in the program was approximately two points and estimated improvement in QI scores was approximately 8.5 points. To illustrate, this might indicate that in a single year, a network progresses two levels on the maturity model (e.g. from ad hoc to defined professional and clinical integration) and has 8.5% more dementia patients for whom all QIs have been fulfilled in comparison to a year before. As the yearly evaluations reflect an iterative transition process, maximal effects within a year are not realistically expected. However, in the long term, major change emerges from aggregation of marginal gains. "

Several enabling factors for this transition to network-based care were identified. These factors included strong and adequate leadership (preferably with leaders from primary care practice), high involvement of motivated primary care physicians, high acquaintanceship with other network members, and network seize with a compact network that operates in a relatively small geographical area. These empirical findings corroborate with theoretical models on primary care collaboration. "

DementiaNet was developed from a system-level perspective. Lessons from previous successful redesign efforts have shown that it is unlikely that single stakeholders can create a highly functioning system. Indeed, some previous studies have shown that interventions and programs aimed at single aspects of care (e.g. lack of expertise) have had limited to no effects on the care system. Following from complexity theory, this may not be surprising, as changes on multiple levels are needed to ensure change on the system as a whole. In line with this assumption, studies targeted at a more comprehensive level, for example case management intensity and health and social services integration, resulted in beneficial effects for dementia patients. Also, other collaborative care models are currently under study, such as the German Delphi-MV study, with positive initial results. However, initiatives taking on a system-wide approach that have been evaluated properly remain scarce.

The major strengths of the DementiaNet program were the simultaneous focus on various essential aspects of high-quality network-based care, the practice facilitation approach with support at local level with local leadership, and its flexibility to be modified to varying circumstances of each individual network. Also, being able to choose and set their own goals appeared to be a major advantage of the program and motivated network member to work on improvements. Following on this, the evaluation study was designed in such a way to on one hand allow flexibility and individualization of the approach, while on the other hand enabling generalizability between networks. The employed mixed methods design allowed for consequences of complexity such as unpredictability in outcomes, by ensuring an open view. In the current study, semi-structured interviews allowed to include unanticipated effects and provided relevant insights on the process of change. Moreover, the multiple case study design permitted for the analysis of group effects as well as to simultaneously study individual networks more closely to identify mechanisms and contextual factors that stimulated or hindered change.
This study had some limitations, including the limited time span. The DementiaNet approach demands considerable changes in behavior and practice from large numbers of actors; such adaptations require time. Even though major changes have been observed, a longer timeframe could have done more justice to networks with a slower change rate. Hence, longer follow-up would be needed to show endured effectiveness. A pattern was identified where networks had to define collaborative efforts before care processes could be addressed; this could be substantiated more strongly with longer follow-up. Another limitation included the fact that the quality indicators used in this study were newly developed. Nonetheless, the initial set of QIs was rigorously developed through multiple consensus rounds and based on existing guidelines and agreements, and was tested for face validity before application in this study. Furthermore, QIs were reviewed prior to analysis for coherence, missingness and floor and ceiling effects.

Findings from this study might well be used to inform future application of network-based approaches. Results might be translated to similar care situations, like for example care for frail elderly, where similar professionals are involved. For that purpose, the achieved diversity in the studied networks (i.e. newly or existing collaboration, small and large network size and catchment areas) is a valuable property in two ways. First, these multiple different networks have ensured information based on wide diversity of healthcare professionals and settings. Secondly, it has shown that the design of DementiaNet allows for adaptation to local complexity and individualization, which might serve as a basis for translation to other populations and various settings as well. When research findings of the current study are to be applied to other settings, the context needs to be taken into account, as this plays an important role in the success of the DementiaNet program.

To conclude, the DementiaNet program resulted in a successful transition towards more integration in primary care networks, which was accompanied by an overall increase in quality of dementia care. Also, collaboration between network members from different disciplines and coordination of care improved. Distinctively, mechanisms through which these improvements were achieved as well as conditions enabling the transition were identified. These findings indicate a beneficial effect of the DementiaNet program and the potential gains to be made by enforcing a transition towards network-based care for dementia patients. Such transitions might benefit patients and informal caregivers, as well as primary care professionals.
Chapter 8 — Longitudinal multiple case study on effectiveness of network-based dementia care towards more integration, quality of care, and collaboration in primary care

References


Chapter 9

Summary and discussion

Six Blind Men and the Elephant

John Godfrey Saxe

And so these men of Indostan
Disputed loud and long,
Each in his own opinion
Exceeding stiff and strong,
Though each was partly in the right,
And all were in the wrong!
SUMMARY AND DISCUSSION

Management of people with dementia is becoming one of the biggest challenges to primary care nowadays. The DementiaNet innovation was developed as a potential answer to these challenges and is based on the following four principles: network-based care, clinical leadership, quality improvement cycles, and interprofessional education. An evaluation study was conducted in conjunction with the implementation of DementiaNet to gain insight into its merits. In addition, this thesis elaborates on prerequisites for rigorous conduct of such evaluation studies.

What is the effectiveness of DementiaNet and what further lessons can be drawn from this study?

— An overall increase in network maturity and quality of care scores was observed in networks over the course of participation in the DementiaNet program.

— There seemed to be an association between network maturity and quality of care scores.

— Meaningful explanations for individual network trajectories on quantitative outcomes could be derived from qualitative logs of networks and more general patterns of change were identified. Factors that enable or stimulate the transition towards more integrated networks and improved quality of care, such as high general practice involvement, strong leadership and good acquaintanceship among network members.

— The DementiaNet program was perceived as beneficial by participating professionals on aspects such as experienced collaboration, care structure and competencies.
What are the strengths and weaknesses of a multiple case study design to study programs such as DementiaNet?

— Mixed methods multiple case studies may provide valuable insights in studying innovations like the DementiaNet innovation that could potentially be missed when studied through more traditional designs.

— Multiple case study designs allow for in-depth studying of cases while maintaining the possibility of assessing group effects.

— Multiple case studies allow for more flexibility in the program or policy under study than do conventional study designs.

— In-depth studying of cases and their contexts can be laborious and overall group effects may have a relatively narrow basis because of limited numbers of cases.

What are the relevant psychometric properties of the IDEAL instrument for informal caregivers and the Perseverance time question in the setting of primary dementia care?

— The IDEAL instrument for informal caregivers showed to be a feasible and valid instrument to assess the severity of dementia patients in a primary care setting.

— The Perseverance time instrument showed adequate construct and predictive validity and responsiveness in informal caregivers for community-dwelling dementia patients.

— The Perseverance time instrument showed adequate construct validity and test-retest reliability in informal caregivers for institutionalized older persons.
Chapter 9 — Summary and discussion

MAIN FINDINGS FROM PART 1

In Part 1, several methodological aspects were addressed that enable the rigorous study of the most relevant topics in primary dementia care. Firstly, a reflection on study design appraisal was given. An illustrative example was used to show the potential value of case study designs, questioning the long-standing but also widely disputed hierarchy of designs. Here, it was argued that when case study designs and other non-experimental types of evaluation methods are precisely and rigorously designed and executed, they can yield highly valuable evidence that may carry much more relevance than experimental designs alone.

Secondly, in this Part attention was given to measurement instruments needed for evaluation of innovations such as DementiaNet. The psychometric properties were assessed of some instruments for the measurement of relevant constructs in the setting of primary dementia care and research. A first hiatus was found in the assessment of dementia severity outside of a clinical setting. A relatively new instrument, the IDEAL instrument, was thought to be highly appropriate for the primary care setting as it transcends more commonly used instruments such as the Clinical Dementia Rating by incorporating the informal and formal care system. This instrument was adapted into a version suitable for informal caregivers. The adapted version of the IDEAL instrument for informal caregivers showed good feasibility and concurrent and construct validity. It showed to be an easy, valid method for staging individuals with dementia by informal caregivers in both clinical practice and research settings by enabling assessment through questionnaires in absence of a doctor.

Thirdly, the Perseverance time question was considered an interesting instrument because of the following properties. The instrument directly addresses the invaluable aspect of informal care for persons with dementia in a manner that yields intuitively interpretable answers. Moreover, it is a single question that is easy to incorporate in questionnaires or interviews with an informal caregiver. Furthermore, it constitutes a useful addition to existing instruments because it takes into account not only the burden of informal care, but also the ability of the informal caregiver to cope with this burden. The Perseverance time instrument showed adequate construct and predictive validity as well as responsiveness in populations of informal caregivers for dementia patients. In informal caregivers for institutionalized older persons, also good construct validity was found as well as good test-re-test reliability. These findings encourage the use of this instrument in those populations. Additionally, this indicated that informal care is an important factor for maintaining the patient at home and it could be a useful screening instrument in clinical practice, for example for early detection of risks for crises and may enable timely intervention.
MAIN FINDINGS FROM PART 2

In Part 2, the development of the DementiaNet program and the study on its effectiveness, making use of the design and instruments discussed in Part 1, was described. Firstly, the development of the programme is described in detail with underpinning theories and background. Secondly, an elaborate account of the effectiveness study was provided including all procedures and considerations. Lastly, the results from the effectiveness study were described.

The DementiaNet program was started in 2014 and the first participating networks were enrolled in the program throughout 2014 and 2015. Seventeen networks were successfully recruited and 13 of them accomplished one or more active years in the program. A wide variety of networks participated, including both large and small ones, networks from rural and urban areas, networks with professionals who just initiated their collaboration in the context of this program and networks who already worked together for years. High degrees of variety between the starting levels of the 13 networks were observed on network maturity and quality of care scores. Overall, the 13 networks showed improved network maturity over the course of the program, indicating a successful transition towards more integrated networks. In addition, an overall increase in quality of care scores was observed. Network maturity and quality of care scores showed an indication of positive association, suggesting that higher level of integration in the network was a favourable factor for achieving better quality of care. The overall tendency in the in-depth interviews was that professionals perceived the program helped forward collaboration, communication and coordination, and also beneficially impacted the care they delivered on some aspects, most often the diagnostic process and multidisciplinary meetings.

Moreover, when studying the data sources of each network jointly and more in-depth, interesting patterns in the network logs explaining the time trends on the quantitative outcomes were revealed. One important pattern was the fact that networks with a collaboration that was only just initiated, often worked primarily on getting acquainted with each other as professionals (e.g. learning more about their competences, tasks, educational background and communication preferences), before they could work on optimizing actual care processes. This was also reflected in the improvement goals that such networks worked on. Moreover, the central role of the general practice was highlighted. Highly involved general practitioners (primary care physicians) as well as strong leadership, preferably situated in the general practice, were found to be favourable factors within the DementiaNet program. Also, studying the characteristics and logs of the networks that ceased to exist within the first year yielded valuable insights regarding the necessary momentum to initiate a transition towards network-based care. On the other hand, looking at “best practices”, two very strong networks, indicated that a well-structured and frequent multidisciplinary meeting with all involved care professionals as a central tool in care processes is an important tool to enable coordination and collaboration. In addition to the fact that these insights and patterns are highly informative, they illustrated the added value of the mixed methods multiple case study approach.

Lastly, from the interviews and the studying of the best practice cases, several contextual factors have been identified that enable or stimulate successful network integration and high quality of care. These factors are for instance physically working in the same building with many involved care professionals and the use of infrastructure to share patient data and multidisciplinary care plans. Such information can help optimize effectiveness for future networks by actively pursuing these factors where possible.

Overall, these findings indicate a beneficial effect of the DementiaNet program and the potential gains to be made by enforcing a transition towards network-based care for dementia patients and their informal caregivers.
DISCUSSION ON PART 1 & 2

Validation of measurement instruments

Part 1 introduced an innovative point of view regarding study designs. This point of view is more elaborately reflected on further, but study designs also have a connection to the internal validity and generalizability (also called external validity) of their products. Internal validity means that the findings from a study are not systematically biased. The process of applying assertions in a particular study to a population of patients in a particular clinical setting is called generalization and the extent to which the results of a study apply to that population is called generalizability. Although internal validity and generalizability are not fixed to specific study designs, some have better properties to ensure these aspects than others. For instance, the randomization process that is key in randomized controlled trials (RCTs) is a mechanism that greatly enhances high internal validity through comparability of groups. And although it is important for studies to produce findings with good generalizability to settings that are of interest, invalid findings are in any case useless. Therefore, internal validity is the first (but not necessarily the most important) problem to any study.

Valid and precise data are indispensable to come to valid conclusions. Validation, i.e. the assessment of relevant psychometric properties of instruments, is therefore an important step. It has to be noted that the psychometric properties are not a characteristic of the instrument itself; it is also dependent on the setting and populations. In primary dementia care research, instruments are not always validated, let alone validated in the correct populations and settings. Therefore, the findings from Part 1 of this thesis could be a valuable contribution towards better substantiated choices regarding and operationalization of data collection.

Dementia and informal care

The Chapters 3, 4 and 5 reveal part of the great value that informal caregivers often have in care settings as well as in research. The data collected on the assessed measurement instruments corroborated that informal caregivers provide major parts of care for their loved ones with dementia. The daily tasks that become too hard or even impossible to the person with dementia are supported by efforts from the informal caregiver. Not only do they spend hours of their spare time caring for their loved ones, they often form the connection between the person with dementia and the many formal caregivers.

Findings from the Perseverance time studies showed that many informal caregivers indicate that they believe maintaining the care situation for longer periods of time is possible, despite considerably high burdens. It is important to note that this burden can have various impacts. Of course, it takes time to care for a loved one, but psychologically it can also take its toll, as well as possible physical and relational burdens. The perseverance can only be maintained if the informal caregiver's capacity to cope with specific burdens is sufficient, if informally caring for people with dementia also offers sufficient value in return, and if support is available to cover hard times.

Ultimately, health care innovations often aim to improve patient (and in this case, informal caregiver as well) health and wellbeing. Although this aim seems logical, just like the logical consequence of focusing on these constructs as outcome measures of evaluation studies, there are some considerations to this choice.

Donabedian conceptualized a health care quality model with the domains of structure, processes and outcomes, where improvements in the structure of care should lead to improvements in processes and subsequently, this should improve patient outcomes. These three domains were also taken
The network maturity, referring to the level of integration of the network, fits in at the level of care structure, whereas the quality indicators refer to actual care processes. Informal caregiver outcomes assessed through questionnaires reflect the outcomes of care.

The DementiaNet program aimed to directly influence the structure by trying to increase the level of integration within networks. In addition, but in a less direct manner, it influences care processes by providing education and performance feedback on the quality indicators, and some networks worked on improving specific processes as part of their improvement goals. However, although the DementiaNet program endeavours to ultimately achieve improvements on patient and informal caregiver outcomes, this was only targeted through structure and process improvements, and not directly. Nevertheless, patient and informal caregiver-reported outcomes constituted part of the comprehensive data collection within the DementiaNet study.

In the protocol of the DementiaNet study, it was already clarified that no observable impact of DementiaNet on the patient and informal caregiver outcomes was to be expected within the timeframe of this study. Analyses of these outcomes based on the questionnaire data were thus not reported in Chapter 8 of the DementiaNet study for several reasons. First, the outcomes that were defined to be relevant (e.g., quality of life, caregiver burden, perseverance time of informal caregiver) were hypothesized to be influenced by structure and processes of care but also to a great extend by many other factors. It is not hard to imagine scenarios in which state of the art care in all aspects is delivered to a patient with dementia and their informal caregivers, where still their quality of life is rather low. This may be due to for instance inevitable disease progression with subsequent relational problems or basically any other factor that affects quality of life in people in general. Because of the fact that the actual effects are difficult to disentangle from all other influences, effects on outcomes (even if present) are much harder to reveal. Second, such outcomes are usually relatively inert. In order to substantially influence outcomes (i.e., an observable effect), a sufficient time frame of the study is necessary. Focusing on short-term effects when in fact it is likely that a “steady-state” in effects is to be expected on a longer term, will bias the effectiveness assessment of innovations. It is likely that for instance an outcome such as quality of life is not influenced by the DementiaNet program to such an extent that it is observable beyond error within one year. This also has to do with the fact that networks were followed from the moment they started participation in the DementiaNet program, but full implementation of the DementiaNet approach takes time or may not be achieved at all. Also, considerable sample sizes would be necessary to do so, which were not feasible in the current setting. Therefore, analyses on the patient and informal caregiver-reported outcomes were omitted.

Although patient and informal caregiver-reported outcomes did not contribute to the substantiation of the DementiaNet program in the report as published in Chapter 8 of this thesis, they do provide a valuable stepping stone for further study of the program. Moreover, they once more underline the great value the informal caregiver has both in care as research setting.
Implications of the DementiaNet program and future directions

For new innovations, a proof of principle is valuable and for that purpose, structure and process outcomes are essential. These were reported in Chapter 8 on the DementiaNet study. Hence, the findings of the DementiaNet study may have various implications for the DementiaNet program itself. For instance, the findings may be used to further optimize the program, to aim at creating optimal conditions to achieve beneficial effects with the program, and to show the value of the program to other stakeholders, such as health care insurance companies.

The study can also have implications outside of the DementiaNet program. For it to do so, a generalization step is necessary. Much debate can be held about the generalizability of findings from (multiple) case studies. In this debate, it is helpful to set a definition for case studies, of which Yin’s is a popular one: “A case study is an empirical inquiry that investigates a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context are not evident.”

Further, we can distinguish empirical (e.g. statistical) generalization and theoretical generalization (or analytic generalization according to Yin). It is evident that statistical generalization is inappropriate (i.e., inferring the statistical results from a sample and applying it to a population) from this multiple case study as the cases in the current study were by no means representative of any larger collection of cases.

In theoretical generalization, researchers develop explanations of the relationships between variables observed in their studies. These theoretical explanations may apply to populations on which the study was based or on other populations. A strength of case studies for such generalization is their ability to show more mechanistic insight into empirical phenomena. Davis and Marquis illustrated this with the following statement: “If a regression tells us about a relation between two variables – for instance, if you wind a watch it will keep running – mechanisms pry the back off the watch and show how.” Case studies generally provide more rich information on processes and by that, are more often able to elucidate the “how”. In addition, by seeking out patterns among a number of cases, one can come to more general inferences about a phenomenon that transcends the particularity of individual cases.

Such inferences could then be more generally applied to other cases. Although possible future cases may be different with respect to various aspects, this is not in itself a problem. As an obvious example, studying animals has taught us a lot about the processes in and functioning of the human body. What is relevant for any generalization are the factors necessary for the generalization to be valid. For DementiaNet, these can be derived from rich information about the studied networks and the context in which they reside. In line with Stake’s view on generalization from case studies, this should enable others to draw well-informed conclusions about the application of findings to their specific situations.

Tentatively, also other applications of the lessons learned from the DementiaNet study may be offered. For instance, it may be reasonable to assume that the approach may have beneficial effects when implemented in primary care in the Netherlands. For example, the DementiaNet program might well serve as an example to organize car for frail elderly in general, since the system throughout the country is more or less the same for the involved professionals and many of the care processes.

Other potential DementiaNet networks will probably have a set of characteristics that are not exactly the same as any network in the study. However, the fact that the DementiaNet program is flexible on several aspects, i.e. the composition of networks, the quality improvement plans, the support provided, means it could fit to a great range of possible networks. Moreover, most networks were only formed in the context of participation in the DementiaNet program, automatically ensuring a fit between most networks...
and the program. In the future, the program can be iteratively adapted to enable as many opportunities as possible for new networks, e.g. with a broader scope than just dementia care. Key players in primary dementia care are the same players involved in care for frail older people with chronic conditions in many cases. This raises the question whether the DementiaNet approach could be valuable outside of the boundaries of care for dementia populations. In several interviews it was already mentioned that DementiaNet networks already applied their network-based setting and collaboration to other patients without dementia. Further study could assess whether this leads to positive results as well.

Furthermore, although initial results in the studied networks showed promising results, the question arises how the trajectories of the studied DementiaNet networks will proceed. DementiaNet was offered as a means of practice facilitation and provided support (e.g. in identifying and forming improvement goals and plans; in realizing adequate leadership from network leaders), training and educational options, performance feedback and a framework for networks to develop in. As it is not feasible to maintain the practice facilitation in function, networks have to stand on their own feet at some point. In order to maintain the transition towards more integrated network-based care, they have to become self-organising, for instance with respect to improvement goals and plans and by maintaining active and capable network leaders to stimulate and coordinate this process. To see if networks can work towards the required level of self-organisation within two years in the program, a new study building on the initial DementiaNet study will be started. It will primarily focus on the sustainability of the transition that has been initiated in existing networks.

**Strengths and weaknesses of multiple case study design**
The employment of the mixed methods multiple case study design exemplified several strengths and weaknesses of the design for evaluation of effectiveness of the DementiaNet program, in comparison to other possible designs such as (quasi-)experimental designs. Before, it was mentioned that in general, case studies are strong in providing rich information on the mechanisms of effects.

One other major strength of using multiple cases instead of studying a single case is the opportunity of in-depth studying of cases while maintaining the possibility of comparisons. In many other study designs, particularly experimental designs, the subjects in the study are only viewed as part of a group, without further scrutiny of the individual subjects. In the DementiaNet study, this scrutiny has resulted in the construction of logs on each DementiaNet network, which subsequently provided rich information on how processes were influenced and how these processes lead to the observed outcomes. Furthermore, the in-depth studying of each network yielded detailed information about the network's backgrounds, enabling inferences about generalizability of the findings. In addition to these aspects, the design allowed for cross-case comparisons. By contrasting specific networks on relevant aspects, the influence of such aspects on outcomes could be considered. Still, an overall group estimates could be calculated with certain precision because of the number of cases, thus allowing for overall time trends to be quantified.

The use of mixed methods was perceived as a strength as well. Whereas effectiveness is usually determined by quantitative data analysis, the complexity of the primary dementia care system and the DementiaNet program warranted a different approach. Experimental study designs often use predefined outcome measures to determine effectiveness. However, with high levels of complexity, both of the context and the program, comes a high level of unpredictability. Only using predefined quantitative outcome
measures puts the researcher at risk of missing important effects that are unexpected and thus not captured by the measures taken. In addition, the unpredictability sometimes results in unclear pathways through which outcomes are achieved. Both unexpected effects and the pathways through which they are achieved can be captured by in-depth interviews with various involved people.

One obvious weakness of the design is the lack of direct comparison to situations without implementation of the DementiaNet program, i.e. a control group. In the context of the DementiaNet program, individual health and social care professionals are encouraged to form a network. This calls into question what a control group could look like that would enable direct comparison among equal units of analysis. Comparing DementiaNet networks to individual professionals is problematic because they exist on different levels. The formation of networks of professionals without further participation in the DementiaNet program would also be problematic because an essential part of the program (i.e. the formation of a network) would also be present in the control group.

Furthermore, dividing networks between the DementiaNet group and the control group would ideally be based on random assignment to ensure two comparable groups of networks. However, such approaches rely on a certain level of homogeneity among subjects. The human body as a subject may demonstrate a certain variability in its characteristics and functions. This variability may be greater among general practices as study subjects. In networks of primary care professionals, this variability may be even greater yet. This would result in huge numbers of networks necessary to arrive at comparable groups, leaving this scenario unrealistic and infeasible.

The fact that the inclusion of a control group, that may or may not use random assignment, is an unrealistic scenario does not mitigate the uncertainty of direct causal inferences. It is often argued that effects cannot be causally contributed to an intervention under study in absence of a control group. However, in traditional experimental research, the control group serves as the counterfactual to approximate what would happen to the intervention group if they had not received the intervention. Hence, a comparison only makes sense if a comparable control group can be achieved. This comparability refers to baseline characteristics of study subjects. However, within the context of complexity and the inherent unpredictability, it is not readily apparent which characteristics are relevant.

Furthermore, it should be noted that causality is not an attribute of a specific study design. The considerations of Hill on causality, of which only one refers to experiments, can also be applied to uncontrolled studies. For instance, mixed methods multiple case studies give opportunity to explore consistency, specificity, temporality, biological gradient and plausibility of observed effects. In this particular case, the complexity of the primary dementia care system also plays a role. Changes in such systems are often rather inert. By studying the conditions under which effects have been observed (e.g. large policy changes), it can be inferred which conditions are most likely to have influenced the outcomes as possible alternative explanations, yielding plausible causality claims.
GENERAL DISCUSSION

Complexity
During the work performed on the DementiaNet program, it has become evident that the primary dementia care system should be viewed as a complex system. Simultaneously, the DementiaNet program that is introduced into this system has to be considered in itself as well. Although some may consider such a program to be an intervention (introducing a program that aims to change care delivery can be seen as intervening in usual care), it does not follow some rules that apply to more simple interventions such as the degree to which it can be controlled and standardized. However, several of the key elements of complex interventions that have been described in the widely cited Medical Research Council Framework apply to the DementiaNet program.\(^3\) In short, the number of interacting components (professionals, organizations) is high, the number and difficulty of behaviours to be altered is considerable, the program targets several groups and organisational levels, there is a high number and variability of relevant outcomes, and the degree of flexibility and tailoring of the program is high.

Although this provides an illustrative image of some complex aspects of the program, the perspective of seeing it as an intervention has led the Medical Research Council Framework to adopt as much as possible a conservative approach to evaluating the effectiveness of interventions. The framework leans towards applying as much as possible an RCT way of thinking, only deviating when no other options are available.

It may be more fitting to see the DementiaNet program as part of the complex system in which it is implemented. The following description of a complex system is based on the article of Plsek and Greenhalgh that was considered highly fitting for health care systems.\(^5\) A complex adaptive system is a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent’s actions changes the context for other agents. Examples include the immune system, a colony of termites, the financial market, and just about any collection of humans (for example, a family, a committee, or a primary healthcare team). Because the agents within it can change, a complex system can adapt its behaviour over time. The evolution of one system influences and is influenced by that of other systems. The behaviour of a complex system emerges from the interaction among the agents and is often non-linear. Because the elements are changeable, the relationships non-linear, and the behaviour emergent and sensitive to small changes, the detailed behaviour of any complex system is fundamentally unpredictable over time. Despite the lack of detailed predictability, it is often possible to make generally true and practically useful statements about the behaviour of a complex system, as there is often an overall pattern. Order, innovation, and progress can emerge naturally from the interactions within a complex system; they do not need to be imposed centrally or from outside. Recognition of this complexity had several implications for the DementiaNet program and evaluating it, but it started by asking the question of why evaluation is needed in the first place.

Evidence and its role in health care
The movement of evidence-based medicine (EBM) started out in the early nineties to promote the use and acquisition of a better empirical basis and systematically incorporating scientific evidence into medicine and health care. It was described by David Sackett as follows in the most quoted line ever published in the BMJ: “Evidence based medicine is the conscientious, judicious and explicit use of current best evidence in making decisions about the care of individual patients”.\(^6\)

Nowadays, EBM (and evidence-based health care as a theoretical extension of it) both has many followers and critics, the latter having provided very
reasonable criticisms to EBM itself or the application and role of evidence in medicine. However, it is undeniable that scientific evidence has stood at the cradle of many major advances in medicine. Leaving all criticism about how evidence should be incorporated clinical practice aside, there is general consensus that we as a society need to invest our resources into medical practices, treatments, innovations and policies that are effective and cost-effective as shown through rigorous research.

Unlike clinical treatments, innovations in primary care (and other fields such as health services or nursing) are not always subjected to such rigorous research. Especially given the complexity of many innovations in primary care and subsequent uncertainty, this is an essential step in forming an empirical basis for policy decisions. Lack of research on these innovations hinders the ability to distinguish innovations that change health care for the better, from those that lack beneficial effects, and subsequently hinders optimal allocation of health care resources.

The EBM movement, in line with their first principle (the higher the quality of evidence, the closer to the truth are estimates of the effects of health interventions) yielded schemas for the assessment of evidence quality, primarily based on research design. As such, randomized controlled trials were said to provide the highest quality evidence, followed by cohort studies and so on. However, quickly it was realized that no single research design was inherently free of bias, resulting in numerous revised schemas.

To balance and broaden the discussion and to provide a comprehensive overview of all advantages and disadvantages of study designs, the case study design deserves commensurate attention in the field of medicine and health care.

To summarize, a study into the effectiveness of the DementiaNet program where the system's complexity was taken into account was deemed necessary. The study protocol provides all relevant details, but the following choices where the direct result of the complexity at hand: a multiple case study design to allow for in-depth studying of each participating network while maintaining comparative opportunities across networks; a mixed methods approach to apply a broad scope on potential effects; and continuous collection of rich data in logs to obtain all relevant information on the context of each individual network. Overall, this led to well-founded inferences regarding the effects of the DementiaNet program.

Evaluation, research and change
The framework to assess whether a policy or program leads to the desired effects is a matter of choice. One can take on an evaluation perspective or a research perspective. In literature, those terms are used interchangeably. Although research and evaluation can be characterised by features based on their shared objective of answering a question, it may be useful to distinguish between the types of question. Evaluation essentially aims to improve the program for the target population, whereas research is more concerned with proving or building hypotheses or theory. In the words of Stufflebeam: “The purpose of evaluation is to improve, not prove.” In this, a summative evaluation addresses the question whether the desired goals are accomplished by the program, whereas research is designed to provide results that go beyond an individual program and can be generalized to other populations, conditions, or times.
However, both are not mutually exclusive. Rigorous evaluation of a program can be shaped in such a way that enables more extensive assessment under the umbrella of research. Therefore, he terms evaluation and research have both been used in the context of the DementiaNet study. The study provided findings regarding the effectiveness of the DementiaNet program based on observations in the participating networks. Findings from this study may be generalizable to other situations by means of theoretical generalization. For this purpose, it should be noted that is not necessary for the studied population to be representative of the population to which one wishes to generalize. Gathering information on characteristics of the networks, contextual factors influencing the program, and the processes leading to the observed effects increases the potential for theoretical generalization and thus yields more generic knowledge.

Now it is safe to assume that most research is performed for other reasons than just the creation of knowledge; presumably we want to go towards solutions for problems, no matter how fundamental the research is. It is important to acknowledge the fact that knowledge, although necessary, often is insufficient in itself to form a solution and to drive change. In order to achieve change, the knowledge has to be translated into action.

Data have to be transformed into information, where numbers convey meaning about the measured phenomena, in order to build knowledge about how a system organisation or clinician is performing. Through this, data, information and knowledge support clinical delivery, the redesign of models of care and the consolidation of organisational structures to respond to changing population needs. They can drive change in various different ways. Levesque and Sutherland have recently published an elaborate typology of levers for change based on existing literature from various fields. They have described eight different levers that can be placed on two different axes: the source of motivation (i.e., internal vs. external) and the origin of change (i.e., emergent vs. planned).

The DementiaNet program uses several levers of change that are based in internal motivation. Cognitive and mimetic levers are found in the provision of feedback on performance. Data collected on the quality indicators of care were given back to the networks to show how they perform on each indicator. This aimed to improve network member’s awareness of gaps (cognitive lever), which is recognized as the starting point of many types of quality improvement. Moreover, by providing benchmarking data of other networks, the feedback appealed to a desire to conform or outperform, or at least not be outperformed by other networks (mimetic lever). Formative and supportive levers were addressed by education and training efforts provided to networks, support in quality improvement actions and support for network leaders in facilitating and coordinating the improvement actions.

With this program, the levers for change that are based in internal motivation are exerted to stimulate a transition towards better quality and network-based care in the DementiaNet networks. By building on existing networks, through the execution of the effectiveness study, new information is gathered that can be directed at a higher level of stakeholders to effectuate change. By gathering experiences with and scientific substantiation on the current networks, other stakeholders such as organizations, local or even national policymakers or health care insurance companies can be addressed. These stakeholders in turn have possibilities to enact more externally motivated levers of change, such as coercive (e.g., financial incentives and sanctions) and competitive levers (e.g., transparent reporting of performance data to put pressure on care providers to attract and keep clients). Through this, a further expansion of the DementiaNet approach can be stimulated while simultaneously building more knowledge on the performance of the approach.
This thesis described the work carried out regarding the DementiaNet program, and in particular the study into its effectiveness. The DementiaNet study has shown the initiation towards a successful transition into high-quality, network-based primary care for dementia patients. The program has resulted in better collaboration among care providers, more knowledge and competencies and more structured care paths. In summary, this thesis has shown the added value of the program in practice and laid the foundation for further optimization and study of the program. In addition, it served as an example to illustrate the necessity of valid instruments and appropriate study design. With respect to approaches to evaluate the effectiveness of new interventions, programs or policies, researchers, funders, publishers, commissioners of research and policymakers should all be receptive to a paradigm shift regarding the valuation of study designs. With the change in population needs for health care, the health care system has to adapt, and the research field addressing the health care system needs to adapt along.

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Chapter 10

Nederlandse samenvatting
About the author
Portfolio
List of publications
Dankwoord
Donders Graduate School
Naarmate jaren verstrijken, verandert het zwaartepunt van ziekte in de populatie. Waar vroeger de meeste ziektenlast werd veroorzaakt door infectieziekten, hebben we tegenwoordig hoofdzakelijk te maken met ziekten die gepaard gaan met welvaart en bijbehorende leefstijl, en ouderdom, zoals hart- en vaataandoeningen, kanker en dementie. Die laatste is een illustratief voorbeeld van een aandoening die veel van ons gezondheidszorgsysteem vraagt. Vaak zijn mensen met dementie oud en kwetsbaar en meestal hebben ze ook nog andere kwalen. Omdat dementie het leven van mensen en hun naasten op zo veel vlakken beïnvloedt, is er naast medische zorg ook sociale zorg nodig. Omdat er naast medische zorg ook sociale zorg en ondersteuning nodig is, dit heeft tot gevolg dat veel verschillende professionals betrokken raken bij mensen met dementie, bijvoorbeeld de huisarts, een casemanager, wijkverpleging, een welzijnswerker, een ergotherapeut, een fysiotherapeut, een wmo-consulent; ook wel eerstelijnszorg genoemd. Sommige professionals zijn langdurig in beeld, zoals de huisarts, terwijl anderen tijdelijk worden ingevlogen, zoals een ergotherapeut.

Het is belangrijk om zorg in de eerste lijn te bieden die van goede kwaliteit is, goed afgestemd op andere vormen van zorg en op wensen en behoeften van de persoon met dementie en zijn/haar naaste, en dat die zorg continu is; daarvoor moeten de verschillende professionals goed samenwerken. Helaas lukt dit nog niet altijd. Problemen die vaak aan de orde komen, zijn bijvoorbeeld dat professionals niet volgens bestaande richtlijnen werken of die richtlijnen niet kennen, dat professionals niet op de hoogte zijn van wat een ander rondom dezelfde persoon met dementie doet, dat sommige zorg dubbeld worden verleend, en dat er gaten vallen in zorg die wel noodzakelijk is omdat het onduidelijk is wie de verantwoordelijkheid draagt.

Als antwoord op de uitdagingen waar ons eerstelijnszorgsysteem mee te maken heeft, is DementieNet ontwikkeld. DementieNet is een zorginnovatie die gericht is op netwerkzorg in de eerste lijn voor mensen met dementie. Centrale pijlers daarin zijn: structurele samenwerking binnen het netwerk van zorgprofessionals, leiderschap om samenwerking en verbeterinitiatieven te faciliteren en stimuleren, kort-cyclische verbetering van de kwaliteit van zorg en inter-professioneel leren om expertise te versterken en eenheid te creëren. De netwerken ontvangen ondersteuning in de vorm van coaching, scholingsmogelijkheden en praktische begeleiding bij het inzetten van deze pijlers. Uiteindelijk beoogt DementieNet dat verschillende zorgprofessionals zich op wijniveau tot een netwerk vormen dat structureel samenwerkt met patiëntoverstijgende afspraken en een vaste infrastructuur voor overleg en gegevensuitwisseling.

Het is van groot belang dat vernieuwingen in de zorg goed onderzocht worden voordat ze grootschalig geïmplementeerd worden, net zoals bijvoorbeeld bij nieuwe geneesmiddelen gebeurt. Innovaties hebben namelijk, net als geneesmiddelen, niet altijd het effect dat men voorspelt. Vandaar dat er, gelijktijdig met het opzetten van DementieNet netwerken, een onderzoek is gestart. Voor dit specifieke onderzoek waren nog niet alle benodigde bouwstenen voorhanden; zo was het bijvoorbeeld niet bij voorbaat duidelijk op welke manier er verschillende uitkomsten het beste gemeten konden worden en welke onderzoeksopzet het meest geschikt was. Deze benodigde bouwstenen zijn verder uitgewerkt in het eerste deel van dit proefschrift, en het uiteindelijke onderzoek over DementieNet staat beschreven in het tweede deel.

Het DementieNet onderzoek is opgezet als een meervoudig casusonderzoek. Daarin werd elk netwerk beschouwd als een casus en ze werden gedurende enkele jaren in het DementieNet project gevolgd. Dit zorgde ervoor dat de netwerken als groep bekeken konden worden, maar ook dat elk netwerk in meer detail bestudeerd kon worden en er zo inzicht kwam in de processen
die binnen de netwerken plaatsvonden en waar die door beïnvloed werden. Hierdoor kon ook gekeken worden naar de invloed van contextuele factoren op de netwerken.

In het DementieNet programma zijn 17 netwerken gestart, waarbij het meestal volledig nieuwe samenwerkingen betrof. Ze bestonden gemiddeld uit ongeveer 9 zorgprofessionals, waarvan de huisarts, wijkverpleegkundige, casemanager en welzijnswerker de meest voorkomende professionals waren. Er zijn op het moment van start en na elk voltooid jaar gegevens bij deze netwerken verzameld. Deze gegevens hadden betrekking op de mate waarin het netwerk geïntegreerd is en wat de kwaliteit van zorg is die zij leveren. Daarnaast zijn er ook interviews gehouden met professionals in de netwerken, om meer inzicht te krijgen in welke veranderingen en processen zij hebben ervaren binnen het DementieNet programma.

Het onderzoek laat zien dat 13 van de 17 netwerken minstens één jaar als netwerk hebben voortbestaan. De overige vier zijn binnen het eerste jaar ontbonden om uiteenlopende redenen, die terug voeren op een gebrek aan intrinsieke motivatie en/of mankracht om invulling te geven aan dit project.

Van de 13 netwerken zijn er 6 voor twee jaar gevolgd, en 7 voor één jaar. De verschillende netwerken zijn eerst als groep bekeken door te bestuderen hoe de scores op netwerkintegratie en kwaliteit van zorg zijn veranderd vanaf hun start in het DementieNet programma. Over de hele groep netwerken gezien, toonde het onderzoek aan dat er een stijging in de mate van integratie binnen de netwerken, en dat ook hun kwaliteit van zorg steeg. Daarnaast bleek dat kwaliteit van zorg hoger was in de meer geïntegreerde netwerken, wat in lijn is met de veronderstelling dat samenwerken als netwerk positief werkt voor de kwaliteit van zorg. Deze waargenomen vooruitgangen ondersteunen daarmee de uitgangspunten van DementieNet.

Omdat dit onderzoek opgezet was als een meervoudig casusonderzoek, werd er ook verder ingezoomd op elk netwerk apart. Door deze informatie te combineren met het verloop in scores op netwerkintegratie en kwaliteit van zorg, werden er enkele patronen zichtbaar. Zo bleek dat netwerken met grote betrokkenheid van de huisartsen(praktijk) en capabele netwerkleders werkzaam in de praktijk de meeste vooruitgang lieten zien op kwaliteit van zorg. Deze netwerken waren tevens relatief klein en zaten vaak in een dorpsomgeving. Een ander patroon dat zich openbaarde, was dat er een zekere mate van integratie in het netwerk bereikt moest zijn, voordat de kwaliteit van zorg verhoogd kon worden. De verschillende zorgprofessionals moesten eerst een verstandhouding krijgen met voldoende bekendheid, vertrouwen en werkafspraken, alvorens ze zich op concrete zorgprocessen konden richten. Ten slotte waren er twee netwerken die gekarakteriseerd kunnen worden als "best practices", die beide een goed gestructureerd en frequent multidisciplinair overleg als essentieel centraal middel hadden voor samenwerking en coördinatie van zorg rondom individuele patiënten.

Deze onderzoeksresultaten zijn een eerste uiting van de meerwaarde die met DementieNet behaald kan worden. Vooruitkijkend is het relevant om te zien wat de effecten op langere termijn zijn; bijvoorbeeld of de stijgende lijn in netwerkintegratie en kwaliteit van zorg verder voorgezet kan worden, ook bij afbouwen van ondersteuning. Daarnaast is het uiteraard ook essentieel dat uiteindelijk mensen met dementie en hun mantelzorgers merkbaar profijt hebben van DementieNet. Omdat dit meer indirecte effecten zijn, die tevens pas op langere termijn worden verwacht, zijn die nog niet bekeken in het beschreven onderzoek.

Wel is er een basis gelegd voor het op juiste wijze meenemen van relevante mantelzorg-uitkomsten in wetenschappelijk onderzoek, door meetinstrumenten ervan verder te onderbouwen. Zo is er gekeken naar de mantelzorgervolhoudtijd en het IDEAL instrument voor mantelzorgers. Het eerste instrument vraagt naar hoe lang mantelzorgers de zorgsituatie voor
hun naaste met dementie nog vol kunnen houden; een weerspiegeling van hun belasting en belastbaarheid. Het antwoord op deze vraag bleek aanzienlijke voorspellende waarde te hebben voor het opgenomen raken of overlijden van de naaste met dementie in het daarop volgende jaar. Het tweede instrument meet de ernst van de dementie, maar dan zonder dat daar een arts aan te pas hoeft te komen, en in een kader dat beter past bij eerstelijnszorgsetting. Het bleek dat mantelzorgers, met al hun kennis en ervaring over hun naaste met dementie, de ernst net zo goed konden inschatten als een arts. Deze twee instrumenten kunnen daardoor goede bouwstenen vormen in onderzoek dat de effecten bestudeert van innovaties zoals DementieNet.
About the author

Anke Richters was born on February 12th, 1990 in Mill. After finishing higher secondary education at Udens College in 2008, she pursued her education at the Radboud University Nijmegen studying Biomedical Sciences. During her Master’s phase, she focused on Epidemiology with minors in Oncology and Immunology. As an intern, she performed research on complications of central venous catheters in stem cell transplantation patients at the Department of Hematology of the Radboud university medical center, and on the surgical treatment of prostate cancer at the Netherlands Comprehensive Cancer Organisation. She received her Biomedical Sciences Master’s degree in November 2013. In January 2014, she started her PhD at the Department of Geriatric Medicine to work on the DementiaNet project. In addition to research, she was the chair of the department’s research meetings and teacher in the Biomedical Sciences and Medicine curricula of the Radboud University Nijmegen, resulting in the attainment of a University Teacher’s Qualification. Moreover, the accomplishment of this doctoral thesis forms the final step of the education to becoming an Epidemiological Researcher at PhD level (Epidemiologist B). As of September 2017, she works at the Netherlands Comprehensive Cancer Organisation as a post-doctoral researcher on the topic of bladder cancer.
Portfolio of Anke Richters

Courses

<table>
<thead>
<tr>
<th>Date</th>
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<tbody>
<tr>
<td>February 2014</td>
<td>BROK course (PAO Heyendaal)</td>
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<tr>
<td>April 2014</td>
<td>Qualitative Research Methods in Health Care (CaRe Research School)</td>
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<tr>
<td>June 2015</td>
<td>Clinimetrics (VuMC)</td>
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<tr>
<td>September 2015</td>
<td>Scientific Integrity for PhD students (Donders Institute)</td>
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<tr>
<td>October 2015</td>
<td>Project management for PhD students (Radboud University)</td>
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<td>October 2015</td>
<td>How to write a medical scientific paper (Radboud University)</td>
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Conference contributions

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<tr>
<th>Date</th>
<th>Conference/Event</th>
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<tr>
<td>May 2016</td>
<td>TOPICS symposium, The Netherlands: Poster presentation: “The IDEAL instrument for feasible and valid staging of dementia patients by informal caregivers” (best poster presentation award)</td>
</tr>
<tr>
<td>June 2016</td>
<td>NEON conference, The Netherlands: Poster presentation: “The IDEAL instrument for feasible and valid staging of dementia patients by informal caregivers”</td>
</tr>
<tr>
<td>May 2017</td>
<td>International Conference for Integrated Care, Ireland: Poster presentation: “Results of a multiple case study to evaluate the merits of a network-based primary care innovation for community-dwelling dementia patients”</td>
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Conference visits

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<tr>
<td>June 2014</td>
<td>NEON</td>
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<tr>
<td>April 2015</td>
<td>International Biometrics Society, The Netherlands</td>
</tr>
<tr>
<td>November 2016</td>
<td>Radboud New Frontiers in Cancer Research, The Netherlands</td>
</tr>
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</table>

Other activities

- Journal club for junior epidemiologists
- Clinical Trials (Pocock)
- A history of Epidemiologic Methods and Concepts (Morabia)
- Measurement in Medicine (De Vet et al.)
- Introduction into Meta-Analysis (Borenstein et al.)
- Clinical Prediction Models (Steyerberg)
- Oxford Textbook of Global Public Health (Detels et al.)
- Modern Epidemiology (Rothman et al.)
- Radboud Research Rounds
- Teaching activities for Biomedical Sciences and Medical students
- Supervision of internship (master)
- Peer reviewer for scientific journals

List of publications


DANKWOORD

Dit proefschrift vormt voor mij de afsluiting van een belangrijke stap in mijn onderzoekscarrière. Deze afsluiting nodigt uit tot een moment van reflectie en dan wordt duidelijk dat er heel veel mensen zijn die dit proefschrift mede mogelijk gemaakt hebben.

Als eerste wil ik graag de mensen in mijn promotieteam bedanken. Marcel, het was altijd fijn om te merken dat jij net als wij allemaal écht in DementieNet geloofde en je daar ook vol voor inzette. We konden altijd rekenen op jouw kritisch meedenken. Ook was ik altijd erg blij met jouw snelle feedback, vanuit je helicopterview heb je veel stukken een flink stuk scherper gemaakt. René, bedankt voor alle discussies die we hebben gevoerd samen. Of het nou over epidemiologische principes en analyses ging of meer over wetenschapsfilosofische zaken, discussies met jou waren nooit saai en altijd leerzaam en scherp. Marjolein, bedankt voor jouw inzet in ons mooie DementieNet project. De stukken werden met jouw inbreng scherper en gelukkig ook korter, zodat alles er uiteindelijk in paste! Marieke, jij ook bedankt voor je actieve rol in ons mooie DementieNet project. We hebben altijd met jouw inzet in het onderzoek. Jij hebt mij als kwantitatieve epidemioloog op het mixed methods pad geleid en dat heeft wat mij betreft wat moois opgeleverd!

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Uiteraard had het onderzoek ook niet tot stand kunnen komen zonder alle medewerking van de zorgverleners in de netwerken en de mensen met dementie en hun mantelzorgers die bijgedragen hebben. Ontzettend bedankt.

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En als laatste maar niet als minste wil ik papa, mama, Bob, overige familie, vrienden, Aurora en Rosso bedanken voor het luisteren naar mijn onderzoeksaanvragen en -struggles en het geven van goede raad. Bedankt, gracias en miauw!
For a successful research Institute, it is vital to train the next generation of young scientists. To achieve this goal, the Donders Institute for Brain, Cognition and Behaviour established the Donders Graduate School for Cognitive Neuroscience (DGCN), which was officially recognised as a national graduate school in 2009. The Graduate School covers training at both Master’s and PhD level and provides an excellent educational context fully aligned with the research programme of the Donders Institute.

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Positions outside academia spread among the following sectors: specialists in a medical environment, mainly in genetics, geriatrics, psychiatry and neurology. Specialists in a psychological environment, e.g. as specialist in neuropsychology, psychological diagnostics or therapy. Positions in higher education as coordinators or lecturers. A smaller percentage enters business as research consultants, analysts or head of research and development. Fewer graduates stay in a research environment as lab coordinators, technical support or policy advisors. Upcoming possibilities are positions in the IT sector and management position in pharmaceutical industry. In general, the PhDs graduates almost invariably continue with high-quality positions that play an important role in our knowledge economy.

For more information on the DGCN as well as past and upcoming defenses please visit:

http://www.ru.nl/donders/graduate-school/phd/