

DEMENTIANET

a sustainable transition towards integrated primary dementia care

Dorien Oostra

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Colofon

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DementiaNet:

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Proefschrift

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General introduction

Challenges for primary care

Due to population aging, the number of people with dementia will increase relevantly the coming years.¹ Currently, the number of people suffering from dementia in the Netherlands is estimated around 290,000 and this number is likely to be doubled in 2050, while depending on the trends in risk factors such as midlife obesity.² Due to healthcare reforms of the Dutch government in 2015, a large number of people with dementia are required to live longer at home with more complex health care needs.³ As a side effect this caused an increase in the number of crisis admissions of people with dementia, since homes for the elderly have been closed and requirements for admission were sharpened.⁴

This shift from institutional to community-based healthcare services increased the complexity of primary dementia care. Especially in later stages of the disease, involvement of many different primary care professionals of medical-, care-, and social disciplines is required.⁵ Frequently up to ten healthcare professionals are involved in the care for one person with dementia living at home⁶ (see Figure 1). Often these professionals work at different organizations and tend to focus on their own field of expertise, which has resulted in fragmented primary care.⁷⁻¹⁰ Consequently, continuity of care is lacking and there is a low satisfaction with the provided care among professionals, persons with dementia, and their informal caregivers.¹¹⁻¹³ Together with an increased workload and a shortage of healthcare professionals, which is likely to increase even more in the future, this poses a major challenge for primary care.¹⁴



Figure 1. Graphical illustration of a sample of the professionals involved in the care for people with dementia living at home.

Caregiver burden

One of the strategies of the government to overcome staff shortage is to promote an active role for informal caregivers in the care for people with dementia living at home. Informal care is non-professional care provided by someone from a person's social environment, usually a partner or child.¹⁵ Providing this care causes a considerable burden on these informal caregivers ¹⁶ but when given in a balanced situation, it may also add to reciprocity and mutual wellbeing.¹⁷ Currently, informal caregivers frequently experience stress and frustration, or suffer from depression or depressive symptoms.¹⁸⁻²⁰ Thirty-nine percent of the informal caregivers for people with dementia experience a heavy burden, and fourteen percent even feels overburdened.²¹ Informal caregivers' perceived burden also increases the risk for institutionalization of people with dementia ²²⁻²⁴ as the dementia progresses and the care system at home becomes more and more vulnerable, as illustrated in the case description below. Minor accidents, whether preventable or not, may push the whole system over a tipping point for which often nobody is prepared.²³ Adequate case management and network-based care is needed to notice the lack of resilience in the system, mention the crisis scenario as a likely outcome and prepare advance directives for all involved.

The case on the next page also shows that it is essential that informal caregivers experience sufficient support to perform their caregiving tasks without becoming overburdened.^{25, 26} Monitoring caregivers' burden and providing them with a network of healthcare professionals able to provide timely support, may benefit the wellbeing of both caregiver and care recipient. Moreover, society as a whole, can benefit since it may decrease healthcare costs by reducing the number of acute hospital and nursing home admissions.^{24,27,28} Given the fragmented care mentioned earlier, this not only requires case management and leadership towards anticipatory care, but also requires a well-linked network of professionals and informal caregivers to be able to support the jointly agreed goals. This shared goal setting most often prioritizes wellbeing above survival.

Interprofessional collaboration

Collaboration between professionals entails that all disciplines look at the care recipient as a team with a shared care plan, shared responsibility, a shared goal and a holistic person-based approach through dialogue with the patient and its informal caregiver.²⁹⁻³¹ Nowadays, due to part-time work of many professionals involved, each with their own institutional loyalty, coordination of care and communication between professionals and informal caregivers is often suboptimal.^{32, 33} Improving interprofessional collaboration and communication, and including the informal caregiver and person with dementia, both are prerequisites to enhance the efficiency and quality of care for people with dementia ³⁴, thereby reducing fragmentation and overcoming the aforementioned challenges primary care faces. To facilitate interprofessional care, strategies are needed to improve interprofessional collaboration and work towards primary care integration. An interprofessional way of working can act as a catalyst for achieving integrated care.³⁵

Case description: example of a crisis situation with an informal caregiver under great stress and an emergency admission to a nursing home due to lack of support at home

Mr. D. is 93 years old and is informal caregiver for Mrs. J, 95 years old, who has been diagnosed with Alzheimer's disease five years ago. They will celebrate their 60th wedding anniversary next year. Mr. D. is therefore motivated to keep caring for his wife so that they can stay together in their own home. Mrs. J. enjoys being in her familiar surroundings and thanks him multiple times a day that he is such a wonderful caregiver for her.

Unfortunately, the Alzheimer progresses and Mrs. J. is not able to be alone in the house anymore. This creates a high burden for Mr. D. since he can no longer spend time on his own hobbies. His main hobby is to paint, and he has a small workplace in the basement of their building. However, it is not doable to go there without upsetting his wife. Consequently, he spends all his time caring for her and keeping her company.

Then the most unfortunate event happens, Mr. D. falls and breaks his hip. He is admitted to the hospital and has to undergo surgery and rehabilitation afterwards. Since Mrs. J. depended so much on his caregiving, she is not able to stay at home either. She is acutely admitted to a nursing home. After a few weeks at the nursing home she becomes ill and has a pneumonia. Suddenly everything deteriorates fast and she dies in the nursing home a few weeks after being admitted.

Mr. D. is able to recover from his hip surgery and is finally able to go home, reflecting on a heart-breaking chain of events.

Integrated care

Integrated care aims to affect all levels of care, i.e. at a patient-, professional- and system level and work with shared patient-oriented goals. It proved to enhance cost-effectiveness, thereby contributing to a sustainable primary care system.³⁶⁻³⁹ However, integrated care is still considered a difficult concept by many professionals due to its dynamic, emergent properties and contextual dependency.⁴⁰ Care integration is never complete, but it evolves depending on the context and involvement of professionals. According to the World Health Organization, *"Integrated health services delivery is defined as an approach to strengthen people-centred health systems through the promotion of the comprehensive delivery of quality services across the life-course, designed according to the multidimensional needs of the population and the individual and delivered by a coordinated multidisciplinary team of providers working across settings and levels of care. It should be effectively managed to ensure optimal outcomes and the appropriate use of resources based on the best available evidence, with feedback loops to continuously improve performance and to tackle upstream causes of ill health and to promote well-being through intersectoral and multisectoral actions".⁴¹*

A framework that captures this comprehensive definition and describes the key domains for achieving integrated primary care is the Rainbow Model of Integrated Care (RMIC) ⁴² that was specifically developed for evaluating integrated primary care settings. The RMIC describes three categories of integrated care: the scope, type, and enablers of integration, including eight domains. It covers all levels, the micro- (self-management and support for patients), meso- (collaboration between professionals and organizations) and macro level (the system level e.g. policy making). Figure 2 is a graphical representation of the RMIC.

Since integrated care is not a single intervention, but as mentioned above rather a framework that helps to understand the concept and guide development of programs, it is a challenge to design an effective program. Previously developed programs designed to improve integrated care in the dementia care setting were often unsuccessful or it was unclear whether their positive effects were sustainable.^{37, 44} Therefore, identification of elements that ensure a sustainable transition towards more integrated dementia care is urgently needed.^{45, 46}

A complex, multi-component approach is needed to enable the realisation of a structural transition towards integrated care. A transition towards network-based care is suggested, since it could improve the quality and efficiency of care and simultaneously improve the satisfaction among care recipients.^{5, 47, 48} It could eventually contribute to the quadruple aim

of improving patient experiences, improving population health, reducing the costs, and improving work satisfaction among professionals.⁴⁹ However, empirical evidence for the effectiveness of such networks for dementia care and the sustainability of its effect is still lacking ⁵⁰, which is essential for implementing such network activities in dementia care.⁵¹



Figure 2. Rainbow Model of Integrated Care. Adapted with permission from Essenburgh Research & Consultancy. $^{\rm 43}$

Network-based approach: DementiaNet

We therefore used a network-based approach to design the DementiaNet program with the collaboration theory of Kaats and Opheij as a basis.^{52, 53} In 2015, a two-year program was developed, that focused on improving interprofessional collaboration by facilitating network development of medical, care and welfare professionals in primary care who jointly provide care to a shared caseload of people with dementia ^{47, 53} (Figure 3). DementiaNet aims to reduce the burden of dementia for all involved in the care, including the care recipient, formal and informal caregivers, while also achieving societal impact by increasing the cost-effectiveness.



Figure 3. Schematic representation of a connected network of professionals involved in dementia care at home. DementiaNet contributes to these connections (bold lines) by its training program for members and leaders.

The DementiaNet program includes key elements about network formation, leadership, quality improvement and interprofessional education ⁵³ (see Figure 4). These are aimed to at increasing dementia -specific expertise on a local scale and to link the professionals from various disciplines. These key elements are all tailored to the needs of the network,



Figure 4. Key elements of the DementiaNet program.

since networks differ in size, available expertise, catchment area, etcetera. The aim of the program was to realize a transition towards a new way of working, which was expected to take time. Therefore, local dementia care networks had support from the DementiaNet team for a period of two years.

DementiaNet networks were formed from 2015 onwards. The roadmap for starting and continuing a network is depicted in Figure 5. When a professional was interested in the DementiaNet approach they could contact the DementiaNet coordinator who helped the professional to gather the other professionals with whom they shared their caseload. Preconditional was the readiness for network participation by a health care, social care, and informal caregiver. When this was met, an introductory meeting was held and when the group of professionals wanted to participate, data on their quality of care was collected. The collected data was used for a feedback report which helped the network to choose an improvement goal during the kick-off meeting of the new network. A quality improvement plan was written and carried out by using the plan-do-check-act cycle. Yearly data was collected, and the networks received a yearly feedback report. This helped them to see whether the improvement plan was successful, and subsequently set a new goal. The feedback report consisted of a radar chart (see Figure 6) which indicated the level of quality of care of the current year, previous year and benchmark data (i.e. the mean of all networks for that timepoint). This cycle was repeated on a yearly basis.



Figure 6. Radar chart of the feedback report provided yearly to the DementiaNet networks.



A short-term evaluation study with a small number of networks already showed positive results regarding collaboration, quality of care, and satisfaction of healthcare professionals.⁶ However, it is unclear whether this initial transition effectively led to improvements in care integration that would sustain for a longer period of time. Therefore, DementiaNet also entailed a follow-up with current networks having been followed up to six years, several years after the official support program had ended (two years). Research on the long-term effects of the DementiaNet program was urgently needed, to assess whether this network-based approach is able to consistently realize its goals and thereby improve resilience of primary dementia care.

Aim of this thesis

The overall aim of this thesis is to evaluate whether the DementiaNet program is a sustainable strategy to facilitate primary dementia care integration, relieve the dementia burden for all involved and to overcome the challenges primary dementia care is facing. Several aspects are important to achieve care integration. Therefore, this thesis focuses on the following research questions:

1. How can we adequately measure the level of integrated (dementia) care?

It is essential to measure the quality of integrated care as well as integrated care performance in practice. When the DementiaNet program started in 2015, no validated, easy-to-use tools were available, which underlined the need for instruments developed that can be used in both daily practice and research contexts. Therefore, the first part of this thesis is dedicated to the development of quality indicators and the evaluation of the RMIC – measurement tool in the primary care setting.

2. How can digital applications facilitate implementation of an integrated care approach, including interprofessional collaboration and caregiver support?

Communication tools are promising to facilitate interprofessional collaboration and caregiver support, but development and implementation of such e-health tools is often difficult, especially in dementia care.^{54, 55} We therefore aim to identify the general barriers and facilitators for implementation of interprofessional digital communication tools for primary elderly care. As digital tools are also increasingly used to support informal caregivers of people with dementia, but evidence whether applying these tools is beneficial is still lacking, we also aim to develop and pilot-test a digital tool to monitor informal caregivers' wellbeing and resilience, thereby striving towards prevention of overburden.

3. What are the (long-term) effects of the DementiaNet program?

The DementiaNet approach has previously been evaluated for a small sample of networks that was active for two years.⁶ To identify the effects of this network-based approach on a larger and longer scale we first aim to describe the effects of DementiaNet on network maturation and specifically identify the success and failure factors for network maturation. In light of these factors, the most important remaining question regarding the DementiaNet approach is in fact whether the positive effects described in a small sample are also present in a large sample of networks. Even more important,

and therefore an important topic in this thesis, is to assess whether these effects are sustainable over time, even after the program support had ended.

Outline of this thesis

This thesis is divided in three parts based on the previously mentioned research questions.

Part I focuses on measuring integrated (dementia) care. **Chapter 2** describes the developmental process in which a content-wise valid minimum dataset (MDS) of quality indicators was constructed to measure quality of integrated primary dementia care. In **Chapter 3** presents the construct validation of the Rainbow Model of Integrated Care - Measurement Tool (RMIC-MT) for healthcare professionals working in an integrated primary elderly care setting in the Netherlands.

Part II identifies how digital tools can facilitate care integration. **Chapter 4** identifies generic barriers and facilitators during implementation of interprofessional digital communication tools experienced by healthcare professionals and informal caregivers for frail older adults. In **Chapter 5**, we describe development and pilot-testing of a digital tool to monitor informal caregivers' wellbeing and resilience to provide timely support and prevent or delay (acute) hospital and nursing home admissions (the so-called REMIND tool).

Part III addresses the effects of the DementiaNet program. **Chapter 6** reports how the DementiaNet approach affects network maturity of interprofessional primary dementia care networks over time and the associated factors for (un)successful network maturation. Finally, in **Chapter 7**, we evaluate the long-term effects of the DementiaNet program on quality of primary dementia care, network collaboration and number of crisis admissions to assess if these effects sustain over time.

Lastly, **Chapter 8** provides a summary and general discussion of the findings from the research in this thesis, including recommendations for research, practice and policy.

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MEASURING INTEGRATED (DEMENTIA) CARE





Development and pilot testing of quality improvement indicators for integrated primary dementia care

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ABSTRACT

Background: Implementation of integrated primary care is considered an important strategy to overcome fragmentation and improve quality of dementia care. However, current quality indicator (QI) sets, to assess and improve quality of care, do not address the interprofessional context. The aim of this research is to construct a feasible and content-wise valid minimum dataset (MDS) to measure the quality of integrated primary dementia care.

Methods: A modified Delphi method in four rounds was performed. Stakeholders (n=15) (1) developed a preliminary QI set and (2) assessed relevance and feasibility of QIs via a survey (n=84). Thereafter, (3) results were discussed for content validity during a stakeholder- and (4) expert consensus meeting (n=8 and n=7, respectively). The stakeholders were professionals, informal caregivers, and care organization managers or policy officers; the experts were professionals and researchers. The final set was pilot-tested for feasibility by multidisciplinary dementia care networks.

Results: The preliminary set consisted of 40 Qls. In the survey mean scores for relevance ranged from 5.8 (SD=2.7) to 8.5 (SD=0.7) on a 9-point Likert scale, and 25% of all Qls were considered feasible to collect. Consensus panels reduced the set to 15 Qls to be used for pilot-testing: 5 quality of care, 3 well-being, 4 network-based care, and 3 cost-efficiency Qls. During pilot-testing all Qls were fully completed, except for well-being Qls.

Conclusion: A valid and feasible MDS of quality indicators for primary dementia care was developed, containing innovative QIs on well-being, network-based care, and cost-efficiency in addition to quality of care QIs. Application of the MDS may contribute to development and implementation of integrated care service delivery for primary dementia care.

INTRODUCTION

The complexity of primary dementia care, caused by the complex nature of this clinical syndrome, often associated comorbidity, and the multiple professionals involved, poses a great challenge to healthcare systems.^{1, 2} As a result, dementia care is often fragmented, which leads to poor quality and inefficient care, because different professionals provide unaligned services resulting in patients' and caregivers' low satisfaction with the services offered.³⁻⁵ Care integration is considered important to overcome fragmentation and improve quality of care.⁶⁻⁹

Integrated care is defined as the delivery of a continuum of care, designed to meet multidimensional needs of the population and the individual, by a coordinated multidisciplinary team of professionals.¹⁰ To achieve dementia care integration, a transition towards network-based care is needed.¹¹⁻¹³ DementiaNet, a healthcare innovation consisting of 36 multidisciplinary networks of primary care professionals

Box 1 - What is DementiaNet?

DementiaNet is a Dutch healthcare innovation focusing on primary network-based care. Networks of professionals from medical, care and social disciplines, caring for the same persons with dementia, are formed.¹⁴ Currently, the DementiaNet approach is being applied in more than 40 networks. DementiaNet facilitates gradual development of self-organized primary care networks providing high-quality integrated dementia care. Strategies to achieve this include clinical leadership and quality improvement cycles. With DementiaNet, we address needs of professionals (increase knowledge, skills, and collaboration); persons with dementia and informal caregiver (personalized care, integration of care and welfare, care coordination, and continuity of care); and the healthcare system (local level, tailor-made, system approach, cost-effectiveness, and sustainable approach). Full description can be found in the paper of Nieuwboer *et al.* ¹⁴ and the first quantitative evaluation of effectiveness is described by Richters *et al.* ²¹

facilitates such a transition.^{11, 14} The essential characteristics of DementiaNet are summarized in box 1. To evaluate the effectiveness of such an integrated care approach in practice and identify areas for improvement, a tailored, feasible and valid set of quality indicators (QIs) is needed.¹⁵ This need is based on extensive literature search and expert

consensus on QIs based on patient reported outcomes of physiotherapy and geriatric patient care showing that, when connected firmly with feedback loops to the health care, can improve outcomes and efficiency on the levels of direct patient care and health services.¹⁶ Several QI sets have been developed to assess quality of primary dementia care, including a set of six QIs used to assess DementiaNet networks' quality of care.¹⁷⁻²¹ However, these sets do not sufficiently adopt the interprofessional context. Furthermore, existing integrated QI sets do not include well-being issues ²², or their large number of indicators limit feasibility.²³ Therefore, the aims of this study were to construct a content-wise valid Minimum DataSet (MDS) of QIs to measure quality of integrated primary dementia care in co-creation with stakeholders and to pilot test its feasibility in practice.

METHODS

Design

Between May 2018 and July 2019, a modified Delphi method was conducted. This methodology is particularly useful to reach agreement on content validity and feasibility; inclusion of a large number of participants prevents domination during the consensus process.^{24, 25} In four rounds we (1) developed a preliminary QI set, (2) sent out a survey to stakeholders, (3) discussed results during a stakeholder consensus meeting, and (4) discussed results during an expert consensus meeting. Thereafter, the final set was pilottested for feasibility.

Delphi method

Participants

Participants were stakeholders and experts in the field of primary dementia care. Stakeholders were healthcare professionals, informal caregivers and care organization managers or policy officers. Experts were professionals and researchers, including all authors, specialised in research or care. Professionals from each discipline were balanced for each round.

Stakeholders for the first physical meeting (round 1) and survey (round 2) were invited by email and recruited via the DementiaNet newsletter database to ensure their familiarity with integrated primary dementia care. Additional caregivers for the survey were recruited via the outpatient clinic or through project contacts. Stakeholders interested to participate in round 1 and participants who showed interest during round 2 were invited for the second physical meeting (round 3). Purposeful sampling was used for the meetings (round 1 and 3),

we made sure all relevant primary care disciplines were represented and the representatives were seen as experts by their colleagues. To include non-expert opinions as well, random sampling of a large group of stakeholders was used for the survey (round 2).

Participants for the expert consensus meeting (round 4) were selected based on their involvement in the DementiaNet project; all were employees at the Radboudumc Alzheimer center or at the General Practitioner organization of Nijmegen.

Delphi rounds

1. Development of the Preliminary Set

In a brainstorm session with stakeholders relevant and easy-to-implement indicators were pre-selected covering three predefined topics: (1) quality of dementia care (process indicators patient level), (2) well-being of person with dementia (PWD) and their caregiver (outcome indicators) ^{15, 26}, and (3) network-based care (process indicators network level).²⁷ Additionally, the existing quality of care indicators used by DementiaNet networks were included in the discussion.^{11, 21} Afterwards, the authors reviewed previous QI sets developed by their group ^{17, 21} and subsequently composed the preliminary set for the stakeholder survey.

2. Survey to stakeholders

In an electronic survey, the preliminary QI set was presented to stakeholders. Consent was asked at the beginning of the survey. Caregivers were only asked to comment on quality of care- and well-being indicators. A glossary was included to explain medical jargon. Caregivers could request a paper version of the survey.

Stakeholders were asked to rate all indicators individually on relevance by using a 9-point Likert scale from 1 (not relevant) to 9 (highly relevant), to identify the three most important indicators per topic, and to add missing indicators. Professionals were also asked to assess QIs on measurement feasibility (yes/no).

Coded questionnaire responses of professionals and caregivers were analysed separately to determine the mean relevance, top-3 indicators, and feasibility of all indicators. An indicator was judged feasible when over 50 percent of respondents indicated the data feasible to collect ²⁸. Descriptive analyses were performed using IBM SPSS version 25.0.

3. Stakeholder consensus meeting

Survey results, for professionals and caregivers separately, were presented to a stakeholder panel for their judgement of content validity. Inclusion of additional indicators, revision of QIs, and exclusion based on relevance and feasibility were discussed.

4. Expert consensus meeting

Results of the survey and stakeholder consensus meeting were distributed to the experts a week prior to the meeting. The expert panel composed the MDS for pilot-testing, based on the rated relevance, arguments from the consensus meeting, content validity, feasibility and correspondence with current guidelines.

Pilot testing

Participants

DementiaNet networks were selected to pilot the new set of indicators (MDS) based on their proactive attitude and timing of their networks' yearly assessment.¹¹

Pilot test

Networks reported their experiences via an open-ended questionnaire, including QI relevance, feasibility of data collection and added value of outcomes.

The authors narratively analysed the questionnaires and evaluated the collected data to determine measurement feasibility. Acceptable measurement feasibility was defined as data collection per QI completed for over 80% of the cases. Thereafter, the set of indicators was adjusted accordingly.

RESULTS

We invited 312 stakeholders for round 1; 19 were willing to participate, and 15 were able to participate. Thirty-one were invited for round 3, 8 were able to participate. Four stakeholders participated in both rounds. Diversity in stakeholders' characteristics was large, with general practitioners, practice nurses, case managers, community nurses and caregivers being most represented. All invited experts agreed to participate. Table 1 describes participants' characteristics.

Round 1	Round 2	Round 3	Round 4
15	114	8	7
11	100 (88%)	6	6
-	1 (1%)	-	3
8	94 (82%)	5	2
	Round 1 15 11 - 8	Round 1 Round 2 15 114 11 100 (88%) - 1 (1%) 8 94 (82%)	Round 1 Round 2 Round 3 15 114 8 11 100 (88%) 6 - 1 (1%) - 8 94 (82%) 5

Table 1. Participants background and years of experience in numbers (and percentages for round2) defined per round

Table 1. Continued				
- General practitioner	1	10 (9%)	1	1
- Practice nurse	1	12 (11%)	-	-
- Case manager	2	21 (18%)	1	-
- Community nurse	1	29 (25%)	1	-
- Other	3	22 (19%)	2	1
Manager/policy officer	5	7 (6%)	-	2
Informal caregiver	2	12 (11%)	3	-
Years of experience dominant background, n (%)				
<5	5	16 (17%)ª	1 ^b	1
5-10	5	25 (27%)ª	3 ^b	-
>10	5	51 (56%)ª	3 ^b	6

..

^aYears of experience of professionals and managers/policy officers, n=92.bn=7.

Indicator development

Figure 1 summarizes the process of QI development.

1. Development of the preliminary set

Fifteen stakeholders developed the preliminary QI set. The meeting yielded a set of 40 indicators; 11 for quality of care, 12 for well-being of PWD and their caregiver and 17 for network-based care, including all 6 QIs previously used by DementiaNet.^{11,21} No indicators were added by the authors after reviewing previously developed QI sets.

2. Stakeholder survey

Eighty-four stakeholders fully, and 30 stakeholders partly completed the assessment of the 40 QIs (Table 1). Mean relevance scores per indicator ranged from 6.0 (SD=2.1) to 8.5 (SD=0.7) for professionals and from 5.8 (SD=2.7) to 8.3 (SD=0.9) for caregivers. Professionals considered collection of 25% of the indicators feasible. Table 2 shows relevance, top-3 and feasibility scores per indicator.



Figure 1. Subsequent stages of the quality indicator (QI) development process for integrated primary dementia care. QoC, quality of care.

Category	Short notation Qla	n Relevance, mean (SD)	n Priority, n (%)	ш У с	easibility, n 'es/No	Relevance, mean (SD)	n Priority, n (%)	Final consensus,	Remark
		Healthcare pro policy officers	fessionals and	man	agers/ In	ıformal caregiv	ers	_Yes/No	
	Assessment of the caregivers' care	101 8.2 (1.1)	99 28 (9%)	87 Y	es 11	1 7.8 (0.8)	36 4 (11%)	No	
	Case manager involved	102 8.3 (0.9)	99 53 (18%)	90	es 11	1 7.3 (2.9)	36 6 (17%)	Yes	
	Future treatment wishes discussed with PWD and caregiver	101 7.9 (1.2)	99 39 (13%)	88	es 11	l 8.1 (0.7)	36 3 (8%)	Yes	
	Geriatric assessment	102 7.0 (1.8)	99 16 (5%)	88	J 1	1 7.4 (1.6)	36 4 (11%)	No	
	Goals of the caregiver discussed	100 8.0 (1.0)	99 17 (6%)	87 N	J1	l 6.1 (2.9)	36 0	No	
Quality of	Goals of the PWD discussed	100 7.6 (1.5)	99 29 (10%)	87 Y	es 11	I 5.9 (3.0)	36 1 (3%)	No	
care	PWD discussed in a multidisciplinary meeting	102 7.6 (1.5)	99 42 (14%)	88	es 11	1 7.0 (2.9)	36 4 (11%)	Yes	
	PWD discussed in a pharmacotherapeutic meeting	102 7.05 (1.9)	99 6 (2%)	88	10 11	1 7.0 (2.2)	36 3 (8%)	Yes	
	Psycho-education offered to caregiver	100 7.7 (1.5)	99 18 (6%)	87 N	Jo 12	2 6.5 (2.7)	36 4 (11%)	No	
	Support offered to caregiver	99 7.8 (1.4)	99 26 (9%)	86 Y	es 12	2 6.7 (2.3)	36 2 (6%)	Yes	
	Changing relationships discussed with PWD and caregiver	NA			Ż	٩		No	Added round 3
	Caregiver feels supported	83 8.5 (0.7)	83 48 (19%)	80 N	10 12	2 7.8 (1.0)	35 4 (11%)	No	
	Caregiver involved in care PWD	83 8.2 (1.2)	83 22 (9%)	80	Jo 12	2 8.3 (0.9)	35 6 (17%)	Np	
	Caregiver involved in own care	83 8.1 (1.3)	83 10 (4%)	80	Jo 9	8.2 (0.8)	NA	No	
	Caregivers knows involved professionals	83 8.1 (1.0)	83 16 (6%)	80	Jo 12	2 7.7 (1.3)	35 3 (9%)	No	
	Formulated goal caregiver	83 7.0 (1.6)	83 0	80	Jo N	4		No	
	Formulated goal for PWD	83 6.0 (2.1)	83 3(1%)	81	Jo N	4		No	
:	PWD feels supported	83 8.3 (1.1)	83 60 (24%)	80	Jo 12	2 7.5 (2.3)	35 7 (20%)	No	
Well- boing	PWD involved in own care	83 8.0 (1.1)	83 21 (8%)	80	Jo 12	2 7.0 (2.3)	35 2 (6%)	No	
nellig	PWD knows contact professional	83 7.8 (1.6)	83 20 (8%)	80	Jo 12	2 7.1 (2.2)	35 3 (9%)	No	
	Perseverance time of the caregiver	83 8.2 (1.3)	83 33 (13%)	80	Jo 12	2 7.7 (2.2)	35 6 (17%)	Yes	
	Psychoactive medication for more than two weeks	83 6.0 (2.1)	83 5 (2%)	80 \	es 12	2 5.8 (2.7)	35 1 (3%)	No	
	PWD satisfied with his/her daily activities	NA			Ż	۷		Yes	Added round 3
	Well-being related goal for PWD	NA			Ż	٩		Yes	Added round 4

nolicy officered of anality indicators (Ole) to 8 700 5 und foncibility (by í, (÷ 5 nrofaccion 141 Tahle 2. Relevance

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Quality improvement indicators

2

Table :	2. Continued										
	Activity to involve broader network (e.g., 7 PWD and caregivers, and dementia initiatives)	78	7.0 (1.7)	17	5 (2%)	74	No	12 7.5 (2.0)	AN	No	
	Agreements with municipality on medical 7 support indications	78	7.4 (1.6)	1	11 (5%)	75	No	NA		No	
	Case review with network	78	7.0 (1.8)	1	10 (4%)	74	No	NA		No	
	Discussion of mutual interests	78	6.8 (1.7)	17	4 (2%)	74	No	NA		No	
	Discussion of mutual personal 7 relationships	[]	6.4 (1.6)	F	1 (0%)	74	No	NA		No	
	Document present with expertise and 7 contact information of all professionals	78	7.9 (1.1)	1	12 (5%)	75	No	NA		Yes	Merged round 4
	Informal activity with network	78	6.4 (2.0)	77	1 (0%)	75	No	NA		Yes	
Network-	Interprofessional education together with 7 network	78	7.1 (1.8)	77	6 (3%)	75	No	NA		No	
based	Network agreements on early signaling 7	78	7.4 (1.8)	77	13 (6%)	75	No	NA		No	
care	Network goals discussed	78	7.1 (1.7)	77	16 (7%)	74	No	NA		No	
	Network has one or two network 7 leaders(s)	79	7.6 (1.5)	77	25 (11%)	75	No	NA		Yes	Merged round 4
	Network worked on at least one challenge 7 or celebrated one success	78	6.8 (2.0)	77	9 (4%)	74	No	NA		Yes	
	Network working arrangements discussed $\overline{7}$	78	7.2 (1.4)	77	12 (5%)	74	No	NA		No	
	PWD and caregiver consulted on 7 experience with network-based care	1	7.1 (1.6)	1	10 (4%)	74	No	12 8.2 (0.6)	NA	No	
	Representative of a welfare organization 7 present	79	8.0 (1.3)	1	44 (19%)	75	Yes	NA		Yes	
	Representative of PWD or caregiver 7 present in network	26	7.5 (1.7)	F	30 (13%)	75	No	12 7.7(2.1)	NA	No	
	Work agreement for the shared caseload 7	78	7.7 (1.3)	1	22 (10%)	75	No	NA		Yes	Merged round 4
	Diagnosed in the primary setting	101	6.0 (2.4)	66	23 (7.74%)	06	Yes	11 6.0 (2.8)	36 5 (14%)	Yes	
Cost- efficiency	Number of emergency consultations 8 PWD care is reimbursed from the long- N term care finance exterm	83 NA	6.0 (2.3)	83	11 (4%)	80	Yes	12 6.3 (3.2) NA	35 3 (9%)	Yes Yes	Added round 4
ªAll QIs cι NA, not α	oncern the past 12 months. valiable, PWD, person with dementia; QI, qua.	ality i	ndicator								
3. Stakeholder consensus meeting

Eight stakeholders discussed the survey results. Stakeholders generally agreed with the survey respondents on relevance and prioritization. Disagreement existed on the QI 'recent pharmacotherapy check', which had a low relevance and feasibility score, though stakeholders considered the indicator crucial for assessing quality of care. They argued that polypharmacy negatively influences quality of life and morbidity. Two new well-being QIs were proposed for inclusion: 'discussing changing relationship between PWD and caregiver' and 'PWD satisfaction with daily activities'. The QI about PWD's goals was nominated for exclusion as it was considered not specific and not feasible.

4. Expert consensus meeting

A geriatrician, two general practitioners, a nursing scientist, two researchers and a coordinator of General Practitioner Organization of Nijmegen decided on the composition of the MDS for pilot-testing considering primarily relevance but also feasibility. The panel agreed with the stakeholders on adding the QI on PWD satisfaction with daily activities. Three network QIs about task division and communication were merged. Experts added the QI: 'whether the network has formulated a wellbeing related goal for the PWD', which replaced some of the excluded network and well-being QIs. During the discussion, cost-efficiency was added as a separate topic, and QIs were arranged accordingly. An additional QI was included for cost-efficiency: 'whether care of PWD is reimbursed from the long-term care finance system'. Twenty-six QIs were excluded, resulting in a pilot-testing set of 15 QIs: five quality of care, three well-being, four network and three cost-efficiency QIs.

Pilot testing

Three DementiaNet networks voluntarily pilot-tested the QI set. Regarding relevance and added value, they preferred the new set above their currently used QIs, as they stated that it represented more aspects of the network collaboration. This information helped them to identify new improvement goals. The QIs focusing on PWD care wishes and on support for caregivers were considered of added value. Measurement feasibility was good; it took one to two hours, depending on the size of the caseload, to complete the QIs. QIs were fully completed, except for the well-being QIs; on average, these were completed for 14% (perseverance time) and 42% (satisfaction with daily activities) of their PWD (range: 11-31). These well-being indicators were difficult to collect as they required caregiver consultation as an additional time-consuming action. Participants suggested the casemanager should complete these questions. Furthermore, pilot answers suggested ambiguity of two QIs, which were therefore reformulated (Table 3).

Category	Quality indicator description
	A case manager is involved.
	The PWD has been discussed in a multidisciplinary meeting in the past year.
Quality of	The PWD has been discussed in a pharmacotherapeutic meeting in the past year.
care	Future treatment wishes were discussed with the PWD and their informal caregiver in the past year.
	Support is offered to the informal caregiver in the past year.
	Assessment of the perseverance time of the informal caregiver.
Well-being	Informal caregiver states that PWD is satisfied with his/her daily activities.
	The network has set at least one well-being related goal for the PWD.
	At least one representative of a welfare organization is part of the network.
Network- based care	Task division and communication: There is a document with expertise and contact information of all the healthcare professionals available for the network in caring for frail older adults, which is updated yearly. The network has one or two network leaders(s). The network has composed written working agreement(s) for their shared caseload
	The network worked on at least one new challenge or celebrated one success in the past year.
	There was an informal activity for network participants in the past year.
_	The PWD is diagnosed in the primary setting.
Cost- efficiency	Number of emergency consultations in the past year.
enterency	PWD care is reimbursed from the long-term care finance system

Table 3. Final set of quality indicator descriptions for integrated primary dementia care

Abbreviation: PWD, person with dementia. QI, quality indicator

DISCUSSION

An MDS of 15 QIs was developed to measure the quality of integrated primary dementia care; QIs for quality of care, well-being, network-based care, and cost-efficiency were included. Most QIs were overall judged positively regarding content validity and feasibility by primary dementia care stakeholders. During pilot-testing most indicators were considered relevant, of added value, and feasible to collect. However, collection of the well-being QIs still needs specific attention.

Strengths and limitations

An important novelty of this set is the inclusion of well-being, network-based care, and cost-efficiency indicators, which supports the triple aim ambitions; improve quality of

care, population health and cost-effectiveness.²⁹ Previous sets mainly included quality of care indicators.¹⁹ Moreover, this novel MDS for integrated primary dementia care is substantially shorter than existing sets.²³ The comprehensiveness of the set, in combination with its high relevance and feasibility, make the MDS useful for daily practice; based on the pilot test future acceptance is expected to be high.

Another strength of the set is its fit with the validated Rainbow Model of Integrated Care.²⁷ This Model's four levels of care provision, the service-, professional-, organizational- and system level, are all represented in the MDS. QIs on quality of care and well-being refer to the service level: processes and outcomes of care for the PWD and caregiver (e.g., QIs on multidisciplinary meetings and satisfaction of PWD with daily activities). Network QIs refer to the professional- and organizational level, the required collaboration between professionals and organizations (e.g., QIs on task division and communication). Costefficiency QIs refer to the system level, the impact of regulations on collaboration between professionals and organizations (e.g., QI on PWD care reimbursement).

Last, stakeholder meetings and the survey included a diverse group of participants regarding background, age and informal caregiver's roles. Their interaction and discussions created broad support for the QIs included; acceptability of the MDS is therefore expected to be high.

However, the stakeholders were mainly active in DementiaNet networks; the MDS is therefore highly applicable to the Dutch network-based dementia care context. Adaptations to the MDS might be necessary when using the set for other health care systems in other countries.³⁰ However, because of their generic content the QIs can be highly transferable to other populations, e.g. vulnerable older adults. Collection of the well-being QIs proved difficult. Evaluation of new strategies to collect these QIs are needed since their relevance is well recognized in practice.

Future implications for research and practice

By addressing various levels of integrated care, the MDS is highly useful for performance feedback in an interdisciplinary setting to encourage professionals to improve the quality of services for their joint caseload. Care coordination, interdisciplinary teamwork and personalized care can be improved by setting improvement goals and assess change over time. Moreover, the complexity in dementia care is captured by clustering QIs in levels related to each other; better network collaboration, leads to better quality of care, leads to better patient and caregiver wellbeing and/or lower health care costs.

The MDS can inform policy makers on best practices to achieve (cost-)effective networkbased dementia care. As most QIs in the MDS are not dementia specific, it is applicable in other populations, e.g. vulnerable older adults which will increase acceptability by preventing fragmentation due to disease-specific QIs.

Future research should include the use of the MDS in long-term follow-up evaluations of integrated primary dementia care programs such as DementiaNet. However, first reliability testing and assessing sensitivity for relevant change are needed.

CONCLUSION

A concise set of QIs with proven feasibility and content validity was developed to assess integrated primary dementia care. Innovative QIs on different relevant aspects of integrated care, well-being, network-based care and cost-efficiency were included next to quality of care QIs. By monitoring changes in QI scores over time and subsequent care improvement cycles, professionals in interdisciplinary primary dementia care collaborations can improve the quality of service for their joint caseload. As such, the set may contribute to the implementation of guidelines and care pathways for integrated primary dementia care.

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Construct validation of the Rainbow Model of Integrated Care Measurement Tool in Dutch primary care for older adults

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ABSTRACT

Introduction: Care integration in primary elderly care is suboptimal. Validated instruments are needed to enable the implementation of integrated primary care. We aimed to assess construct validity of the Rainbow Model of Integrated Care measurement tool (RMIC-MT) for healthcare professionals working in an integrated primary elderly care setting in the Netherlands.

Methods: In a cross-sectional study, the RMIC-MT, a 36-item questionnaire covering all domains of the Rainbow Model of Integrated Care (RMIC), was sent out to local networks of primary elderly care professionals. Confirmatory factor analysis with maximum likelihood estimation was used for the validation of the factor structure of the RMIC-MT. Model fit was assessed by the chi-square test and fit indices.

Results: The RMIC-MT was completed by 323 professionals, primarily general practitioners, community nurses, practice nurses, and case managers. Confirmatory factor analysis and corresponding fit indices showed moderate to good fit, thereby confirming a nine factor model with a total of 36 items.

Conclusions: Construct validity was established for the RMIC-MT for the primary elderly care setting in the Netherlands. It can be used for evaluating integrated care initiatives in a primary care setting, thereby contributing to implementation of integrated primary elderly care.

INTRODUCTION

The number of older persons living at home with complex healthcare needs is rising.¹ Currently, care for older persons is fragmented as a result of suboptimal communication and coordination among the multiple healthcare professionals that are often involved in a primary care setting.²⁻⁴ It is considered essential to cross the disciplinary boundaries between professionals to enable care coordination between multiple healthcare services.³ Especially people suffering from complex conditions such as dementia benefit from integrated service delivery at home. Moreover, integrated care is an important strategy to overcome fragmentation of care. Integrated care is defined by the World Health Organization as *"a coordinated way of working with multiple professionals, organizations and sectors in order to improve the health, quality of care and economic outcomes for a targeted (sub)population"*.⁵ A framework that captures this comprehensive definition and describes the key domains for achieving integrated primary care is the Rainbow Model of Integrated Care (RMIC)⁶ that was specifically developed for evaluating integrated primary care settings. Improving care integration and thereby quality of care could contribute to a more sustainable, patient-friendly, and affordable health care system.^{7,8}

To enable implementation of integrated care for older people it is essential to measure integrated care performance in practice.⁹⁻¹¹ Nevertheless, validated measurement instruments are lacking ¹²⁻¹⁶, because of the complexity of integrated care as a construct.¹⁶ Available instruments are thus either of poor psychometric quality ^{13,16} or are too elaborate for use in practice.¹⁷ Based on the RMIC framework, the Rainbow Model of Integrated Care Measurement Tool (RMIC-MT) was developed.¹⁸ This questionnaire was tested for internal consistency and construct validity internationally for renal care and in Chinese primary care.^{18, 19} Since the RMIC-MT is a valid measure to evaluate integrated care in several care settings, it may have the potential to validly measure the integration of elderly care networks and support professionals to improve their interprofessional collaboration and eventually the quality of care for older persons living at home. Therefore, we aim to assess the construct validity of the RMIC-MT for healthcare professionals working in an integrated primary elderly care setting in the Netherlands.

METHODS

Study design

A cross-sectional study design was used for construct validation of the RMIC-MT for healthcare professionals in elderly care. Data were collected between February 2020 and February 2021.

Setting and study population

Participants were healthcare professionals active in primary elderly care networks throughout the Netherlands. Networks were recruited via two routes, first through the DementiaNet program.²⁰ In this program, networks of primary care professionals with a medical, care, and social professional background provided interprofessional care to a shared caseload of persons with dementia. The networks started between 2015 and 2020 and are located in the east of the Netherlands. More information about the DementiaNet program is available elsewhere.^{20, 21} Second, networks of primary care professionals for older adults were invited to participate in the study by using newsletters of general practitioner- and geriatric specialists organizations and by approaching all regional elderly care networks. An overview of the networks' geographical location can be found in Appendix I.

We used convenience sampling with the following inclusion criteria for the primary elderly care networks: 1) at least a general practitioner practice and community nurse present, 2) professionals from at least two organizations present, 3) a network leader is appointed, 4) all network members share a caseload of at least two persons, 5) work agreements are made or a regular multidisciplinary meeting is held, and 6) at least three persons of the network are willing to complete the questionnaire. When inclusion criteria were met, network members or the contact person were invited via email to participate in the study. All participating networks received a feedback report, enabling them to identify areas of improvement.

Sample size

To determine the a priori sample size we used the rule of thumb of including 10 subjects per questionnaire item.²² Given that the RMIC-MT for professionals has 36 items our targeted sample size was 360 participants.

Theoretical framework

The RMIC is a validated framework that was developed to operationalise the construct of integrated primary care. Primary care is considered the focal point for integrating various medical, care, and welfare services close to people's homes. The RMIC defines the necessary integration mechanisms by also emphasizing its final (Triple aim) outcomes.²³ Different integration domains are specified in the RMIC, making it possible to identify specific areas for improvement. The RMIC describes three categories of integrated care: the scope, type, and enablers of integration, consisting of eight domains. The scope entails the person-focused and population-focused view of health issues at the micro and meso-macro level respectively. The type of integration refers to four domains: clinical integration, professional integration, organizational integration, and system integration. Enablers entails functional and normative integration. Further explanation of the RMIC can be found in Appendix II.

RMIC Measurement Tool

The RMIC-MT consists of a 36-item questionnaire for professionals ²⁴, covering all aspects of integrated care as described by the RMIC.⁶ The development and international validation of the RMIC-MT is described elsewhere.¹⁸ The RMIC-MT was translated to Dutch using forward translation by an independent translator and adapted to the Dutch primary care setting for older adults. The Dutch RMIC-MT was reviewed and pilot-tested by six experts in the field of primary elderly care, including three authors (DO, MP, and MN) and three external reviewers with a healthcare professional (general practitioner, community nurse, and case manager) and managerial backgrounds. The version of the RMIC-MT used in this study can be found elsewhere.²⁵

In this case, the RMIC-MT assessed how formal providers of primary care for older adults perceived their network's ability to deliver integrated care on a five-point Likert scale (options were: don't agree at all, don't agree, neutral, agree, fully agree, I don't know or never, rarely, sometimes, often, always). In this study we added the 'I don't know' option. It consisted of 36 items divided over nine integration domains, with one additional domain about results-oriented compared to the RMIC framework (see Appendix III for scale and response options). The RMIC-MT has the following domains: Person-centeredness (e.g. needs assessment), population-centeredness (e.g. population screening), clinical coordination (e.g. personal care plan), professional coordination (e.g. multidisciplinary team), organizational coordination (e.g. inter-organizational partnerships), system coordination (e.g. policy and financing), technical competence (e.g. interoperable medical records), triple aim (e.g. outcome assessment), and cultural competence (e.g. collaboration culture).²⁴ We reformulated the name of the domain 'triple aim' to 'results-oriented', which better describes the items of this domain. Finally, background information on professional background was collected.

Data collection

The RMIC-MT questionnaire was sent by email between February 2020 and February 2021. The RMIC-MT questionnaires were completed online using a web-based survey platform. Consent was asked at the beginning of the questionnaire. To prevent missing answers all questions were mandatory and open textboxes were provided in case participants wanted to provide an elaboration on their answer.¹¹ The response rate per network was assessed through network-specific codes assigned to each questionnaire. Participants received a reminder after one week and after two weeks when the questionnaire was not completed.

Analysis

Number and percentage were calculated for the background characteristics of the participants. For the final dataset we merged the 'I don't know' scores with the 'neutral' option. Confirmative factor analysis was used to build upon the previous results of the RMIC-MT for renal care.¹⁸ The tested factor structure was based on the outcome of the previous exploratory factor model with nine factors and 36 items.^{18, 19}

Maximum likelihood estimation was used on the variance-covariance matrix and model fit was assessed using the chi-square statistic and goodness-of-fit indices. The fit indices that we used were the Comparative Fit Index (CFI) and Tucker Lewis Index (TLI) (both considered adequate if above 0.9 and good if above 0.95), Root Mean Square Error of Approximation (RMSEA, good if close to 0.06 or below), and Standardized Root Mean Square Residual (SRMR, good if close to 0.08 or below).²⁶ RMSEA is an absolute fit index that assesses the difference between the hypothesized and a perfect model.²⁷ CFI and TLI are incremental fit indices which compare the fit of the data and the hypothesized model.²⁷ The SRMR is the average of the standardized residuals between the covariance matrix of the data and the model.²⁸ These fit indices were considered in combination, as good model fit entails meeting all these criteria.^{26, 29} Significance of the chi-quare statistic indicates good model fit when the p-value is not significant (i.e. above .05). R Studio version 3.6.2 ³⁰ with the Lavaan package ³¹ were used for analysis.

Ethical approval

The study was conducted according to the principles of the Declaration of Helsinki (2013). The research ethics committee of the Radboud university medical center stated that the study did not fall within the remit of the Medical Research Involving Human Subjects Act (WMO) (file number: 2019-5599).

RESULTS

Participant characteristics

Three hundred twenty three healthcare professionals started the survey, of which 282 completed the RMIC-MT. In total, 262 of 450 DementiaNet professionals participated (58% response rate), divided over 34 networks. Furthermore, 60 external professionals from 10 different networks participated. The majority of professionals were case managers (18%), community nurses (18%), general practitioners (12%), and practice nurses (11%). Median time needed for completing the RMIC-MT was 15 minutes (Inter Quartile Range=13 minutes). Table 1 provides an overview of the participant characteristics.

Table 1. Characteristics of the primary healthcare professionals participating in the RMIC-MT for elderly care.

Characteristics	Participants, n=323
Professional background, n (%)	
General practitioner	40 (12%)
Community nurse	57 (18%)
Practice nurse	35 (11%)
Physiotherapist	9 (3%)
Geriatric specialist	12 (4%)
Occupational therapist	11 (3%)
Welfare worker	23 (7%)
Pharmacist	3 (1%)
Case manager	57 (18%)
Other	30 (9%)
Unknown	46 (14%)
Number of networks, n (%)	
DementiaNet	34 (77%)
External networks	10 (23%)
Participants per network type, n (%)	
DementiaNet	262 (81%)
External networks	61 (19%)

Missing value pattern

Forty-one participants partly completed the RMIC-MT. Since all questions were set as required (see details in method section) these incomplete RMIC-MTs are all missing the answers to the later items. See Table 2 for an overview of the total number of responses per item.

Item	N	Median	Mean	Mode	Standard	Skewness	Kurtosis
					Deviation		
Person-centeredness							
Interpersonal trust	323	5	4.65	5	0.532	-1.197	0.427
Listening	323	4	4.45	5	0.568	-0.423	-0.785
Social circumstances	323	5	4.43	5	0.652	-0.842	0.239
Preference integration	323	4	4.02	4	0.696	-0.136	-0.588
Questioning	323	4	4.14	4	0.707	-0.364	-0.399
Community centeredness							
Community partnerships	318	4	4.38	4	0.612	-0.519	-0.170
Health promotion	318	4	3.93	4	0.882	-0.559	0.053
Community collaboration	318	4	3.75	4	0.856	-0.244	-0.419
Population needs	318	4	3.65	4	0.853	-0.207	-0.254
Clinical coordination							
Case management	307	4	3.73	4	0.964	-0.734	0.486
Follow-up of care	307	4	3.97	4	0.958	-0.862	0.489
Shared decision-making	307	4	4.30	5	0.814	-1.011	0.746
Professional coordination							
Interdisciplinary communication	299	3	2.73	3	0.698	0.187	0.119
Interdisciplinary fragmentation	299	3	2.65	3	0.645	-0.117	-0.118
Interdisciplinary coordination	299	3	2.75	3	0.662	0.193	-0.130
Interdisciplinary follow-up	299	3	2.85	3	0.580	-0.082	0.068
Interdisciplinary teamwork	299	3	2.77	3	0.670	0.311	0.428
Organisational coordination							
Inter-organizational coordination	298	3	3.26	3	0.785	-0.407	0.408
Inter-organizational resources	298	4	3.39	4	0.979	-0.490	-0.197
Inter-organizational staff	298	3	3.41	4	0.860	-0.632	0.557
System coordination							
Inter-organizational incentives	295	3	3.03	3	0.751	-0.153	0.374
Interdisicplinary incentives	295	3	3.07	3	0.750	-0.069	-0.047
Care coordination incentives	295	3	3.10	3	0.695	-0.257	0.572
Results-oriented							
Needs assessment	292	4	3.79	4	0.747	-0.787	1.492
Experience assessment	292	3	3.47	4	0.972	-0.173	-0.528
Quality objectives	292	4	3.72	4	0.832	-0.508	0.347
Monitoring & follow-up	292	4	3.67	4	0.846	-0.445	0.325
Outcome assessment	292	3	2.99	3	0.945	-0.145	0.265

Table 2. Summary measures of the 36 items of the RMIC-MT for elderly care.

Table 2. Continued							
Technical competence							
Interoperable IT tools	288	3	2.99	3	1.095	-0.309	-0.680
Interoperable EHRs	288	3	2.64	3	0.995	-0.174	-0.752
Data integration	288	3	3.07	3	1.030	-0.294	-0.345
Outcome transparency	288	3	2.76	3	0.920	-0.282	-0.034
Cultural competence							
Fellowship	282	4	4.23	4	0.613	-0.641	2.334
Teamwork	282	4	3.76	4	0.754	-0.424	0.603
Respect	282	5	4.68	5	0.539	-1.430	1.115
Support	282	4	3.64	4	0.820	-0.307	0.409

Confirmatory factor analysis

Table 3 shows the factor loadings of the RMIC-MT and appendix IV provides the item correlation matrix. The chi-square test was significant, indicating bad model fit: $\chi^2(558) =$ 945.08, p < .001. Using the previously mentioned cut-off values, both RMSEA (0.046) and SRMR (0.055) are considered good, while CFI (0.895) and TLI (0.0882) are slightly under their cut-off and are therefore considered moderate. Summary measures including median, mean, and standard deviations for all items are depicted in Table 2.

Item	Ν	Estimate	SE
Person-centeredness			
Interpersonal trust	323	1.000	
Listening	323	1.417	0.166
Social circumstances	323	1.550	0.185
Preference integration	323	1.807	0.226
Questioning	323	1.909	0.234
Community centeredness			
Community partnerships	318	1.000	
Health promotion	318	1.811	0.209
Community collaboration	318	1.667	0.197
Population needs	318	2.036	0.238
Clinical coordination			
Case management	307	1.000	
Follow-up of care	307	1.116	0.122
Shared decision-making	307	0.580	0.092

Table 3. Factor loadings and standard errors of the confirmatory factor analysis of the 36-itemRMIC-MT for elderly care.

Table 3. Continued			
Professional coordination			
Interdisciplinary communication	299	1.000	
Interdisciplinary fragmentation	299	0.868	0.081
Interdisciplinary coordination	299	0.802	0.084
Interdisciplinary follow-up	299	0.680	0.075
Interdisciplinary teamwork	299	0.858	0.088
Organisational coordination			
Inter-organizational coordination	298	1.000	
Inter-organizational resources	298	1.361	0.177
Inter-organizational staff	298	1.233	0.159
System coordination			
Inter-organizational incentives	295	1.000	
Interdisicplinary incentives	295	1.041	0.062
Care coordination incentives	295	0.928	0.058
Results-oriented			
Needs assessment	292	1.000	
Experience assessment	292	1.188	0.120
Quality objectives	292	1.272	0.107
Monitoring & follow-up	292	1.238	0.107
Outcome assessment	292	1.027	0.116
Technical competence			
Interoperable IT tools	288	1.000	
Interoperable EHRs	288	1.021	0.098
Data integration	288	0.862	0.147
Outcome transparency	288	0.741	0.129
Cultural competence			
Fellowship	282	1.000	
Teamwork	282	1.446	0.186
Respect	282	0.524	0.096
Support	282	1.307	0.177

SE, Standard Error

DISCUSSION

Principal findings

This study provides the first assessment of the construct validation of the Dutch RMIC-MT version for professionals working in the integrated primary elderly care setting. Construct validity of the nine factors of the RMIC-MT was proven by passing the majority of goodness-to-fit tests using CFA, even though we had a relatively small sample. Given the small number of items (N=36), the RMIC-MT's utility is promising to assess integrated care in daily practice.

Comparison with existing evidence

We were able to build upon previous international validations of the RMIC-MT and were able to successfully validate the RMIC-MT construct in Dutch for the elderly care setting. The RMIC-MT construct is now validated in different countries, languages, and for different conditions ^{18, 19, 32}, which contributes to the evidence of its applicability and representativeness in the primary integrated care setting.

We found moderate rather than good results for a few of our fit indices. This could be the result of our relatively small sample size compared to the previous validation studies of the RMIC ^{18, 19}, as fit indices tend to indicate inappropriate fit in smaller sample sizes.³³ Another explanation could be that the factor structure of the data of this study is slightly different, because our explained variance for some of the domains may have differed from the internationally validated RMIC-MT. As previous RMIC-MT validation studies already showed, the explained variance between studies varied for e.g. the domain cultural competence and care integration ^{18, 19}, which are likely due to cultural differences between countries or the difference in target condition (e.g. renal care or mental health care).

With this study we add to the evidence that the RMIC-MT questionnaire is a valid tool to measure primary elderly care integration. Until now, valid easy-to-use instruments to measure integrated care in the primary elderly care setting were lacking and available tools are of poor quality.^{12-16, 34} Almost all other available tools only focus on a single aspect of care integration, mainly person-focused care and clinical integration and do not represent normative and system integration.¹³ The RMIC-MT questionnaire is based on the RMIC framework, and therefore covers all relevant domains of integrated care, therewith doing justice to complexity of integrated care.^{17, 18, 35}

We observed that thirteen percent of professionals did not complete the questionnaire. Reasons could be that the RMIC-MT is perceived as too time consuming or professionals find it difficult to interpret the questions. The last explanation is also supported by the fact that professionals frequently answered 'I don't know/neutral'. In previous validation studies of the RMIC-MT the 'I don't know' option was not added.^{18, 19} We therefore decided to combine the 'I don't know' and 'neutral' option to be able to compare these results with previous outcomes. Since for system coordination, professional coordination, and technical competence the majority of the answers were 'I don't know/neutral', we assume that the RMIC-MT questions for these topics might be outside the scope of the participating professionals. Extra explanatory notes might be necessary. Especially the answers given for system coordination can be explained, since professionals find it difficult to assess system domains of integrated care.⁶ Perhaps system coordination policies are not experienced by professionals in daily practice and out of their scope of influence and therefore not recognizable. Previous studies also found that professionals find it difficult to improve their system integration ³⁶ and interventions are not designed to do so.⁹ We did not expect and cannot explain why professionals had difficulties with answering questions about professional coordination as this is obviously part of their daily practice. Previous research shows that professionals focus and improve most on this domain.³⁶ Possibly, the terminology or formulation used in the questionnaire to describe this domain did not match the vocabulary of the participating professionals. Maybe, the recoding of the scale (from negative to positive) might have had an influence. This should be clarified in future research.

Strengths and limitations

One of the strengths of this study is that we could build upon previous results from RMIC-MT construct validations for various conditions in primary care, which solidifies the results for this Dutch version for primary elderly care.^{18, 19} Moreover, this will contribute to the comparability of the results for different settings by using the same measurement tool.

Another strength is that we used convenience sampling by inviting networks of elderly care professionals throughout the Netherlands, even though a large part of the networks were DementiaNet networks located in the east of the Netherlands. The participants also had varying professional backgrounds with all relevant disciplines represented.

A limitation is our sample size. We had a high number of non-responders, reasons for which remained unclear. However, data was collected during times of COVID-19, which potentially hampered the responses, since professionals were extremely occupied with patient care. We reached 90% of the intended sample size (i.e. 323 of 360 participants). Nevertheless, literature suggests that 300 cases is generally sufficient for a CFA.³⁷ For the CFI and TLI fit indices the results were considered moderate, for which the cause might have been the relatively small sample size. The results of the chi-square test tend to be less reliable with a small sample size and the other fit indices also tend to show a worse

fit.³³ Most networks had existing interprofessional collaborations, therefore the construct validation might not hold for newly formed groups of professionals.

Implications for research and practice

The construct validation of the RMIC-MT for Dutch elderly care is a valuable next step for a broader application of the RMIC-MT in the Netherlands. The RMIC-MT can be used for performance assessment (e.g. network evaluations) of the collaboration processes ^{11, 18} in primary care networks. These assessments can reveal areas for further improvement of their care integration according to the different domains of integrated care, for example improving interprofessional communication by using a digital tool or by implementing a multidisciplinary meeting.^{11, 18} Moreover, insights from the RMIC-MT assessments can be used for educational purposes, thereby tailoring trainings to the needs of a network. In research, RMIC-MT has the potential to become the preferred instrument for measurement of care integration, as, with the current study included, it was already validated in different primary care settings and for various conditions.¹³

Since this is still a relatively small study, feasibility of the RMIC-MT for elderly care and its applicability for improvement purposes should be studied within a larger group of professionals and in other countries. It should also be explored if the tool indeed enables networks to improve their care integration, e.g. by doing pre- and post-measures using the RMIC-MT. Its application can also enable primary elderly care professionals to improve their care integrating the feedback reports in their improvement plans.

Although the vast majority of professionals filled in the entire questionnaire, we did receive incomplete questionnaires. A shorter and easier formulated version might be essential to achieve improved response rates. A previous study about the RMIC-MT showed positive results for a shortened version for physical and mental healthcare.³⁸ Moreover, identifying if the questions that are frequently answered with 'I don't know' are not too difficult or irrelevant for this target group is essential. In this study, we focused on the RMIC-MT version for professionals. To give professionals an even more complete overview of their current care integration, incorporating multiple stakeholder perspectives' is needed. It is therefore desirable to also include patients' experiences, by e.g. using the RMIC-MT patient version in addition to the professional version.^{18, 39, 40}

CONCLUSION

We confirmed the construct validity of the RMIC-MT for the primary elderly care setting in the Netherlands. Application of the RMIC-MT enables professional networks in the elderly care setting to evaluate and improve their care integration and thus contribute to better quality and more sustainable primary elderly care. Feasibility and added value of the tool should be studied after this small-scale validation study. The instrument has the potential to facilitate care integration, but first research is needed to identify whether its implementation actually leads to improvement in daily integrated care practice. Broader use of the RMIC-MT for elderly care should be investigated, including other contexts and countries.

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APPENDIX I – Overview of the networks' geographical location in the Netherlands



APPENDIX II – Rainbow Model of Integrated Care

The RMIC describes three categories of integrated care: the scope, type, and enablers of integration, including 8 domains. Figure 1 is a graphical representation of the RMIC.

Scope of integration

The scope entails the person-focused and population-focused view of professionals, e.g. focusing on patient's needs and abilities instead of the disease (person-focused care) and meeting a target group's specific healthcare requirements (population-focused care).

Type of integration

The type of integration consists of integration on the micro (individual), meso (population) and macro (system) level, and refers to four domains: 1) delivered and coordinated services to patients (clinical integration), 2) collaboration between healthcare professionals (professional integration), 3) collaboration between healthcare organizations (organizational integration) and 4) implementation of new policies and regulations (system integration).

Enablers of integration

Functional and normative enablers are needed to establish connectivity between the micro, meso and macro level. Functional enablers are for example communication tools that can be used by all professionals and organizations in a network, whereas normative enablers refer to the development and maintenance of a common goal or plans for improvement.



Figure 1. Rainbow Model of Integrated Care. Adapted with permission from Essenburgh Research & Consultancy [1].

Reference:

1. Essenburgh Research & Consultancy. *The Rainbow Model of Integrated Care*. 2017; Available from: https://www.essenburgh.com/en/rainbow-model-of-integrated-care.

Scale	Example	No. of items	Response options
Person-centred care	interventions are used to promote clients' self- care ability	5	Never (1) – All the time (4)
Community- centred care	population needs are included in the objectives of the partnership	4	Never (1) – All the time (4)
Clinical coordination	professionals have agreements on the referral and transfers (follow-up) of clients	3	Never (1) – All the time (4)
Professional coordination	professionals use multidisciplinary guidelines and protocols	5	Never (1) – All the time (4)
Organisational coordination	interest of the organizations involved are considered	3	Never (1) – All the time (4)
System coordination	the partnership is hampered by the rules and/ or policies set by the ministries (e.g. Ministry of health)	3	Never (1) – All the time (4)
Technical competence	incentives are used to improve teamwork, coordination and continuity of care among professionals	4	Never (1) – All the time (4)
Cultural competence	activities are undertaken to better understand other organizational cultures	4	Never (1) – All the time (4)
Results-oriented	patient satisfaction is measured regularly	5	Never (1) – All the time (4)

APPENDIX III – Scale and response options of the 36-item RMIC-MT for primary elderly care professionals

Based on Valentijn et al. (2015) [1]

Reference:

1. Valentijn PP, Vrijhoef HJ, Ruwaard D, Boesveld I, Arends RY, Bruijnzeels MA. Towards an international taxonomy of integrated primary care: a Delphi consensus approach. BMC Fam Pract. 2015;16: 64-015-0278-x.

		:	;								!																				
	۱	2	3	4	5	9	7	8		10	11 1	12 1;	3	4 15	16	17	18	19	20	21	52	23	24	25 2(27	27 28	27 28 29	27 28 29 30	27 28 29 30 31 3	27 28 29 30 31 32 3	27 28 29 30 31 32 33 34
1. Person. centeredness_1	-																														
2. Person. centeredness_2	,458**	-																													
3. Person. centeredness_3	,482**	,474**	-																												
l. Person. enteredness_4	,277**	,513**	,461**	-																											
. Person. enteredness_5	,327**	,508**	,477**	,633**	-																										
. Community. enteredness_1	,228**	,191**	,172**	,168**	,253**	-																									
. Community. enteredness_2	,150**	,138*	0,107	,120*	,111*	,411**	-																								
. Community. enteredness_3	,242**	,165**	,202**	,156**	,171 ^{**}	,419**	,424**	-																							
. Community. enteredness_4	,168**	,178**	,125*	,155**	,110*	,407**	,605**	,572** 1	-																						
0. Internal.care. pordiation_1	. 0,103	0,106	,186**	,121*	,173**	,143*	,168**	,119°	209**	-																					
l. Internal.care. oordiation_2	. 0,106	0,102	,162**	,157**	,198**	,231**	,225**	,149**	222**	,533**	-																				
2. Internal.care. pordiation_3	, ,261"	,292**	,346**	,377"	,326**	,218**	,121*	,146°,	119*	,238** ,	380** 1	_																			
3. External.care	<u>.</u> -,172**	-0,094	-,170**	-,161**	-,123*	-0,103	-0,085	- 260'0-	-,147° -	-,154** .	-,241** -,	,142* 1																			
4. External.care oordination_2	,125*	-0,029	-,117*	-0,075	-0,095	-0,093	000'0	- 0/0/0-	- 0,059	-,134* .	,122* -	0,107 ,5	56** 1																		
5. External.care oordination_3	0,107	-0,039	-,157**	-0,070	-0,091	-,140*	-0,093	-0,078	- 0,092	-,118* .	-0,077 -	0,047 ,4	75** ,4	26** 1																	
6. External.care oordination_6	-0,087	-0,036	-,129*	-0,018	-0,081	-0,102	-0,030	- 0,083	-0,005	-,136*	- 0,094	0,108 ,4	11" ,4	05** ,3£	^{**} 1																
7. External.care	'135 [*]	-0,054	-0,113	0,001	-0,026	-,141*	-,119*	- 0,068	-,142* -	-,183** .	,175** - <u>-</u>	,126* ,4	53** ,4	61** ,42	5* ,47	9" 1															
8. Regional. artnership_2	,152**	0,103	0000'0	0,107	0,069	,213**	,147*	0,071	202**	,160** ,	152** 0	080'	162** -(,076 -0,	054 -0,	J62 -,12	3* 1														
9. Regional. artnership_3	0,065	0,045	0,024	0,078	0,064	,206**	,161**	,126* ,	242** ,	,116* ,	196**	150** -;	188** -(,034 -,1	54** -0.	10 -,14	1* ,395	-													
0. Regional. artnership_4	0,112	0,080	0,066	660'0	0,079	,278**	,224**	,187"	321" ,	, 221** ,	203**	200** -;	188** -(,032 -0,	101 -0,(45 -,13	4° ,412														
1. Laws.and. egulation_1	0,064	-0,052	0,046	0,024	0,036	0,023	,150**	0,076 ,	138°	,114* (0,083 C),094 -C)- 560(,011 -0,	Yo- 660	0'000	46 ,130	, 0,084	4 ,142*	-											
2. Laws.and. egulation_2	0,043	0,003	0,034	-0,035	0,057	0,095	,164**	0,059 ,	121* ,	,142* ,	119* 0),075 -C	,081 -C	'0- 900'	060 -,15	0'06	56 ,172	. 0,087	7 ,198*	, 732**	-										

APPENDIX IV – Correlation matrix of the RMIC-MT for primary elderly care professionals

APPEN	XIC	' ≥	Co	ntin	ued																			
23. Laws.and. regulation_3	0,042	-0,002	0,041	0,010	0,068	,125*	0,108	0,086	,130*	,180**	,125*	0,060	-,114*	-0,069	-,153*	-,182*	-0,040	,166**	,149*	,211*	**769,	,723**	-	
24. Internal. performance. management_1	,152**	,120*	,183**	,197"	,252**	,224**	,127*	,182**	,220**	,373**	,350**	,200**	-,207*	* -,201*	* -0,080	0,114	-,179*	* ,177**	,226**	,236*	,152**	0,111	,233**	-
25. Internal. performance. management_2	,152**	,203**	,126*	,158**	,176**	0,107	,236**	,223**	,269**	,335**	,280**	,242**	-0,112	t -0,113	9-0,035	0,037	-0,072	2 ,201**	0,107	,170**	,225**	,224**	,272**	. ,462" 1
26. Internal. performance. management_3	,175**	,151**	,123*	,174**	,274**	,151**	660'0	,167**	,167**	,336**	,332**	,263**	-,197*	* -,172*	* -0,065	-,141*	560'0-	, 219**	,231**	,169*	,168**	,185**	,240**	, ,551" ,527" 1
27. Internal. performance. management_4	,170**	,191**	,198**	,173**	,268**	,215**	0,094	,192**	,186**	,333**	,379**	,199**	-,225*	* -,172*	* -0,106	-,117*	-,171*	* ,211**	,227**	,230**	0,070	,160**	,173**	, ,543°, ,431°, ,653° 1
28. Internal. performance. management_5	0,055	,119*	60'0	,159**	,178**	0,057	,195**	0,063	,208**	,223**	,241**	0,067	-0,105	-0,104	t -0,022	-0,004	-0,070	,175**	,152**	,222*	,262**	,296**	,233**	, 400", 411", 441", A24" 1
29. External. performance. management_1	0,073	0,027	0,008	-0,017	-0,047	0,024	0,010	,136*	860'0	,228**	,167**	0,063	-,152*	* -0,052	,146*	-0,042	-0,057	, ,225**	,387"	0,115	060'0	,125*	,183**	, 167", 193", 183", 231", 203" 1
30. External. performance. management_2	-0,004	0,013	-0,102	-0,042	-0,076	0,052	0,080	0,072	,120*	,224**	,135*	0,018	-0,105	3 -0,056	-,127*	-0,026	-0,045	; ,255**	,306**	,172**	0,077	,131*	,161**	, 156", 196", 199", 175", 179", 529" 1
31. External. performance. management_3	,129*	0,040	0,114	-0,031	0,025	,133*	,152**	0,108	,191*	,266**	,245**	,123*	-,130*	-0,096	-,190*	-0,070	-,150*	,226**	,228**	,298*	0,091	0,111	,147*	,241" ,193" ,231" ,202" ,158" ,301" ,398" 1
32. External. performance. management_4	0,038	0,073	0,031	0,030	0,042	0,026	,161**	0,026	,152**	,254**	,271**	760'0	-0,050	0,015	-,140*	-0,036	-0,065	, 136*	,154**	,286*	0,111	,139*	,132*	209", 233", 231", 189", 390", 277", 388", 580" 1
33. Safety. culture_1	,284**	,264**	,191**	,128*	,189**	,323**	,139*	0,089	,141*	,220**	,279**	,206**	-,164*	* -,160*	* -,147*	-0,054	-0,057	, 218**	,144*	,207**	0,092	,136*	,120*	,229" ,193" ,243" ,239" ,157" 0,115 0,022 ,150° 0,084 1
34. Safety. culture_3	,207**	,189**	,178**	,123*	,189**	,321**	,158**	,201**	,202**	,260**	,301**	,192**	-,161*	* -0,043	-,131*	-,122*	-,124*	,259**	,263**	,276*	,135*	,175**	,169**	, ,254" ,232" ,309" ,430" ,190" ,159" ,118' ,239" ,160" ,435" 1
35. Safety. culture_4	0,115	,119*	0,047	0,027	0,108	,167**	0,026	0,071	,118*	0,072	,171"	0,044	,142*	-0,082	-0,084	900'0- 1	-0,076	; ,152*	,124*	,148*	-0,048	0,095	0,013	,120' 0,097 0,094 ,176" 0,085 0,040 0,025 0,042 0,030 ,417" ,228" 1
36. Safety. culture_5	,158**	,128*	0,085	0,093	,122*	,131*	0,049	0,025	0,066	,285**	,197**	,125*	-,186*	* -0,071	-,161*	* -,156*	-0,072	, 218**	,230**	,228**	0,058	0,067	,156**	, 147° ,268° ,217° ,149° ,180° ,187° ,184° ,259° ,232° ,375° ,505° ,148° 1

*P<0.05 **P<0.01

3



DIGITAL TOOLS TO FACILITATE CARE INTEGRATION





Implementation of interprofessional digital communication tools in primary care for frail older adults; an interview study

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ABSTRACT

Communication and coordination between primary healthcare professionals and informal caregivers involved in the care for frail older adults is suboptimal and could benefit from interprofessional digital communication tools. Implementation in daily practice however frequently fails. We aim to identify generic barriers and facilitators experienced by healthcare professionals and informal caregivers during implementation of interprofessional communication tools to improve their long-term use. Qualitative content analysis using individual semi-structured interviews was used for evaluating three different digital communication tools used by interprofessional primary care networks for frail older adults by 28 professionals and 10 caregivers. After transcription and open coding, categories and themes emerged. Barriers and facilitators identified were related to: tool characteristics, context of use, involvement of professionals and caregivers. The tool improved availability, approachability and users' involvement. The large number of digital systems professionals simultaneously use, and different work agreements hampered tool use. The tools facilitated care coordination, and professionals declared to be better informed about patients' current situations. Overall, interprofessional digital communication tools can facilitate communication in networks for primary elderly care. However, integration between digital systems is needed to reduce the number of tools. Organizations and policy makers have an important role in realizing the tools' long-term use.
INTRODUCTION

Due to population ageing, the number of frail older adults with complex care needs is globally increasing. In the Netherlands, frail older adults with complex conditions (e.g. dementia) remain living at home, as a result of policy changes focused on prolonging domestic living and restricted access to residential long-term care.^{1, 2} Multiple primary healthcare professionals are involved in the care for this population and they tend to focus on their own field of expertise.³ Coordination of care and communication among professionals involved is often suboptimal ^{4, 5}, resulting in fragmented care ^{5, 6} and a high caregiver burden.¹ Interprofessional collaboration and communication are therefore promising strategies to improve the quality of care for frail older adults.^{4, 5, 7} In this study we focus on interprofessional collaboration, by stimulating an integrated care approach where professionals, informal caregiver and patient are all involved in the care planning and coordination.^{8, 9}

BACKGROUND

Interprofessional communication could be supported by digital communication tools ^{10, 11}, as they enable more frequent and less time-consuming interactions between healthcare professionals. These tools can therefore improve interprofessional coordination of care in various ways by: clearly dividing tasks and defining each professional's responsibility ¹²; enabling more efficient and safer transfer of clinical information ⁷; and partly replacing time- and resource consuming face-to-face multidisciplinary meetings.¹³ Moreover, digital communication tools have the potential to improve caregiver involvement. They allow for easier and more approachable interactions between caregivers and professionals, which could thereby reduce the individual caregivers' burden.¹⁴

Even though interprofessional digital communication tools have promising advantages, realizing a successful implementation phase has proven to be very difficult.^{15, 16} Many information and communications technology (ICT) tools for interprofessional settings are still too fragmented in their functionalities or complex to use.^{15, 16} Studies on the use and effects of interprofessional tools are still scarce and refer to tools that were not frequently used.¹⁷⁻¹⁹ Moreover, these tools were only individually evaluated and an overview of common implementation facilitators and barriers is missing. Identification of these factors is needed to improve interprofessional collaboration and healthcare services.^{16, 20}

Thus, research is needed to identify these generic factors that facilitate successful implementation of interprofessional communication tools to eventually establish

long-term use in everyday practice. Therefore, we aim to identify generic barriers and facilitators experienced by healthcare professionals and informal caregivers during implementation of three interprofessional communication tools in care for frail older adults to further improve their implementation.

METHODS

Study design

In a qualitative study, content analysis using semi-structured interviews with professionals and caregivers was used to explore views and experiences on interprofessional digital communication tools use in the primary care for frail older adults. We hereby focused on generic implementation facilitators and barriers, relevant to all three tools, rather than on differences in specific functionalities or user experiences of the three different tools. The Consolidated Criteria for Reporting Qualitative Research (COREQ) were applied to ensure high reporting quality of this study.²¹

Setting and participants

The tools that were evaluated are used in the network-based setting of DementiaNet.⁹ Within the DementiaNet program, networks of primary care professionals were formed from 2015 onwards aimed at improving the quality of care for people with dementia and their caregivers by improving their networks' care integration.²² These local networks of primary care professionals also care for the same caseload of frail older adults.⁹, ²³

Four DementiaNet networks, all located in the East of the Netherlands, with an already formed collaboration were invited to participate in this study. They recently implemented an interprofessional communication tool, initiated by the local general practitioner (GP) practices, and explicitly expressed improving digital interprofessional communication as one of their network-goals. Networks were purposefully selected based on 1) their setting (urban, urbanized countryside and rural) and 2) the digital communication tool they already used. Professionals and caregivers of the networks were invited verbally or via e-mail by the network leader to participate. Convenience sampling was used for professionals from two networks, due to the large network size. All professionals active in the smaller two networks were invited to participate. Convenience sampling was used for informal caregivers of patients receiving care from the networks. Exclusion criterion was the inability to speak Dutch. Inclusion of new participants ended when data saturation occurred.

Tools

Three different tools frequently used in the DementiaNet setting were evaluated in the participating networks to identify generic (non-tool specific) barriers and facilitators. These tools, VIPLive ²⁴, OZOverbindzorg ²⁵, and Doktr.nl are largely similar in their functionalities. Their main functionality is a chat function, to be used for mutual communication by professionals or between a professional and an informal caregiver. Furthermore, VIPLive and OZOverbindzorg allow professionals to start a group chat conversation about a patient. All tools are available through a web portal, VIPLive and OZOverbindzorg can be used with a smartphone application as well. Additional functionalities differed between the tools (see Table 1).

Functions: VIPLive OZOverbindzorg Doktr.nl			
Web portal or app	Both	Both	Web portal
One to one chat function	Х	Х	x
Group conversation	Х	Х	
Participation of informal caregiver	Х	Х	Х
Multidisciplinary care planning support	Х	Х	
Store results of medical investigations	Х		
Order drug prescription		Х	
Send questionnaires and documents			Х

Table 1. Overview of functionalities of the digital communication tools.

x = functionality present

Data collection

The individual semi-structured interviews took place between February 2020 and July 2020. The interview guide was based on implementation frameworks suitable for digital communication tools ²⁶⁻²⁹, and evolved from the data collected. Topics of the interview included usability of the tool, barriers and facilitators of the tool and added value. The interview guide is available upon request. Background variables including gender, age, discipline and frequency of use were collected for each participant. Interviews were conducted by trained research interns (CF and MA) who did not support implementation or had no other personal connection to the participants. Interviews were performed face-to-face or via videocall or telephone due to COVID-19 pandemic regulations and depending on the preference of the participant. All interviews were audio recorded and lasted 40 minutes on average (range 25 to 60 minutes). Before the start of the interview, participants written consent was obtained by the interviewer.

Data analysis

The interview recordings were transcribed verbatim. ATLAS.ti (version 8.4.20) was used to support the content analysis method.³⁰ Data collection and analyses were performed simultaneously to improve quality of future interviews and facilitate data saturation. Focus was the identification of common rather than different themes and patterns between the tools. Open coding was applied to the transcripts (CF or MA) in consultation with two trained researchers (DO and MN). Codes were subsequently categorized in code groups and categories and themes were identified by reaching consensus within the research team (CF, MA, DO, MN, MP).

Ethical Considerations

The study was conducted according to the principles of the Declaration of Helsinki (2013). The research ethics committee of the Radboud university medical center stated that the study did not fall within the remit of the Medical Research Involving Human Subjects Act (WMO).

RESULTS

Participant characteristics

Twenty-eight professionals and ten caregivers of the four networks participated. Two networks used VIPLive, one network OZOverbindzorg and one network Doktr.nl. The tools were implemented between a half year and three years prior to the interview.

Participating professionals were diverse regarding background and 89% were female. The majority, 79%, used the tool at least once a week. Tool use varied greatly from daily to less than once a month, depending on the current health situation of the older adult. Professionals used the tool on average for six patients, some had several conversations per patient. On average in five group conversations an informal caregiver was included.

Caregivers used the tool for their parents (in law) or spouse. Their mean age was 59 years and 70% were female. Tool use varied greatly, depending on the current situation of their relative, ranging from almost daily to less than once a month when the situation was stable. Professionals' and caregivers' characteristics are summarized in Table 2 and 3.

	Professionals, n=28
Dominant profession, n (%)	
General practitioner	4 (14%)
Practice nurse	4 (14%)
Community nurse	10 (36%)
Case manager	7 (25%)
Geriatric specialist	1 (4%)
Dieucian	I (4%) 1 (4%)
	1 (4%)
Woman, n (%)	25 (89%)
Work experience in current profession in years, n (%)	
≤5	5 (18%)
5-10	14 (50%)
>10-20	9 (32%)
Tool, n (%)	
VIPLive	19 (68%)
O2Overbindzorg	6 (21%)
Doktr.ni	3(11%)
Number of patients for who the tool is/was used,	C (1, 20)
median (min-max)	6 (1-30)
Number of healthcare professionals available to contact,	
median (min-max)	4 (1-8)
Number of conversations with an informal caregiver,	
median (min-max)	5 (1-30)
Mean frequency of use, n (%)	
Once per day or more	6 (21%)
1-2 times per week	13 (46%)
1-2 times per month	6 (21%)
Less than once a month	3 (11%)

Table 2. Characteristics of primary healthcare professionals using one of the three interprofessional digital communication tools.

Table 3. Characteristics of informal caregivers using one of the three interprofessional digital communication tools.

	Informal caregivers, n=10
Informal caregiver (IC) for, n (%)	
Spouse	1 (10%)
Parents (in law)	9 (90%)
Age, median (min-max)	59 (50-71)
Woman, n (%)	7 (70%)
Tool, n (%)	
VIPLive	8 (80%)
OZOverbindzorg	2 (20%)
Doktr.nl	-
Number of healthcare professionals available to contact,	
median (min-max)	3 (1-7)

Barriers and facilitators

From content analysis, 15 categories and four themes were derived related to barriers and facilitators for implementation of interprofessional digital tools. Themes and categories are displayed in Table 4 and quotes for each theme are displayed in Table 5.

Table 4. Themes and categories related to the barriers and facilitators of implementation of interprofessional digital communication tools experienced by professionals and caregivers.

Themes	Categories
Tool characteristics	Training
	Ease of use
	Functionalities
	Sharing information
Context of use	Attitudes towards the tool
	Work agreements
	Overload communication tools
	Situations for application
	Remote care
	Availability
Involvement of professionals	Interdisciplinary involvement
	GP Involvement
Involvement of caregivers	Increased caregiver involvement
	Approachability of professionals
	Professional jargon

Table 5. Quotes on the experienced barriers and facilitators of interprofessional digital communication tools by healthcare professionals and informal caregivers.

Category	Participant	Quote
Tool characteristics	IC 1	(1) It (the tool) is self-explanatory, it is not that difficult at all. It is very user-friendly.
	GP 1	(2) You need to use it (the tool) in practice, otherwise you forget how it works.
	CM 1	(3) I frequently do house visits, then I use it (the app) in between visits.
	CN 1	(4) I do not exactly know the possibilities of the tool, I neither have gotten around or confronted with it.
Context of use	GP 1	(5) We have used a digital interprofessional tool. I was therefore also enthusiastic about this new tool. Although I also thought, another way of information sharing, we already use many applications.
	IC 10	(6) Everything went via phone.
	CM 2	(7) I hope for uniformity, we already work with a lot of GP practices, and it (work agreements) cannot differ between them. Then it does not work, and you cannot remember it.
	PN 1	(8) During the start of the project we talked about work agreements with our team. No urgent problems via the tool.

Table 5. Continued			
	CN 8	(9) Including more professionals would be nice, they can be contacted more easily then, but it is difficult that they can see all information. You would like to hide some information.	
	GP 2	(10) Once I counted all lines of communication, I came to fifteen or so. Which you all use at least once a week, that is just too much.	
	CN 2	(11) The first person where we implemented the tool was for someone where a lot was happening in a short time with many different professionals involved.	
	CN 4	(12) Because of the COVID-19 pandemic we decided to include more and a broader range of patients in the tool to enable easier communication and to lower the number of GP home visits.	
	IC 1	(13) We all work of course. So sometimes you want to ask a question in the evening I like this flexibility.	
Involvement professionals	CM 1	(14) The tool works really well, but you really need involvement of professionals, especially the GP. Otherwise, you will never get anywhere.	
	PT 1	(15) It is nice to sit together at a virtual table and let each other know what you are working on, if it is progressing or if you need help from someone. I think this is a great advantage.	
	PN 2	(16) We know how to find each other sooner and ask questions, then you can immediately adapt things. The communication lines are just much shorter.	
	CN 3	(17) Adding other professionals to a conversation was something the GP was reluctant about. The GP wanted to keep it rather small, but I thought for some patients it is quite important that other professionals can read along, but that made the GP uncomfortable.	
Involvement caregivers	IC 8	(18) With shorter communication lines problems can be solved instantly.	
	CM 1	(19) We talk in a completely different way when caregivers are not present.	
	CM 1	(20) Now I have to think very carefully, do I have the right chatgroup.	

GP = general practitioner; PN = practice nurse; CN = community nurse; CM = case manager; PT = physiotherapist; IC: informal caregiver

Tool characteristics

Professionals generally experienced the introduction training of the tool as helpful. Training was perceived as easier by digitally skilled healthcare professionals. Some experienced the large training groups and the difference in knowledge level about the tool as a disadvantage. Caregivers perceived their training by the practice nurse or GP as sufficient.

Most professionals and caregivers experienced the tool as user-friendly, self-explanatory, and very similar to a normal chat function. *"It [the tool] is self-explanatory, it is not that difficult at all. It is very user-friendly."* [IC 1]. Some experienced difficulties getting used to

the tool, because of limited digital skills and sporadic use. "You need to use it [the tool] in practice, otherwise you forget how it works." [GP 1]. Additionally, a few participants experienced annoying and time-consuming technical problems such as difficulties with registering or logging in, which decreased their usage of the tool.

Most professionals and caregivers indicated it was an advantage that the tool could be used on a smartphone as well (quote 3). Professionals and caregivers mainly used the (group) chat function of the tools. Professionals hardly used the care plan function, because they believed it generated extra work. Nevertheless, professionals expressed interest in trying the care plan function in the future (quote 4).

Professionals and caregivers think it is a great advantage that the tool is well-secured, especially for sharing case-sensitive personal information. Professionals appreciated the functionality of measurement outcomes (e.g., blood glucose level) and messages that are registered and directly copied into the user's own registration system, which prevents errors. For GPs and practice nurses there was a direct link to the GPs information system, which they thought worked fine.

Other professionals (e.g., community nurses, case managers) were not able to easily link this interprofessional tool with their own discipline specific registration system, which they experienced as a disadvantage.

Context of use

Most professionals and caregivers were enthusiastic about this new approachable way of communicating, while some were more neutral or even reluctant. Some professionals mentioned prior unsuccessful use of other digital tools, which decreased their enthusiasm to start using yet another tool. Other barriers mentioned were lack of knowledge about why the tool was implemented, unclear added value of the tool, and personal preferences for alternative forms of communication (quote 5). For most caregivers digital communication with professionals was a new phenomenon (quote 6).

Some professionals indicated the need of clear and uniform agreements for the use of the tool to achieve broad implementation. Work agreements, including content of messages, required response time and who to add to a conversation, were issues that were not always discussed within the network or known by all participants. Moreover, professionals working with patients of various GPs indicated the need for uniform regional agreements, because it is difficult to remember specific work agreements per GP practice. "I hope for uniformity, we already work with a lot of GP practices, and it [work agreements] cannot differ between them. Then it does not work, and you cannot remember it." [CM 2]

Most professionals and caregivers agreed that the tool should be used for non-urgent matters. Telephone contact was preferred for urgent matters or when more explanation or context was needed (quote 8).

Professionals indicated it was difficult to determine who should be included in a conversation. Several conversations per patient existed within the tool with a different combination of professionals, which sometimes caused confusion. There were different views on which professionals may read along group chats and if caregivers should be informed about everything. Some professionals and caregivers indicated that they preferred a small group of professionals experienced difficulties in daily practice because they often had to switch between different communication methods because professionals from other healthcare organizations did not have access to the tool and they also have their discipline-specific digital systems with varying functionalities. As a result, they experienced an overload of different tools and ways of communication, which sometimes made them use general forms of communication (e.g., phone or email) (quote 10).

Professionals and caregivers found the tool to be helpful to keep each other well informed about the current situation of a patient, discuss practical issues and sometimes to provide feedback to the caregiver after a home visit. *"The first person where we implemented the tool was for someone where a lot was happening in a short time with many different professionals involved"* [CN 2] Some professionals and caregivers mentioned the tool was very useful as a registration system for chronological listing of past events, whereas others did not prefer to use the tool in this way.

The possibility to provide remote care was generally considered as a relevant added value of the tools. During the COVID-19 pandemic participants experienced that some physical appointments could be replaced by using the tool (quote 12). Moreover, the tool facilitated use by a larger group of professionals and caregivers, as it enabled them to communicate, coordinate and provide support from a distance.

Professionals and informal caregivers frequently mentioned the improved availability and time saved as an advantage of using the tool. Due to the limited availability of both professionals and caregivers, they frequently missed each other when they tried to call. Professionals felt they could let go of patient-related issues more easily as they could directly share questions and concerns in a message to the care team. Caregivers mentioned that the possibility to send messages in the evening was an advantage, because it prevented disruption from their work . "We all work of course. So sometimes you want to ask a question in the evening ... I like this flexibility." [IC 1]

Involvement of professionals

Professionals and caregivers mentioned that the involvement of healthcare professionals in using the tool was generally good, though not everyone was equally active. Some professionals and caregivers had expected more involvement of GPs, paramedics or specific home care organizations. Participants mentioned that a tool must be regularly used by most professionals for implementation to become a success.

Professionals mentioned large differences in the involvement of GPs; some GPs were very enthusiastic about the tool while others preferred other ways of communication (e.g., by phone). Professionals expected the GP to take the lead in the implementation of the tool because of their gatekeeper function for their patients (quote 14).

Professionals and informal caregivers expressed that the tool led to better communication and coordination between all healthcare professionals involved, because it enables alignment of services. *"It is nice to sit together at a virtual table and let each other know what you are working on, if it is progressing or if you need help from someone. I think this is a great advantage."* [PT 1] By using the tool everyone was informed about the current situation at the same time, and the team of professionals involved was clearly defined.

Professionals and caregivers frequently mentioned that other professionals or caregivers could be contacted easier than before (quote 16). Some professionals experienced a lower threshold in sending a message to a GP compared to making a phone call when in doubt of certain minor issues.

Some GPs indicated that they thought it was rather disturbing to receive messages on a regular basis that (they perceived) were not relevant to them. Partly because of this, one network decided the GP was left out of the group conversations. "Adding other professionals to a conversation was something the GP was reluctant about. The GP wanted to keep it rather small, but I thought for some patients it is quite important that other professionals can read along, but that made the GP uncomfortable." [CN 3]

Involvement of caregivers

Caregivers experienced an increased involvement in the care for their relative; they were easily kept up to date by professionals. Professionals also indicated it was an advantage that the tool clarified which of the informal caregivers was the (first) contact person.

Caregivers considered the improved approachability of professionals one of the main advantages of the tool. It enabled easy and quick contact about their relative, they could ask questions and express their anxiety via the tool. They also asked minor questions they would previously not have asked, because they thought it was too unimportant, but were actually very helpful for them as caregiver. Professionals confirmed that the tool lowered the threshold for caregivers to contact them, which increased the caregivers' involvement in the care for the patient. *"With shorter communication lines problems can be solved instantly"* [IC 8] Some professionals had negative experiences with adding a caregiver, as they were flooded with questions and information.

A barrier mentioned by professionals to include a caregiver in the group message was the use of professional jargon, which caregivers sometimes did not understand (quote 19). Several professionals mentioned they adapted their language once a caregiver was present. Professionals often chose to have a different chat conversations with and without an informal caregiver, which sometimes led to confusion among professionals. *"Now I have to think very carefully, do I have the right chatgroup."* [CM 1]

DISCUSSION

Overall, interprofessional digital communication facilitated easier and more frequent contact between professionals and caregivers, due to their improved accessibility and approachability resulting in more coordination of care. All identified barriers and facilitators were related to tool characteristics, context of use, and involvement of the professionals and caregivers within the tool. Professionals and caregivers mentioned the advantage of the tools well-secured (group) message function and options for safely sharing information. Related to the context, improved accessibility to and for professionals and caregivers was a frequently mentioned advantage. Lack of working agreements hampered efficient use of the tools and resulted in frequent use of alternative methods of communication. Professional and caregiver involvement and approachability seemed to improve by using the tool, while a disadvantage was that not all relevant professionals were yet included in the tool. The tool were better informed and informed at the same time about patient's situation.

The benefits of interprofessional communication tools were confirmed in this study, including the potential to divide tasks, enabling more efficient and safer information exchange, replacing some less important face-to-face meetings or telephone calls and improving caregiver involvement.^{7, 12-14} In our study we found great variety in frequency of use, which is common in using digital tools.³¹ Several caregivers and professionals indicated that use was mainly dependent on the current health situation of the older adult. The tools in our study were not yet available for all relevant caregivers and disciplines, which was one of the major barriers to successful implementation. This concept is confirmed in previous research that found that especially for interprofessional tools, a large scale roll-out is extremely important ³² and that a higher number of involved disciplines resulted in more tool use.³³

This study also confirmed the importance of GP involvement because, due to their gatekeeper function, other professionals expected the GP to take charge during implementation of these tools.^{34, 35}

A major barrier mentioned by participants was the large number of tools they had to use, which was confusing. Due to digitalization, all disciplines already have their own discipline specific tools with varying functionalities. This lack of interoperability of systems was identified as major barrier before ^{16, 36}, and sometimes resulted in the use of 'old-fashioned' forms of communication (e.g., phone or email).

The necessary facilitator to overcome this lack of interoperability of systems, organizational involvement and commitment, was absent within this study setting because tool implementation was initiated by the local GP practices.^{15, 29} This approach prevented uniformity of communication, which is considered essential.³⁷ Digital tools alone cannot be blamed for absent or inefficient communication as long as healthcare organizations lack a view on how to improve or support interprofessional collaboration.¹⁶ In previous literature, this was mentioned as a prerequisite for successful implementation of digital communication tools, as it indicates organizational and system readiness ¹⁵ and integration among the micro, meso and macro level.³⁸ Our study supports previous research advocating implementation of interprofessional tools in networks in which collaboration is already established.

Implications for research and practice

Implementing an interprofessional communication tool will be more successful if established collaboration already exists. In the participating networks of this study,

an established collaboration already existed ³⁹, and the tool was merely a new way of communication. Implementing these tools was especially important to facilitate communication ⁴⁰ and should therefore not be considered as a goal, but meant to support a transfer toward more highly coordinated care.⁴¹ Digital tools are mentioned as important facilitators in frameworks for integrated care and should be part of integrated care implementation programs.^{38, 42}

We still think there are important steps to take to achieve long-term use of these tools. Our study highlighted the importance of overarching work agreements regarding the use of a tool, and the need for suitable training especially for less digitally skilled users. It is important to engage the entire interprofessional team to participate and actively use the tool ^{15, 43}. It is also essential to evaluate these innovations regularly to identify unexpected barriers to establish long-term use ^{37, 40}. These tools could be useful for various target groups, which could contribute to wide-scale implementation.

Interoperability is still lacking resulting in a large number of tools professionals have to use. Integrated systems are recommended, which could be realized by reducing the number of tools or increasing interoperability between tools. Integration is frequently lacking because tools are developed and implemented by individual ICT-parties as part of a pilot or project grant, resulting in a large variety of tools with limited functionalities. Healthcare organizations and funders should focus on these aspects and make sure that ICT systems are better aligned in our digital future.^{16, 36, 42, 44, 45} Commitment at all levels is needed and strategies at the organizational level are crucial.

Strengths and Weaknesses

A major strength of this study is the broad perspective, we included three different tools and focused on the overarching themes important for successful implementation and longterm use instead of tool specific factors. Evaluation studies regarding interprofessional communication tools are scarce. But since interprofessional communication tools are highly promoted, with this research we contribute to this current knowledge gap, which is essential for the digitalization in healthcare settings.

Additional methodological strengths were the following. Coding was regularly checked by independent researchers and results were interpreted by a group of authors with different research and healthcare discipline backgrounds, which enhanced the validity of the results.⁴⁶ We generated rich data by interviewing a large sample of professionals with varying backgrounds and from different organizations, including both non-users and early adopters. This contributed to data saturation and a heterogeneous perspective. A limitation is that the caregiver sample was less multiform including mainly adult children caring for their parents, because spouses often lacked digital skills. Moreover, this study took place within an interprofessional network-based setting, in which professionals were already collaborating with each other: the tool thus fell on fertile ground. This context should be taken into account when transferring these barriers and facilitators to other care settings, where the collaborative context is still to be developed.

CONCLUSIONS

This study shows the barriers and facilitators to the use of interprofessional digital communication tools in local primary care networks for frail older adults. For most professionals and informal caregivers, the tools facilitated easier communication, mainly due to improved accessibility of both professionals and informal caregivers which also resulted in easier approachability of professionals. Everyone was informed about a patient's situation at the same moment, which improved coordination of care. To establish long-term use, broader implementation of these tools in a catchment area is necessary. And, more importantly, the number of tools should be reduced or interoperability between tools should be increased. Organizations or policy makers should facilitate the availability of tools and related work agreements. Further research is warranted to identify requirements for sufficient organizational support for the implementation of interprofessional digital communication tools.

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Digital resilience monitoring of informal caregivers of persons with dementia: a promising concept for early detection of overburden

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ABSTRACT

Objectives: Informal caregiving is becoming increasingly important in dementia care, but causes a considerable burden on caregivers which impacts their wellbeing. We aimed to develop and test a digital monitoring tool (REMIND) for wellbeing and resilience of informal caregivers to provide timely support and thereby prevent their overburden and eventually crises admissions of persons with dementia.

Methods: A human-centered design method based on co-creation with informal caregivers and professionals was used to design REMIND. During co-creation meetings and in-between sprint sessions, a point of focus was formulated, and a prototype was created. Case manager-caregiver duos pilot-tested REMIND for three months. Semi-structured interviews were conducted to determine usability and acceptability. Thematic analysis was applied to the transcripts.

Results: Informal caregivers and professionals with varying backgrounds participated in three co-creation meetings. Defined point of focus was to develop a tool that is able to provide insight into the experienced burden of informal caregivers. The REMIND prototype consisted of weekly questions about wellbeing and resilience for informal caregivers and a dashboard with answers for case managers. Eight case managers and 13 informal caregivers considered REMIND easy-to-use. Informal caregivers mentioned that REMIND stimulated self-reflection. Case managers appreciated the tool's ability to gain insight in the actual wellbeing of informal caregivers.

Conclusions: The REMIND tool developed in co-creation with end-users potentially increases insight in actual wellbeing of informal caregivers for both caregivers and case managers. A long-term (controlled) follow-up study is needed to evaluate REMIND's impact on caregiver burden and crisis admissions.

KEY POINTS:

- Informal caregivers find it difficult to acknowledge feeling overburdened to healthcare professionals but also to themselves.
- Healthcare professionals often do not notice informal caregiver overburden and therefore cannot provide timely support.
- A monitoring tool enables informal caregivers to self-reflect on their wellbeing.
- Digital monitoring of wellbeing and burden facilitates informal caregivers to easily report their burden to a healthcare professional.
- Healthcare professionals gained better insights about the actual wellbeing of informal caregivers by using the monitoring tool.

INTRODUCTION

The majority of people with dementia live at home, often resulting in complex care situations in the primary care setting.¹ A substantial part of the care for people with dementia is provided by informal caregivers. Informal care is non-professional care provided by someone from a person's social environment, usually a partner or child.² Providing this care causes a considerable burden on informal caregivers.³ It is essential that these informal caregivers experience sufficient support to perform their caregiving tasks.

In the Netherlands, people with dementia and their informal caregivers receive support from a case manager, who coordinates the care and examines the informal caregiver's wellbeing a few times per year.⁴ Still, 39 percent of informal caregivers for people with dementia experience a heavy burden and 14 percent feel overburdened.⁴ These caregivers frequently feel stressed and frustrated, are depressed or have depressive symptoms.⁵⁻⁷ Informal caregivers' perceived burden also increases the risk for institutionalization of people with dementia.⁷⁻⁹

If wellbeing and resilience are preserved, the risk of overburden decreases.^{10, 11} Resilience is an important measure to identify which informal caregivers are in need of supportive interventions to improve their wellbeing.¹² Better understanding of caregivers' resilience can help case manager to offer the right support at the right time. Adequate support will not only benefit the wellbeing of both caregiver and care recipient, but also society as a whole since it may decrease healthcare costs by reducing the number of unexpected hospital and nursing home admissions.^{13, 14}

However, due to frequent fluctuations in wellbeing and resilience ¹⁵, assessment only a few times a year, as is currently performed by Dutch case managers, may give a distorted view on informal caregivers' actual burden. Frequent monitoring of informal caregivers' might be a very promising solution.^{5, 16} It may reveal early deterioration of wellbeing and resilience, and subsequently enable timely interventions to decrease the development of mental health problems (e.g. depressive symptoms or overburden), increase their perseverance time ^{17, 18} and reduce acute admissions.

Evidence whether monitoring informal caregivers' wellbeing decreases the experienced burden is still lacking. Furthermore, user-friendly tools to monitor the wellbeing of informal caregivers are scarce, and refer to other conditions or combined interventions.^{19, 20} Therefore, our aim is to develop and pilot-test a digital tool to monitor informal caregivers' wellbeing and resilience to provide timely support and prevent or delay

(acute) hospital and nursing home admissions. To ensure the feasibility and acceptability of such a tool, we will use a co-creation approach.^{21, 22}

METHODS

Design

Between November 2018 and February 2021, a human centered design approach based on co-creation and iteration was used by inviting informal caregivers and healthcare professionals to participate in the development process of the tool.^{23, 24} We used the Design Thinking Guide developed by the Hasso-Plattner Institute of Design at Stanford (d.school). The Design Thinking Guide includes the empathize, define, ideate, prototype and test phase (see Figure 1).²⁵

Human centered design is an iterative process in which the test phase is considered an essential part of the developmental process. For clarity purposes, we describe the test phase separate from the other developmental phases.



Figure 1. Graphical representation of a human centered design methodology

Development

Participants

Potential end-users, being informal caregivers and healthcare professionals, were invited via email to participate in the co-creation meetings via the DementieNet program.^{26, 27} Purposive sampling was used by selecting persons who were: 1) working regularly with persons with dementia (in the primary care setting), 2) working in the region Nijmegen or surroundings. We recruited professionals with varying backgrounds for all co-creation meetings. The combination of end-users present differed between the meetings. Experts

preparing and participating in the meetings were researchers, clinicians, innovation experts and application developers involved in the project initiation; all were employees of the Radboudumc or application developers building the tool.

Methods

Three co-creation meetings with end-users and experts took place between November 2018 and July 2019, with a duration of two hours. The overall structure of the meetings was similar; starting plenary with an introduction and purpose of the meetings, thereafter the topic was discussed in separate groups of professionals and informal caregivers. The meetings ended with a plenary discussion to exchange and specify ideas and search for similarity and synchronization. Moderators (experts from the project team) were present to lead the group- and plenary discussions. After each meeting, the project team discussed the outcomes and discussed the practical implications for the tool. In between the group meetings, experts worked according to the scrum methodology²⁸: after short building trajectories the application and dashboard were discussed with the end-users and project team to make adjustments when needed. The meetings were audio recorded and verbal consent was asked at the start of the meeting.

1. Empathize

In the empathize phase, the wishes and needs of end-users, healthcare professionals and informal caregivers, were identified by discussing the care pathway of persons with dementia and identifying current difficulties for informal caregivers and professionals.

2. Define

The exact problem, 'point of focus', the tool needed to address was determined during the define phase by discussing this in separate groups of healthcare professionals and informal caregivers. Thereafter, consensus was reached during a plenary discussion. Moreover, possible digital solutions to address the point of focus were discussed.

3. Ideate

The outcomes of the previous phases were summarized, and the application developers presented their first ideas based on these outcomes. Thereafter, concrete ideas for the lay-out, user-friendliness and content of the prototype were further discussed with the end-users and experts.

4. Prototype

A schematic version of the tool was designed, presented and discussed with end-users. Application developers build the prototype in consultation with innovation experts and the authors.

Analysis

Co-creation meetings were analyzed using the audio files and were discussed with the experts, results were directly used in the next meeting.

Testing

Participants

For pilot testing of the first working prototype, convenience sampling was used to include case managers and informal caregivers, as the Covid-19 pandemic prevented purposive sampling. Case managers were recruited via the DementiaNet program ^{26, 27} and authors' professional networks, no exclusion criteria were applied. Each case manager was asked to invite 2-3 informal caregivers caring for a relative with dementia to participate in the pilot.

Methods

5. Pilot test

Case managers and informal caregivers received a written manual and instruction movie with an explanation on how to register and use the tool. Support was available by phone or via an in-person meeting (DO). At the start of the pilot written informed consent was asked for using their data.

Semi-structured interviews were used to identify usability, acceptability and added value of the REMIND-tool. The interviews were conducted by an independent researcher via telephone due to COVID-19 regulations. A topic list was developed for informal caregivers and case managers separately, focusing on users' experiences in terms of perceived benefits, major concerns, and further desired functionalities and improvements, based the structure of a previous study.²⁹ The interviews were audio recorded and transcribed verbatim.

The duration of the interviews varied between 15 and 30 minutes. Informal caregivers' adherence rate was calculated with data retrieved from the backlog of the REMIND-tool.

Analysis

ATLAS.ti version 8.4.20 was used for the inductive content analysis of the interview transcripts. Two trained researchers (DO, MSc; WV, BSc) individually coded the first four interviews, consensus on these codes was reached through discussion. The rest of the interviews were coded by one researcher (WV) in consultation with two trained researchers (DO, MN). Open and axial coding was applied to the transcripts (DO, WV). Data saturation was reached since the last three interviews did not reveal new themes.³⁰ Hereafter, categories and themes were derived during a group discussion by reaching consensus within the research team (WV, DO, MN, MP).

RESULTS

Development

We describe the results of the development of REMIND per phase of the human centered design method starting with the participants present at the meetings.

Participants end-user meetings

Between 10 and 15 end-users participated in each meeting. Informal caregivers and healthcare professionals with varying backgrounds were present. Table 1 describes the characteristics of the participants per meeting. Background of experts involved are presented in appendix A1. Not all experts were present at each meeting.

	Meeting 1	Meeting 2	Meeting 3
Number of participants	13	10	15
Female, n	12	6	14
Dominant background, n			
Healthcare professional			
Case manager	3	4	3
General practitioner	1	1	1
Practice nurse	1	-	1
Community nurse	2	2	2
Welfare worker	2	-	1
Informal caregiver	4	3	7

Table 1.	Participant	characteristics	defined	per meeting
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1/2. Empathize and define

The following wishes and needs were identified during the first end-user meeting. It emerged that most informal caregivers find it difficult to acknowledge feeling overburdened to professionals but also to themselves. Case managers are often not able to notice when an informal caregiver becomes overburdened, therefore they cannot provide timely support. Although case managers visit the client and informal caregiver regularly, the moment an informal caregiver becomes overburdened often happens at a different time. Informal caregivers mentioned they needed a tool where they can very easily report their increased burden to the case manager.

This would also help them to reflect and become aware of their own burden. Case managers indicated the need to be sooner aware of informal caregivers' experienced burden. End-users mentioned the tool should feel personal, just like a conversation. During an expert meeting, results were translated to concept screens for possible applications. During the second meeting the point of focus of the application was specified and defined: to monitor wellbeing and resilience of the informal caregiver to reduce crisis situations of the person with dementia.

3. Ideate

During the second meeting, we presented concept screens of a possible application and dashboard, to verify and optimize the idea. Practical features were discussed, including the lay-out, language, and for which informal caregivers (caring for a relative with early versus advanced stage of dementia) the tool should be designed. Also, the content of the app was discussed, there should be a possibility for reflection on one's wellbeing. The idea emerged to frequently assess informal caregivers' wellbeing through weekly questions. By analyzing the answers over time, deterioration in wellbeing could then be noticed by case managers. Possible topics for questions were based on the literature ^{10, 12, 31} and emerged during the meeting: perseverance time, stress, coping, physical and mental condition of the person with dementia and the experienced social support. During expert meetings, standardized questionnaires were collected, and additional questions were formulated. Standard questionnaires to measure resilience and wellbeing included the topics perseverance time ³², burden ³³, social support ³⁴, physical health ³⁵, mental health ³⁶, person with dementia ^{37, 38}, and resilience.³⁹

In a third meeting with end-users adjusted concept screens of the application and dashboard for case managers were presented and their relevance and user friendliness were discussed. During the meeting, the previously collected questionnaires and self-formulated questions were evaluated until consensus was reached among end-users. Furthermore, end-users indicated it would be viable to fill in approximately seven questions per week.

During an expert meeting, we used the output of the meeting and the standardized questionnaires to construct two sets of questions for weekly assessment for pilot testing covering various topics, see Table 2.

Set	Category	Question
1	Social support	Do you see enough possibilities to find alternative informal care (for example, when you are ill or need a day off)? $^{\rm 34}$
	Reciprocity	Do you have enough headspace to listen to the problems of family members and friends? ³³
	Physical health	Did you have had any physical complaints the past week? ³⁵
	Wellbeing PwD	The person with dementia is satisfied with the day-to-day activities. ³⁸
	Own activities	There are enough moments where I am able to relax. ³³
2	Mental health	Do you still enjoy things? ³⁶
	Small crises	How many difficult situations did you experience with your loved one with dementia the past month? (for example, incontinence or wandering)
	Social support	Do you experience incomprehension about your role as informal caregiver from your surroundings? ³⁵
	Burden	Do you ever fall out to your loved one with dementia? $^{ m 40}$
	Burden	If the care for your loved one continuous like it is now, for how long can you maintain the situation? ³²

Table 2. Two sets of questions for weekly assessment by informal caregivers using the REMIND-tool

PwD=person with dementia

4. Prototype

During expert meetings, we iteratively translated all information collected to design the tool for pilot testing which led to the first prototype of the REsilience Monitor for INformal caregivers in Dementia (REMIND). REMIND consists of a weekly assessment for informal caregivers and a dashboard for case managers where answers are depicted as trajectories over time. Hereby, both informal caregivers themselves and their case managers obtain better insight into the wellbeing of the informal caregiver. When wellbeing of the informal caregiver deteriorates case managers can offer support in time. See appendix A2 for a screenshot of the prototypes.

Testing

Participant characteristics pilot test

Thirteen informal caregivers and eight case managers participated, the majority was female. Half of the informal caregivers were caring for their spouse and the other half for one of their parents. Table 3 provides an overview of the participant characteristics. All informal caregivers completed at least 95% of the weekly digital monitoring assessment.

5. Pilot test

Eleven categories and four themes emerged from the data. Themes are presented in Table 4.

· · · · · · · · · · · · · · · · · · ·	1	
	Informal caregivers (N = 13)	Case managers (N = 8)
Gender, n		
Male	2	1
Female	11	7
Age in years, mean (±SD)	62.2 (± 12.6)	47 (± 12.2)
Relation to person with dementia, n		
Daughter/son	7	
Spouse	6	
Time in years, mean (±SD) as informal caregiver	4.8 (± 3.0)*	-
as case manager	-	5.5 (± 4.8)
SD, standard deviation; *N=9.		

Table 3.	Participant	characteristics	of the	pilot test
10010 01	i ai cicipai ic	characteristics	ortic	phot test

Theme 1: Usability

Most informal caregivers and case managers did not encounter any difficulties regarding the usability of the monitor, the system was easy to use with a clear lay-out as was the twofactor authentication security process. Some case managers indicated that registering was difficult, due to their lack of digital skills. For some informal caregivers, the digital aspect is still too difficult.

The majority of informal caregivers considered the frequency of the assessment (every week) as sufficient and not burdensome. *The frequency is good. Once a week is easy to oversee. If you ask questions about your emotions, then once a month is a very long period' (IC12).* Some informal caregivers would prefer a larger time interval between the assessments (e.g. once per two weeks or monthly), as their situation was stable, and answers did not differ between the weekly intervals. Case managers mentioned that they sometimes forgot about this tool, because in this small-scale pilot they had only one or two informal caregivers using it.

Themes	Categories
Usability	Training
	Ease of use
	Frequency of use
Benefits and concerns monitoring	Insights by monitoring
	Outcome monitoring
Benefits and concerns assessment	Awareness and self-reflection
	Relevance questions
	Target group
Future use	Future use
	Satisfaction
	Suggestions for improvement

Table 4. Themes and categories related to the use of the REMIND-tool by case managers and informal caregivers.

Theme 2: Benefits and concerns monitoring

All case managers recognized the potential of digital monitoring, although not all case managers obtained additional insights during the pilot period. They said that the tool could be of added value in the future, when used for a longer period of time. Case managers experienced that time is needed to visualize a trend, which is necessary for intervening.

Some case managers obtained new insights using the tool. One case manager noticed positive effects in the visualized wellbeing data the next few weeks after additional support. *'In the next few weeks it was visable, the scores regarding overburden were different' (CM5).*

Another case manager thought that a specific caregiver situation was very stable, however the tool revealed several stressful situations in the past week. Several case managers mentioned the tool's ability to provide information that is not mentioned during a regular visit. Informal caregivers confirmed this: when they did not want to express their feelings of burden in front of their loved one, this tool was considered a safe space to do so.

Some case managers pointed out they intervened after checking their dashboard by making a phone call or talking about the results in their next meeting. However, not all case managers acted on the results, they said they needed directions in when and how to intervene.

The feeling of being monitored by a case manager was described as comforting by informal caregivers. '*If someone is keeping an eye on you that is a nice feeling' (IC9)*. Case managers also empazised this feeling: '*Personally, I think that an informal caregiver appreciates the feeling that we [the case managers] monitor the situation and that they will be contacted to check if everything is all right.' (CM7)*. Case managers emphasized it is important to let informal caregivers know that you have seen the results of the self-assessment. Some informal caregivers also wondered if their case manager was checking the results, as they received little feedback. Case managers expressed that their lack of reaction to the answers could lead to a decline in informal caregivers' engagement with REMIND.

Theme 3: Benefits and concerns assessment

The majority of the informal caregivers appreciated the self-reflection induced by REMIND. They explained that by filling-in the weekly assessments they took a moment to reflect on the past week and it also led to insights into the burden of the caregiving. *You take a moment to reflect on the situation. What are the effects on me? And because of that monitor I take some time to reflect on it.' (IC1).* One informal caregiver found it desirable to see the previous answers to gain even more insight into their own situation. Case managers indicated that some informal caregivers could benefit from the tool but were not willing to use it because monitoring was too confronting for them.

Informal caregivers perceived the tool as a valuable instrument to provide their case manager with information about their wellbeing, particularly information that was not discussed during a regular home visit.

The current questions were mainly applicable to spouses of the person with dementia, according to the care-providing children. Informal caregivers also perceived too little variation in the weekly questions. *It (the questions) provides a general picture... it is not very specific.' (IC7)*.

It was frequently mentioned that tailor-made questions are essential for informal caregivers to experience the relevance also on the long term. Users mentioned that tailor-made questions can make the tool applicable for a broad range of target groups, e.g. for different caregiver roles and for caregiving outside dementia. 'I do not think that there is a special target group, I think it could be applicable for everyone.' (CM2).

Theme 4: Future use

The majority of users was willing to keep using the tool after the pilot. The benefits of the tool were recognized by the users and all of them would recommend the tool to other informal caregivers and case managers.

Essential improvement suggested by users was an open text field for explanation and additional comments. informal caregivers would appreciate some tips and tricks to deal with their loved one with dementia.

Case managers would like to receive a notification when new assessments are completed or when wellbeing decreases below a certain threshold. Almost half of the case managers mentioned that they would like this tool to be integrated within already existing system they use in daily practice.

DISCUSSION

In this study, we used co-creation to develop a tool to monitor wellbeing of informal caregivers of persons with dementia. Such a tool is essential as informal caregivers find it hard to acknowledge their caregiver burden, while case managers have difficulty recognizing the level of burden in time. The developed REMIND tool was perceived as user-friendly and as an addition to regular care. Completing a weekly assessment was not perceived as burdensome by informal caregivers. Some case managers had difficulties acting upon the results, whereas others almost automatically included the outcomes in their routine. Overall, the tool increased informal caregivers' self-reflection and insight into their caregivers' wellbeing. However, several suggestions to improve adherence were mentioned, including more tailor-made questions, open text field and providing tips and tricks for informal caregivers and add notifications for case managers.

The end-user meetings in our study showed that case managers find it hard to provide suitable support to informal caregivers, since their wellbeing fluctuates and can even differ per day.¹⁵ Therefore, our study focused on continuous monitoring of the wellbeing of informal caregivers in order to facilitate timely, tailored interventions. Our study showed that the concept of monitoring informal caregivers' wellbeing has potential to prevent and manage overburden by offering timely support. Previous studies have investigated combined web-based interventions mainly using educational/informational resources, and peer support. They found positive effects on distress, perceived burden and thus overall wellbeing, although the level of evidence is low and available studies lack methodological quality.^{16, 41-43} A combined intervention including monitoring did find similar results.⁴⁴

As the current level of evidence of these interventions is low ⁴³, there is an urgent need for objective measures to monitor differences in wellbeing as a result of these tools.

Literature suggest to use standardized questionnaires to assess the effects of these interventions.^{12, 41, 45} In this study we already based our monitoring questions on standardized questionnaires. However, as informal caregivers in our study mentioned, their wellbeing fluctuates a lot. This reduces the validity of single of before-and-after measurements.

This tool may improve self-reflection among informal caregivers. This is an important result, since literature showed that providing adequate support can also be hindered by the fact that informal caregivers are not always aware of their own situation and do not ask for support.⁷ In this study, we ran into a phenomenon described before: some informal caregivers were afraid of being confronted with their caregiver burden and declined participation in the study.⁴⁶ This was unfortunate as the involved case managers expected this group to especially benefit from such a tool. All informal caregivers that did participate showed a high adherence to REMIND. The frequency of use among case managers however was lower, which is probably caused by the limited number of informal caregivers that used the tool in this pilot study. This prevented REMIND from becoming part of their routine. Including notifications may help case managers to react in a timely manner.²⁹

A challenge for the use of REMIND is to maintain long-term relevance for informal caregivers, especially for those without an urgent request for help caring for persons with an early stage of dementia. A strategy mentioned to keep informal caregivers engaged was including tips and tricks to the tool (e.g. information resources or possibilities for support groups). Previous studies also demonstrated the potential of a multi-component web-based interventions for improving wellbeing of informal caregivers of people with dementia.^{43, 47-49}

Strengths and limitations

A major strength of this study is the co-creative process during the developing phase by using a human centered design methodology. Informal caregivers and professionals with diverse backgrounds were included in the development phase, which has led to a concept fitting to the needs and wishes of a variety of the end-users.^{29, 50, 51} Another strength of this study is the diverse group of users that tested the tool, e.g. caregiver spouses versus children and older versus younger case managers. This resulted in a heterogeneous perspective regarding the concept of this monitoring tool.

The users were interviewed by an independent researcher, which improves the internal

validity. Additionally, during data analysis multiple researchers discussed the results (investigator triangulation) which added to the correct interpretation of the study outcomes.

A limitation is that we had to use convenience sampling due to difficulties with recruiting case managers and informal caregivers willing to participate. As a result, case managers approached more digitally skilled informal caregivers. Ideally, we would have used purposive sampling for inclusion of both case managers and informal caregivers. Although, we reached data saturation and are therefore confident that we included all relevant themes, one should be cautious when interpreting these results, as they may not be transferable to the entire population of informal caregivers.

Implications for practice and research

Our pilot study identified essential features that could be included in the next version of REMIND, such as adding notifications for case managers (in order to react in a timely manner) and making the questions more tailor-made for informal caregivers (by making them role specific, e.g. spouse versus child).²⁹ Lastly, including tips and tricks for informal caregivers can stimulate continuous engagement with the tool. After adjusting REMIND according to these practical suggestions, a larger and longer follow-up study is needed to determine if REMIND works on a larger scale to improve our understanding of the tool's working and its quantitative effects on informal caregivers' burden. Thereafter the final step will be to perform an effect evaluation using an RCT design to identify the long-term effect on informal caregivers' wellbeing and resilience and consequently acute admissions of their relative with dementia.

Digital solutions frequently fail to reach the implementation stage ⁵²; co-creation might be a crucial strategy to overcome this. Using co-creation, we were able to develop a tool that suits the wishes and needs of informal caregivers and professionals. Various definitions are used for human centered design methods including co-creation. More unified guidelines and evaluation methods may facilitate for the increased use of these co-creative methods.⁵¹

Lastly and very relevant today, the tool developed for this study also offers possibilities in dealing with the COVID regulations. During social periods of mandatory social distancing, digital monitoring can be a useful tool to remain in contact with each other.^{16, 29, 41} Especially, since caregiving in COVID time is even more burdensome and reducing the caregiver burden is essential to maintain informal caregivers mental health.⁴¹

CONCLUSION

A co-creation approach resulted in REMIND, a digital well-being and resilience monitor for informal caregivers of persons with dementia, consisting of a weekly questionnaire and information dashboard for caregivers and case managers respectively. REMIND was considered easy to use. REMIND increased informal caregivers' self-reflection and insight into their burden. Case managers reported better insight into caregivers' wellbeing which facilitated opportunities for earlier intervening. A future long-term follow-up study is warranted in order to evaluate the effectiveness and efficacy of REMIND in preventing overburden of informal caregivers and resulting crises in people with dementia.

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APPENDIX A1 – Dominant background of experts

Dominant background	Number, n
Application developer	1
Innovation expert	2
Geriatrician/ researcher	1
General practitioner/ researcher	1
Researcher	2

APPENDIX A2 – Screenshots of the questionnaire for informal caregivers and the dashboard for case managers



PART !!

EFFECTS OF THE DEMENTIANET PROGRAM





Care integration in primary dementia care networks: a longitudinal mixed-methods study

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ABSTRACT

Introduction: Currently, care integration for community-dwelling persons with dementia is poor and knowledge on how to effectively facilitate development of integrated dementia care is lacking. The DementiaNet program aims to overcome this with a focus on interprofessional collaboration. The objective of this study is to investigate how care integration in interprofessional primary dementia care networks matures and to identify factors associated with (un)successfully maturation.

Theory and methods: A longitudinal mixed-methods study, including 17 primary care networks participating in the DementiaNet study, was performed. Semi-structured interviews based on the Rainbow Model of Integrated Care were conducted at start, at 12- and 24 months. Network maturity scores (range 1-4) were derived from the interviews and qualitative data was used to explain the observed patterns.

Results: Networks consisted on average of 9 professionals (range 4–22) covering medical, care and social disciplines. Network maturity yearly increased with 0.29 (95%-CI: 0.20-0.38). Important factors for improvement included getting to know each other's expertise, having a capable network leader(s), stable network composition and participation of a general practitioner.

Conclusions: The DementiaNet approach enables a transition towards more mature networks. Identified success factors provide better understanding of how network maturity can be achieved and gives guidance to future care integration strategies.

INTRODUCTION

The rapid ageing population together with the rising number of older adults with chronic conditions creates a major challenge for healthcare systems.¹ In the Netherlands, many older adults with dementia remain living at home, due to policy changes that led to closing of elderly homes. Consequently, the burden on primary care is increasing. Dementia is a condition that affects multiple aspects of the lives of persons with dementia and their caregivers. Especially in later stages of the disease, several professionals of medical, care and social disciplines are involved. Often these professionals work at different organizations, and fragmentation of care is likely to arise.² As a result, continuity of care is lacking and there is a low satisfaction with the provided care among professionals, persons with dementia and their informal caregivers.^{3, 4}

Integrated primary care is considered a strategy to overcome care fragmentation, by increasing the collaboration between professionals and care organizations thereby improving the healthcare system's continuity of care.⁵⁻⁸ Integrated care is a complex term and different terminologies are used to describe this concept.⁹ The WHO defines integrated care as the delivery of a continuum of care, designed to meet multidimensional needs of the population and the individual, by a coordinated multidisciplinary team of professionals.¹⁰ To achieve integrated care, a transition towards network-based care is suggested.^{6, 11, 12} However, empirical evidence is still lacking ¹³, which is essential for implementing such network activities in dementia care.

The DementiaNet approach brought the transition towards network-based care into practice. DementiaNet is designed to facilitate the development of interprofessional networks of primary care professionals from the medical, health and social care services.^{11, 14} As in other transitions, sufficient time is needed for collaborations to mature and achieve care integration. Support from the DementiaNet team is therefore provided for a period of two years. However, it is unclear whether this intentional transition leads to improvement of care integration.

We aim to investigate how the DementiaNet approach affects network maturity of these interprofessional primary dementia care networks over time. Additionally, we will identify factors associated with (un)successful network maturation.

THEORY AND METHODS

Study design

A longitudinal multiple case mixed-method study was performed to evaluate the development of network maturity of networks participating in the DementiaNet program. We chose a mixed-method design, applying and integrating quantitative and qualitative data sources, to gain deeper understanding of the mechanisms behind (un)successful network maturation.^{15, 16} Each DementiaNet network served as a case with a 24 months follow-up. This study was conducted within the Dutch primary dementia care setting. Detailed description of primary care in the Netherlands can be found in Appendix I.

The study protocol was submitted for review to the local ethical committee, and they declared that formal judgment was not required according to the Dutch law (protocol number: 2019–5599).

Study population

New and existing local collaborations of primary care professionals, with a shared caseload of dementia patients, could voluntarily participate in the DementiaNet program. Composition of the networks was tailored to local availability and preferences. Consequently, each network was different in terms of size and represented disciplines and starting levels of collaboration and quality of care. Desirably, networks included at least one professional of the medical (e.g. general practitioner), care (e.g. community nurse) and social (e.g. social worker or case manager) discipline. The networks started with the DementiaNet program between 2015 and 2017.¹¹ All participating networks were located in the east of the Netherlands.¹⁷

DementiaNet program

The DementiaNet program is a stepwise, bottom-up approach to facilitate integrated care implementation. The DementiaNet program consists of four key elements (see Figure 1) aimed at achieving networks to become independent, sustainable and interprofessional collaboratives, in which members can provide better quality of care and achieve higher effectiveness.

The first element of the DementiaNet program is interprofessional collaboration. The networks of professionals, offering services to a shared caseload of people with dementia, should want to achieve structured local interprofessional collaboration to ensure continuity in care. Second, at least one network participant is the network leader and is trained and coached by the DementiaNet team to support them in their leadership role. The key tasks of the network leader include: connect professionals, stimulate collaboration and support the quality improvement process. Third, networks should engage in quality improvement cycles to improve the quality of care. At least once a year an improvement plan is carried out based on their yearly quality of care assessment and benchmark feedback. Based on these results the network members jointly identify improvement goals.

Fourth, interprofessional education about self-selected topics is offered to the networks to increase collaboration, knowledge and skills acquisition. The contents of these training and coaching sessions are tailored to each network's own goals.

The elements of the DementiaNet program are tailored to the needs of the networks, thereby allowing for the large practice variation present in daily clinical practice. Networks are supported by the DementiaNet project team during a period of two years. More detailed information about the DementiaNet program is described in Appendix II and elsewhere.¹⁴



Figure 1. Key elements of the DementiaNet program

Theoretical framework

Theoretical frameworks were used to assess network maturity towards integrated care, which we define as "a coordinated way of working across multiple professionals, organizations and sectors in order to improve the health, quality of care and economic outcomes

for a targeted (sub)population".¹⁸ During the development of the DementiaNet approach (2014), we focused on interprofessional collaboration and network development, which was, at that time, still a novel approach. We used the collaborative network theory of Kaats and Opheij ¹⁹ as a foundation. The Rainbow Model of Integrated Care (RMIC), developed in the same period, provided a theoretical framework for integrated care ²⁰ and had important parallels with the DementiaNet approach since the programs' core elements were all represented in the model (e.g. professional integration, leadership and quality improvement). The RMIC is a validated framework that emphasizes the complexity of integrated primary care and defines key elements for achieving it.²¹ Different integration domains are specified in the RMIC, therefore it is possible to identify areas for improvement. The RMIC describes three categories of integrated care: the scope, type and enablers of integration, including 8 domains (see Figure 2). The DementiaNet approach includes most RMIC domains.



The Triple Aim

Figure 2. Rainbow Model of Integrated Care. Adapted with permission from Essenburgh Research & Consultancy. $^{\rm 22}$

Scope of integration

The scope is the person and population focused view of professionals, e.g. focusing on patient's needs and abilities instead of the disease (person-focused care) and meeting a target groups' specific healthcare requirements (population-focused care).

Both person-focused and population-focused care are incorporated in the DementiaNet program. The overall aim of DementiaNet is to improve person-focused care for people with dementia and their caregiver(s). Networks are stimulated to, for example, consult the person with dementia and their caregiver before a multidisciplinary meeting or to talk about future care wishes. Additionally, DementiaNet aims for networks to identify the population with dementia better, for example, by earlier recognition of signs of cognitive deterioration.

Type of integration

The type of integration consists of integration on the micro (individual), meso (population) and macro (system) level. The type of integration refers to four domains: 1) delivered and coordinated services to patients (clinical integration), 2) collaboration between healthcare professionals (professional integration), 3) collaboration between healthcare organizations (organizational integration) and 4) implementation of new policies and regulations (system integration). The network leader facilitates collaborations between and within the micro, meso and macro level. The DementiaNet program mainly focuses on clinical and professional integration. Network members are encouraged to share their tasks and expertise, thereby getting to know each other's expertise. Moreover, they are stimulated to schedule frequent multidisciplinary meetings and implement multidisciplinary care plans for their shared caseload. The networks are encouraged to not only coordinate the care for their shared patients but also make work agreements about the care for the entire population.

Enablers of integration

Functional and normative enablers are needed to establish connectivity between the micro, meso and macro level. Functional enablers are for example communication tools that can be used by all the professionals and organizations in a network. Normative enablers refer to the development and maintenance of a common goal or plans for improvement. The DementiaNet program actively facilitates multiple enablers such as leadership, quality improvement cycles, interprofessional education, discussing the shared vision and implementing digital communication tools.

As described above these eight integration domains, divided in three categories are almost all incorporated in our DementiaNet approach. Currently, a validated integrated care measurement tool, considering the different levels of care provision, is lacking.²³⁻²⁷ Therefore, during the start of DementiaNet program, we considered the RMIC domains the best option to assess the network maturation towards integrated care of these networks. We developed a scorings system based on the conceptual representation of network maturity at four different maturity levels ad hoc, defined, controlled and synchronized collaboration from qualitative data. Thereby, we were able to assess the collaboration between care professions as a network and identify improvement areas for practice and research.²⁸⁻³⁰ Detailed information about the protocol for evaluation of DementiaNet can be found elsewhere.¹¹

Data collection and measurements

Network maturity

To assess network maturity, yearly semi-structured face-to-face interviews were conducted by trained researchers (IM or DO) with the network leader(s). Network maturity was assessed at three timepoints (T0, T1 and T2) by conducting an interview at 12 and 24 months. During the first interview at 12 months we combined the baseline (T0) and 12 months (T1) data-collection by determining the differences between the current situation and before they started with the DementiaNet program. Data was collected between January 2015 and June 2019. A topic list was used (Appendix III), based on the eight domains of the RMIC. Interviews were audio recorded, the length of the interviews varied between 20 and 60 minutes. Network leaders gave written informed consent prior to the interview.

A network's maturity was defined by rating the interviews for the eight domains of the RMIC. A scale with four predefined levels was used: 1=ad hoc, 2=defined, 3=controlled and 4=synchronized collaboration. Scores ranged from 1-4 (including half points) and a higher score indicated higher network maturity. Rating was performed independently by two researchers (DO, AH), using an elaborate protocol (on request available) to standardize the scoring after which consensus was reached on each item. A total network maturity score and sub scores eight domains of the RMIC were calculated.

Network characteristics

The researchers documented the network characteristics at start, changes in network composition, network leaders, and their leadership abilities (Table 1).

Analyses

We calculated the mean score (range 1-4) for total network maturity to account for missing data when the interview data was not rich enough to score one of the domains. We presented descriptive data for each timepoint as means and standard deviations.

Differences in mean network maturity scores (total and sub scores) between timepoints were analysed using linear mixed models, to account for repeated measures within networks and missing data. We included random intercepts per network and a fixed effect for time. We used SPSS version 25.

Data integration

Network maturity scores over time were plotted in a graph and by closely inspecting these graphs, networks were identified with similar network maturity patterns. Networks with similar patterns were clustered, based on their improvement in network maturity score over time. Networks with a network maturity score above two at T2 were classified as successful, which represented a change from ad hoc to defined collaboration. Networks with a score below two at T2 were classified as unsuccessful, as their collaboration remained ad hoc after two years. By using the qualitative data from the interviews and log data we explored whether clustered networks had similar characteristics, such as existing collaboration, network size, differences in network composition or network leader(s) and leadership abilities. Moreover, by analysing the interviews we identified which positive or negative factors were important for each cluster of networks.

RESULTS

DementiaNet networks

Twenty-five networks of primary dementia care professionals started with the DementiaNet program between January 2015 and April 2017. Six networks ceased active participation within the first year, reasons were either lack of intrinsic motivation (e.g. participation was initially not based on own motivation) or lack of time, resulting in insufficient momentum for a transition process. Two networks were not able to participate in the data-collection. Hence, results refer to 17 networks.

The average number of network members per network at the start was 9 (range 4-22). The average number of disciplines per network was 5 (range 3-9) at start, and 6 (range 3-10) after 2 years. Three network leaders had to stop due to sickness or change of jobs and were replaced by another network participant. A detailed description of the network characteristics can be found in Table 1.

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Table 1

Network	Disciplines involved	Disciplines involved	Network leader(s)	Network leader(s)	Network member	Collaboration before	Catchment area
	At start	End year 2		changed	changes	DementiaNet	
A	1 GP; 1 PN; 2 CN; 2 CM; 1 GS (total: 7)	1 GP; 1 PN; 2 CN; 2 CM; 1 GS (total: 7)	CM, GP	No	Some	Yes	Small
в	3 GP; 3 CN; 2 CM; 1 GS; 1 OT; 1 PT; 1 WF; 1 MM (total: 13)	2 GP; 4 CN; 2 CM; 2 GS; 2 OT; 1 PT; 1 WF; 1 MM (total: 15)	WF	Yes	Some	Yes	Large
U	1 GP; 1 PN; 11 CN; 1 CM; 2 GS; 4 WF; 2 MM (total: 22)	1 GP; 1 PN; 11 CN; 1 CM; 2 GS; 4 WF; 2 MM (total: 22)	: GP, PN (both period absent)	No	Some	Yes	Large
Δ	2 GP; 5 CN; 1 CM; 2 WF (total: 10)	2 GP; 5 CN; 1 CM; 2 WF (total: 10)	CM, CN (both period absent)	No	Many	No	Large
ш	2 GP; 1 PN; 2 CN; 1 CM; 1 GS; 1 WF (total: 8)	2 GP; 1 PN; 2 CN; 1 CM; 1 GS; 1 PH; 1 WF; 1 PT (total: 10)	PN, CM	No	Some	No	Small
ш	2 GP; 2 PN; 1 CN; 1 CM; 1 IC (total: 7)	2 GP; 2 PN; 1 CN; 1 CM; 1 IC (total: 7)	PN, CM	No	None	No	Large
ט	2 GP; 2 CN; 1 CM; 1 WF (total: 6)	1 GP; 2 CM; 1 WF; 1 MM (total: 5)	GP, CM	No	Some	Yes	Small
т	2 GP; 4 CN; 1 CM; 2 GS; 1 OT; 5 WF; 1 IC (total: 16)	2 GP; 3 CN; 1 CM; 2 GS; 1 OT; 1 PT; 5 WF; 1 IC (total: 16)	CN	No	Some	No	Large
_	1 GP; 1 PN; 1 CN; 1 CM; 1 MM (total: 5)	1 GP; 1 PN; 1 CN; 1 CM (total: 4)	CN	No	Some	No	Small
_	1 CN; 2 CM; 1 OT; 1 PH; 2 WF; 2 MM; 3 other (total: 12)	3 PN; 3 CN; 2 CM; 1 OT; 2 PH; 3 WF; 1 MM; 3 other (total: 18)	WF, OT	No	Some	No	Small
¥	1 GP; 9 CN; 1 CM (total: 11)	1 GP; 9 CN; 3 CM (total: 13)	CN, CM	No	Some	No	Small
	1 GP; 1 PN; 1 CN; 1 CM; 1 GS; 1 WF (total: 6)	1 GP; 1 PN; 1 CN; 1 CM; 1 GS; 1 WF (total: 6)	PN	No	None	No	Large
Σ	1 GP; 2 CN; 1 CM (total: 4)	1 GP; 2 CN; 1 CM (total: 4)	CN	No	None	No	Small
z	1 GP; 1 PN; 2 CM; 2 GS (total: 6)	1 GP; 1 PN; 2 CM; 2 GS (total: 6)	PN	No	None	Yes	Small
0	1 GP; 1 PN; 2 CN; 1 GS (total: 5)	2 GP; 1 PN; 1 CM; 1 GS (total: 5)	PN	Yes	Many	No	Large
д.	1 GP; 1 POH; 2 CN; 1 CM; 1 GS; 1 WF (total: 7)	1 GP; 1 POH; 2 CN; 1 CM; 1 GS; 1 WF (total: 7)	PN	No	None	No	Large
o	1 GP; 2 POH; 2 CN; 1 CM; 1 GS (total: 7)	1 GP; 2 POH; 2 CN; 1 CM; 1 GS (total: 7)	PN	Yes	None	No	Small
Catchment density; lar specialist; H	t: area = area from which the netv ge = more than approximately 7,5 PH = pharmacist; OT = occupatior	<pre>work attracts its population of pat 500 persons. GP = general practitio nal therapist; PT = physiotherapist;</pre>	ients with demention ner; PN = practice n · WF = welfare worke	; defined by ge urse; CN = com er; MM = manc	eographical size imunity nurse; igement or mu	e and population di CM = case manager nicipality; IC = infor	stribution and ; GS = geriatric mal caregiver.

CHAPTER 6

Network Maturity

On average the networks significantly matured with a yearly increase in total network maturity score of 0.29 (95%-CI: 0.20-0.38) on a scale of 1-4, as the mean bold line graphically presents in Figure 3. On average networks matured on all the integration domains except for organizational integration and system integration (Table 2). Network maturity domain scores increased the most for professional- and functional integration (respectively, 0.32 (95%-CI: 0.22-0.43) and 0.4 (95%-CI: 0.09-0.71)). Figure 3 shows that networks with an already existing collaboration have, on average, a higher starting level and networks with a new collaboration were able to increase their network maturity the most in these two years.



Figure 3. Network maturity trajectories of all networks with Network Maturity Scores on a scale of 1-4. Dashed lines represent networks with an existing collaboration, solid lines represent new networks and the bold line is the mean.

	Т	0	Т	1	Т	2	Linear mixed mo	dels
	Mean	SD	Mean	SD	Mean	SD	β (95% CI)	р
Total network maturity	1.66	0.53	2.11	0.50	2.24	0.50	0.29 (0.20-0.38)	<0.001
Scope								
Person-focused care	1.38	0.57	1.72	0.60	2.06	0.66	0.27 (0.18-0.36)	<0.001
Population-based care	1.53	0.78	2.13	0.76	2.27	0.69	0.23 (0.13-0.33)	<0.001
Туре								
Clinical integration	1.65	0.79	2.13	0.76	2.21	0.66	0.16 (0.06-0.26)	0.003
Professional integration	1.59	0.75	2.41	0.64	2.56	0.58	0.32 (0.22-0.43)	<0.001
Organizational integration	1.97	0.33	2.22	0.36	2.32	0.50	0.05 (-0.01-0.11)	0.108
System integration	1.96	0.56	2.25	0.5	2.03	0.62	0.05 (-0.04-0.15)	0.246
Enablers								
Functional integration	1.47	0.65	1.84	0.63	2.09	0.59	0.40 (0.09-0.71)	0.012
Normative integration	1.82	0.68	2.25	0.66	2.44	0.68	0.18 (0.07-0.28)	0.001

Table 2. Total and domain specific Network Maturity scores on T0, T1 and T2 (Crude means and standard deviations; β -coefficients, 95 % confidence intervals and p-values)

SE = standard error, significant at p-value below 0.05, 95% CI = confidence interval.

6

Network Maturity patterns

Successful network maturity

Eight networks showed a pattern of increasing network maturation that was classified as successful (see Figure 4A). Based on the interviews with network leaders several facilitating factors for professional and functional integration were identified in the majority of these networks. First, these networks focused on getting familiar with each other's expertise by organizing moments of interaction (e.g. by implementing multidisciplinary meetings) and drafting a document with everyone's expertise and contact information. This resulted in mutual trust in the competence of the various disciplines involved. Second, this process added to more patient-related communication (e.g. by implementing a communication tool). Third, they developed work agreements regarding the populationfocused view, thereby they improved their ability to identify persons with dementia in their shared population. Lastly, networks that showed successful network maturation were also characterized by an improvement in normative integration. Logs showed that network leaders' improvement in structuring and organizing the network processes. After two years, several network leaders mentioned that their involvement had become less pronounced, due to increased commitment of the other members in the network. Maturation on organizational and system integration was more difficult to achieve, some networks explicitly mentioned that, as a local network, they have very little influence on policy development and regulations.

Three networks with relatively high network maturity scores were able to maintain the scores throughout the two-year period after initiating the DementiaNet approach (see Figure 4B). These networks were pre-existent collaborations and were already matured as a network before they started with the DementiaNet program. These networks were characterized as small, experienced little changes in the team's composition and had a clear person-focused view. The network's stability was beneficial for the professional and normative integration. They mentioned that there was already a good foundation and serious commitment from the network members. This made it easy to work on new improvement goals. However, they indicated they were content with the current network performance, which hampered further maturation.

Unsuccessful network maturity

Four networks were unable to improve their network maturity score (see Figure 4C). The interviews showed that this was mainly caused by factors related to normative integration: a lack of commitment from the network members and absence of general practitioner

(GP) involvement. Additional reasons related to normative integration retrieved from the logs showed the absence of a capable network leader and many changes in the composition of the network. Especially when the network composition was not stable, network leaders mentioned difficulty in building trust, communicating about patient care and defining work agreements.

Most of these networks were not able to improve their scores related to person- or population focused view, because the tasks and expertise of the individual network members were unclear within the network. As a result, it was difficult, if not impossible, to define work agreements. The networks indicated that change regarding professional integration was limited. For example, it was difficult or impossible to implement multidisciplinary meetings. Furthermore, the network leaders indicated mutual respect and trust still needed to grow.





DISCUSSION

This study showed that the DementiaNet program seems to successfully facilitate a transition towards more mature networks, as shown by the significant yearly increase of total network maturity score of 0.29. In practice, this would mean that each year the network maturity will increase on two domains from for example ad hoc to defined collaboration. Networks with new collaborations were able to significantly improve their network maturity whereas existing collaborations maintained their already high network maturity scores. Networks showed improvement on almost all the RMIC domains except for organizational- and system integration. Professional and normative integration improved most. Facilitators to successful network maturation were 'getting to know each other' and building trust during the first years. Factors that could hamper successful integration were inadequate leadership, absence of active GP involvement or changes in the network composition or network leader.

The RMIC theory, that was the basis for our evaluation of network maturity development, suggests that a transition on all levels of the network (micro, meso and macro) is required to achieve complete care integration. Our study showed no significant improvements for organizational and system integration. A likely explanation it that the DementiaNet program was deliberately designed using a bottom-up approach with a focus on the local collaboration, thus the professional level. Consequently, integration mainly took place on the domains within the micro and meso level. Local networks felt, they have very little influence on policy development and regulations. This is in line with previous research, where lack of policy influence and available funds were mentioned as reasons it was difficult to include the meso and macro level in the maturation process of healthcare.^{31, 32} Moreover, improvements on the meso and macro level are in general very difficult to achieve ^{23, 31, 32}, because of the complexity of tackling all the integration levels with an integrated care approach. Even though it is suggested that stakeholders from all levels need to be involved to achieve a sustainable collaboration ^{31, 33}, further studies are warranted to identify successful strategies to achieve this goal.

In our study, professional integration scores showed the most prominent increase. A likely explanation is that getting to know each other, building relationships and thereby trust, is crucial during the start of a network or collaboration in general.³⁴⁻³⁶ Our study suggests that, thereafter, networks were able to focus on implementing work agreements related to improving populations health and improvement of their care processes. This was illustrated by the subsequent prominent increase in functional integration in our networks.^{37, 38}

A capable network leader was deemed of major importance for the network maturation. Current literature confirms the importance of leadership for achieving care integration. Capable leaders should have relational, organizational and management skills.³⁹ The success of leaders increases when they are also able to involve the network and help the network members develop a sense of ownership.⁴⁰

The importance of GP involvement is to network maturity development is supported by previous research.^{41, 42} GPs were revealed as the most adequate leaders in integrated primary care initiatives, mainly due to the hierarchical structure and competences of GPs.³⁹ Moreover, within a local network a GP has a central role, because it is the gatekeeper of all the persons within a geographical area.

Strengths and limitations

To our knowledge, it is a novelty to take an in-depth look at network maturation over time. The mixed-methods evaluation with innovative measurements and data integration strategies is an important strength of the study, as it does justice to the complexity of the DementiaNet program and local network dynamics. This approach contributed to a deeper understanding of the mechanisms behind network maturity development.

The lack of a validated measurement tool for network maturity forced us to use our own developed tool which is considered a limitation. However, the measurement tool was based on the validated RMIC and included a doubled independent and protocolized rating procedure. Interviews used for the ratings were only conducted with the network leader(s). Ideally ratings would include opinions of all network members. The missing data on the domain of system integration when data richness was lacking may have influenced the results, however the number of missing data was not substantial and we corrected for it in our analyses.

The study was carried out in the local Dutch dementia care setting, but the results are not restricted to this setting. A strength is that the tailor-made DementiaNet approach could be translated to other populations in primary care where multiple primary care professionals are involved for example in frail older adults, palliative care or other chronic conditions. This does not mean that the results of this study are also directly transferrable as different settings will have different system dynamics.

Implications for research and practice

Whereas facilitators for network maturation identified in this study at the micro and meso level have direct practice implications (i.e. getting to know each other, building relationships and trust), achieving integration among the meso and macro level is more difficult and future research is needed to develop successful strategies ^{31, 33} including stimulation by care organizations or the government.^{32, 34}

For integrated care initiatives to significantly contribute to the transformation of the healthcare system, it is important that validated easy-to-use measurement tools are developed.⁴³ The in-depth look at network maturation over time in this study will be helpful for the development of such measurement tools. Currently, we are validating a questionnaire to measure integrated care maturation based on the RMIC domains. By using a questionnaire experiences of all the network members and also patients and informal caregivers can be taken into account.

Our study showed positive results on network maturity when using the DementiaNet approach. The DementiaNet approach is tailored to networks' own needs and thereby reflects the variation in daily practice to a great extent. Networks can decide which educational training they want to perform and set their own improvement goals. We therefore expect that the positive outcomes of the DementiaNet approach will be sustainable when implementing this approach at a larger scale. However, future research should identify whether these changes are sustainable and if networks are able to show even more improvement. Time is necessary for networks to mature and two years is still a short timeframe.²³ Performing a long-term follow-up study to identify network maturation is therefore essential.

CONCLUSION

The DementiaNet program facilitated progress towards more mature primary care networks in the first two years after inception, with diverse trajectories. Capable network leaders, GP commitment, and a stable, committed network were identified as essential factors for a successful transition towards integrated care networks. Changes in organizational and system integration appeared difficult to achieve. More focus on meso and macro level improvement strategies is required to achieve complete care integration. Our findings provide a better understanding of the mechanisms behind network maturation; future research should evaluate the sustainability of these effects and their influence on quality of primary dementia care. Such a study could profit from the development of validated instruments to measure care integration.

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APPENDIX I – Primary care in the Netherlands

Primary care for community-dwelling dementia patients in the Netherlands 44

- 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. There is fragmentation in finances of services: 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 in practice is low.
- Dementia care on a local level is determined by national, regional and local policies as well as existing facilities and by individual initiatives undertaken by the healthcare professionals. As a result, services and quality of local care are highly variable throughout the Netherlands.

APPENDIX II – 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 tailormade 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 (1) 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 takes3–6 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 (2). 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 (3, 4) 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 behavioural problems and shared decision making.

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RMIC domain	Topics
Professional integration	Tasks and expertise's
	Respect and trust
Clinical integration	Work agreements
	Multidisciplinary care plan and meeting
Normative integration	Goal
	Commitment network members
	Leadership
Person focused care	Person-centredness
Population base care	Early signalling
	Coordinator for persons with dementia
Functional integration	Digital systems
	Feedback
Organisational integration	Support from organization
System integration	Policy developments

APPENDIX III - Topic list Network Maturity DementiaNet





DementiaNet facilitates a sustainable transition towards integrated primary dementia care: a long-term evaluation

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ABSTRACT

Introduction: Rearrangements in primary care are needed to cope with the increasing number of people with dementia living at home. Care integration is a promising strategy to achieve a more sustainable health care system. With DementiaNet, an network-based program, we facilitated collaboration between healthcare professionals from medical, care and social domains. We evaluated the long-term effects of the DementiaNet program on quality of care, network collaboration and crisis admissions.

Methods: Networks of professionals working in primary dementia care followed the two-year DementiaNet program. Networks started between 2015 and 2020 and follow-up ended in 2021. Networks collected data on their quality of care on four indicators (case manager involved, discussed in multidisciplinary meeting, discussed in pharmacotherapeutic meeting, diagnosis made in primary care; scored 1-4) and number of crisis admissions annually. Network collaboration was assessed through semi-structured interviews, which were converted to a network maturity score (range 1-4). Growth modelling was used to identify changes over time.

Results: Thirty-five primary care networks participated and consisted of on average nine professionals. Network collaboration and quality of care of newly formed networks increased significantly in the first two years (respectively, 0.35/year, p<0.001; 0.29/year, p<0.001). These levels were already higher at baseline in networks with pre-established collaboration. After two years, quality of care and network collaboration seemed to stabilize.

Conclusion: The DementiaNet program improved dementia care integration and quality of care, which persisted after the network development program ended. This indicates that DementiaNet facilitates a transition towards sustainable network-based integrated primary dementia care.

INTRODUCTION

Providing dementia care in the home setting is complex and requires the involvement of many different primary healthcare professionals.¹ Primary care could benefit from care integration across disciplines. However, healthcare professionals rarely structure their collaboration, because they are employed in different organizations and focused on their own discipline.²⁻⁴ Additionally, they experience an increased workload which will increase due to a shortage of staff. This leads to poor continuity of care and low satisfaction with the provided care among professionals, persons with dementia and their informal caregivers.^{5, 6} This care fragmentation may also contribute to the increasing number of impactful and costly crisis admissions of persons with dementia to hospitals or nursing homes.^{7, 8}

Improving interprofessional collaboration and coordination of primary care can contribute to a more sustainable healthcare system delivering high-quality care and being able to cope with this expected rising care demand.⁹⁻¹² It can improve quality of life of persons with dementia, reduce caregiver burden and lead to more satisfaction among professionals.^{10, 13} However, as integrated care is an emergent and dynamic property of a complex system of the professionals and services involved, that is at the same time inseparable from context ¹⁴, designing an effective improvement program remains challenging. Consequently, earlier programs designed to implement integrated care in the dementia care setting did not lead to improvements in collaboration nor patient outcomes.^{1, 15-17} Current health care systems thus seem to be far away from strategies that ensure a sustainable transition towards more integrated primary care.

We therefore designed the DementiaNet program, a network-based approach focusing on improving interprofessional collaboration by facilitating network development of medical-, care- and welfare professionals in primary care.¹⁸ A short-term evaluation study with a small number of networks already showed positive results regarding collaboration, quality of care and satisfaction of healthcare professionals.^{13, 19} Currently, networks have been followed up to six year, several years after the 2-year support program had ended. This enables study of sustainability of the DementiaNet program. Therefore, our aim is to evaluate the long-term effects of the DementiaNet program on quality of primary dementia care, network collaboration and number of crisis admissions.

METHODS

Study design

A mixed-methods cohort study was performed to identify the effects of the DementiaNet program. Networks started between 2015 and 2020, and consequently follow-up of the networks varied between 1– 6 years.

The study protocol was reviewed by the local ethical committee, and they declared that formal judgment was not required according to the Dutch law (protocol number: 2019–5599).

Study population and setting

Networks were all composed of primary care professionals in the Dutch primary dementia care setting (Appendix I). Participation in the DementiaNet program was voluntarily. New and existing local collaborations of primary care professionals with a shared caseload of dementia patients could join. Network composition was based on local preferences and availability of professionals and therefore networks could differ in size, represented disciplines and their level of pre-existing collaboration. We stimulated the networks to include at least one professional of the medical (e.g. general practitioner), care (e.g. community nurse) and social discipline (e.g. social worker). All participating networks were located in the east of the Netherlands.

DementiaNet program

The DementiaNet program was developed to facilitate a transition towards integrated care using a network-based approach based on the collaboration theory of Kaats and Opheij.^{18, 20} This stepwise, bottom-up program consisted of four key elements (see Figure 1) to support networks to become self-organizing, sustainable, and interprofessional collaboratives.¹⁸ First, a network had to be formed with professionals in the community who were willing to invest in achieving structured, interprofessional collaboration and continuity of care. Second, one or two of the network participants were appointed as network leaders. Third, networks were trained in applying quality improvement cycles, using their yearly collected data for quality improvement plans.^{21, 22} Fourth, networks were invited to engage in interprofessional education about self-selected topics. These key elements of the DementiaNet program were all tailored to specific contexts of the networks and they received support and coaching from the DementiaNet team for a period of two years.


Figure 1. Key elements of the DementiaNet program

Measurements and data collection

Networks started between January 2015 and March 2020 with the DementiaNet program. Data on network collaboration, quality of care, crisis situations, and network characteristics were collected yearly between January 2015 and December 2021.

Network collaboration

To assess network collaboration, we rated network maturity in transcripts of yearly conducted interviews on a scale of 1–4 based on the eight domains of the Rainbow Model of Integrated Care (RMIC).^{21, 23}

Yearly semi-structured, face-to-face interviews with the network leader(s) were conducted by trained researchers (IM or DO). We developed a topic list based on the eight domains of the RMIC: person focused care, population focused care, clinical integration, professional integration, organizational integration, system integration, functional integration and normative integration ²³ (Appendix II). The first interview took place after 12 months, combining baseline (TO) and 12 months (T1) information on network collaboration. Interviews were audio recorded and varied in length between 20 and 60 minutes. Prior to the interview, network leaders gave written informed consent.

In the transcripts, the eight domains of the RMIC ²³ were rated on four predefined network maturity levels: 1=ad hoc, 2=defined, 3=controlled and 4=synchronized collaboration ²⁴ (Table 1). Scores ranged from 1–4 (including half points) and a higher score indicated

higher maturity. Two researchers (DO and AH or ST) independently and blindly rated the interviews using an extensive protocol (available upon request). In case of disagreement, discussion led to consensus. After two third of the interviews, the second researcher only checked the ratings of the first researcher.

Level	Collaboration	Description
1	ad hoc	The network works from its primary, clinical, and basis care tasks. Most professionals work monodisciplinary and only ad-hoc collaboration takes place with other professionals. The organization focuses on the individual patients.
2	defined	Several professionals in the network start making work arrangements. The collaboration between professionals is mostly based on informal, still new contacts and is not yet structured. The network focuses on the individual patients and the organization focuses more on the population- based care.
3	controlled	Collaboration is more formalized and the network works with uniform processes, procedures and systems around the frail older adults with dementia. The professionals in the network share information and work structurally together to improve population health.
4	synchronized collaboration	The network is fully integrated in the local context. The organization level has included partners form the local context to optimize population health. Systems and processes are internally and externally embedded. Together the triple aim goal is being realised.

Table 1. Levels of network collaboration

Quality of care and crises

Data on quality of care and crisis situations was assessed yearly using a registration file filled in by the network leader(s) for their shared caseload of dementia patients. A researcher (DO, AR) was available to help upon request. Quality of care indicators were 1) case manager appointed, 2) diagnosis in primary care, 3) discussed during multidisciplinary meeting, and 4) pharmacotherapeutic meeting during the last 12 months, were scored absent (=0) or present (=1). We defined crisis situation as an acute (needed within 24 hours) consultation or admission to a hospital or nursing home. The total number crisis situations per patient in the last 12 months were collected.

Logs and network characteristics

Network characteristics, including network composition at start and end, (changes in) network leader by the researchers in a log file. This data was also used for the background characteristics of the networks.

Analysis

For the network maturity score per network per timepoint, the average score of the eight RMIC domains (score range from 1=ad hoc, to 4=structured) was calculated for each network separately.

For quality of care, the patient data was used to calculate an average per indicator per timepoint (score 0 – 1). Thereafter, a sum score per network was calculated by summing up the scores for the indicators case manager, primary care diagnosis, multidisciplinary meeting and pharmacotherapeutic meeting (range 1 – 4).

Growth model

A growth model was used to analyse the effects of DementiaNet program on network maturity, quality of care and crisis situations over the course of the follow-up, whilst simultaneously accounting for repeated measures within networks and missing data. For all outcome measures, we first identified whether a linear, quadratic or spline unconditional growth model best fitted the data to explain the within network changes over time. We identified if a random intercept and random slope improved the model. Next, we added one-by-one potential predictors to the model and assessed whether this significantly (alpha <0.05) explained the between network variance in the random effects. We included relevant factors collected via logs: already established collaboration before the start with DementiaNet, discontinuity in network leader(s) and the number of network members at start. We used R version 4.1.3 for all analyses.

RESULTS

Forty-four networks started with the DementiaNet program between January 2015 and March 2020. Nine networks ceased active participation within the first year. Reasons were either lack of intrinsic motivation, lack of time, or a vacancy for network leadership resulting in insufficient momentum for a transition process. Some networks have delayed or missing data on one (or more) timepoint(s) due to factors including, COVID-19 and lack of time.

We followed 35 networks longitudinally for a period of 1 – 6 years with a median of 3 years (interquartile range: 2-5). Networks without a collaboration before start had a median of 10 professionals and networks with a pre-existing collaboration a median of 7 professionals (range 3-41). The number of disciplines involved in the networks ranged between 3 and 16. The majority of the networks included a general practitioner, practice

nurse, community nurse and case manager. 63 percent of the networks had a welfare worker (Table 2 and Appendix III).

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	No collaboration before start (networks=29)	Pre-existing collaboration before start (networks = 6)
Median number of professionals at start, n (range)	10 (4 - 17)	7 (6 - 22)
Median number of professionals at end, n (range)	10 (4 - 25)	7 (5 - 41
Number of networks with active GP at start, n (%)	23 (79%)	6 (100%)
Number of networks with welfare professional involved, n (%)	18 (62%)	4 (67%)

Table 2. Baseline characteristics of the DementiaNet primary dementia care networks

Network collaboration

To determine network collaboration, we first identified the unconditional spline growth model (Appendix IV: model 1, graph Appendix V). The best fitted model contained two linear splines representing linearly improving scores in the first 2 years and a more or less stable score trajectory after to two years. (Appendix IV: model 2 and 3).

We found a large negative correlation between random intercept and random linear slope for network maturity score, meaning networks with a higher network maturity score at start tend to show less increase in network maturity score (model 1). This correlation is smaller in model 2 and 3 after we adjusted for pre-existing collaboration, implying that, as expected, networks with an already existing collaboration could only achieve limited improvement in their collaboration.

Networks without a collaboration before start significantly improved their collaboration in the first two years with 0.35 (p < 0.001) per year (Figure 2 and Model 3 in Appendix IV). Networks with an existing collaboration also significantly improved their collaboration with 0.17 network maturity points (p = 0.03), but over two years, this increase was significantly lower than networks without a pre-existing collaboration (0.36, p=0.027). Larger networks showed higher increase in network maturity scores (0.009, p=0.03 per extra network partner) than smaller networks. After two years, a stabilization was shown for both newly formed networks (0.043 difference in network maturity per year, p=0.251) and networks with an existing collaboration before start (-0.056 difference in network maturity per year, p=0.306).



Figure 2. Graph of the network maturity score over time of the DementiaNet networks (model 3). *Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Bold lines indicates the mean.*

Quality of care

For quality of care, we first identified the unconditional spline growth model (Appendix VI: model 1, graph Appendix VII). The best fitted model contained two linear splines (Appendix VI: model 2 and 3) and a random intercept.

Networks without a collaboration before start (n=4) who enrolled in the DementiaNet program significantly improved their quality of care in the first two year with 0.29 (p < 0.001) per year (Figure 3 and Model 3 in Appendix VI). After the two years, a stabilization occurred (0.014, p = 0.084). Networks starting with already existing collaboration did not significantly increase their quality of care in the first two years (-0.017, p = 0.92), nor in the period after the program had ended (0.04, p = 0.68).

Crisis

For crisis situations, we first identified the unconditional growth model. No significant effects of time were found. The number of persons with a crisis situation appears to be stable over time, per year around 25% of the caseload had one or more crisis situations (Figure 4).



Figure 3. Graph of the quality of care over time of the DementiaNet network (model 3). *Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Bold lines indicates the mean.*



Figure 4. Graph of the crisis situations over time of the DementiaNet networks. *Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Black line indicates the mean.*

DISCUSSION

Principal findings

The 2-year DementiaNet program improved network collaboration and quality of care in primary dementia care networks, which persisted after the network development program ended, even up to six years. The main improvements in network collaboration and quality of care were seen during the first two years when the networks received support and in networks with-out pre-existing collaboration. These results imply that the DementiaNet program led to a successful transition to more integrated primary dementia care. Improvements did not impact the number of crisis situations.

Comparison with existing evidence

The results from our study show that the short-term benefits of the DementiaNet program, in a smaller number of networks ¹³, sustained. These positive effects may in part be attributed to the multifaceted nature of the program, which is different from previous described programs that focused primarily on interprofessional education or case management and showed less favourable results regarding implementation and sustainability of improvement.^{25, 26} By designing a two-year facilitation program, we focused on a transition instead of quick implementation. We facilitated the tools networks needed to eventually self-organize their network. Implementation periods and follow-up are frequently too short to respectively establish and assess the effects of interprofessional collaboration.^{3, 15, 27-29} The time for this transition is needed as network members need to get to know each other and build trust.¹⁹

Stabilization of network maturity levels in our study after two years suggests that a certain level of network maturity is sufficient to maintain active collaboration and a high quality of care. This is concordant with critical transition theories that state that the likelihood actual change will occur increases when a so-called tipping point is reached.³⁰ In our case, a network maturity level between defined and controlled level of collaboration seemed to be this tipping point. Part of the explanation of the fact that this level is not the maximum score of 4 may be that local networks are not expected to reach total integration, including integration on the system level (policy level) as that is beyond their influence.³¹

Even though network collaboration increased, we found no effects of the program on the occurrence of crisis situations, whereas previous studies found a reduction in the number of emergency room visits in older persons as a result of collaboration.^{32, 33} The

absence of a similar finding may be attributed to the complexity of dementia care and of crisis events: many context-specific variables influence their occurrence. Moreover, the number of crises likely increased during the study period as a result of the higher number of people with dementia living longer at home ³⁴, and specifically during the COVID-19 pandemic. Lastly, crisis as an outcome in our study may have been heterogenous as we did not define crisis as specific as an admission and data on this outcome were self-reported.

Strengths & weaknesses

The key strength of this study is its extensive follow-up period of up to six years needed to investigate the sustainability of integrated care implementation by our two-year DementiaNet program. The with-in network comparisons in multiple complex network contexts allowed us to describe and analyse the process of transition facilitated by our multi-faceted and long-term DementiaNet program. It enabled us to draw conclusions on the effects of the program despite the complex circumstances that hinder traditional evaluation methods such as RCTs.

The study has the following limitations. First, no validated tool was available to measure network collaboration, which forced us to develop our own method. As this method was based on a validated theoretical framework, included independent ratings and showed consistent changes over time, it is likely that we were able to measure network maturity as intended. Second, validity of the data may have suffered because of self-reporting of quality of care and crisis data by professionals. However, stricter protocolization or control of data collection could be considered an intervention on its own and would limit feasibility of broader implementation. Last, the COVID-19 pandemic hampered data acquisition in the last two years of follow-up resulting in more missing data or time intervals between data point of over one year. The effect of the program might have been underestimated since COVID-19 negatively affected network development: it hindered physical network meetings, such as multidisciplinary meetings. The meetings are essential to get to know each other and build trust.¹⁹

Implications for research and practice

This study showed that the DementiaNet strategy of improving integrated primary dementia care may contribute to the quadruple aim of improving patient's experiences and health, improving population health, improving work satisfaction and reducing costs.^{10, 35} This study showed that population health improved as we found quality of

care improvements and improvements in collaboration are likely to have positively impacted work satisfaction. We still need to identify patients' experiences and the effects on costs. Identifying patients' experiences is challenging since patients and caregivers find it difficult to reflect on the changes in care they receive, it could be identified by for example using caregiver perseverance time or number of crisis situations. A future cost-effectiveness study, with a focus on hospital versus primary care costs could further support the evidence-based and wide-spread implementation of the program. So far, study on the cost-effectiveness of integrated care were of low quality and outcomes were mixed.³⁶⁻⁴¹ Further exploring the program's impact on work satisfaction is highly relevant in light of the growing shortage of healthcare professionals.

This study's outcomes support large scale implementation of the DementiaNet program as it is currently the best available in the line of improved value-based dementia care across the Netherlands. This is enforced by its tailor-made approach and generalist elements, which make it applicable to a broad variety of contexts and healthcare systems nationally and internationally and to multiple different target groups and diseases. Large-scale implementation in the Netherlands, however, requires a transition in primary care reimbursement. Currently, activities not directly linked to patients, such as interprofessional meetings, are excluded from reimbursement, resulting in only the earlier adopting and intrinsically motivated professionals taking up these tasks. Instead, healthcare payers should develop more structural funding for such key elements of integrated care programs.^{10, 29, 41} Changes at the policy level regarding care reimbursement are needed to facilitate this new, network-based way of working.^{41, 42}

CONCLUSION

The DementiaNet program resulted in a pronounced improvement in primary dementia care collaboration and quality of care. Our long follow-up showed that these effects sustained. Newly formed networks benefitted more during the first two years of the program than those with an existing collaboration at the start. The two-year program acknowledged the time needed for professionals building trust and getting to know each other and enabled this sustainable transition to integrated primary dementia care. The number of crisis situations was not clearly affected by the network collaboration. Future studies should focus on identifying the effects of network-based care on the prevention of crises, other outcomes relevant to patients and carers and on cost-effectiveness. Organizational and financial reforms should be stimulated to achieve a sustainable transition to network-based care.

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APPENDIX I – Primary care in the Netherlands

Primary care for community-dwelling dementia patients in the Netherlands¹

- 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. There is fragmentation in financing of services: 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 in practice is low.
- Dementia care on a local level is determined by national, regional and local policies as well as existing facilities and by individual initiatives undertaken by the healthcare professionals. As a result, services and quality of local care are highly variable throughout the Netherlands.

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RMIC domain	Topics
Professional integration	Tasks and expertise's
	Respect and trust
Clinical integration	Work agreements
	Multidisciplinary care plan and meeting
Normative integration	Goal
	Commitment network members
	Leadership
Person focused care	Person-centredness
Population base care	Early signalling
	Coordinator for persons with dementia
Functional integration	Digital systems
	Feedback
Organizational integration	Support from organization
System integration	Policy developments

APPENDIX II - Topic list network maturity interviews with DementiaNet network leaders

Network	Active since	Number network members at start	Number network members at end	Network leader(s) at end	Network leader(s) changed	Collaboration before DementiaNet	Catchment area*
-	2015	7	10	CM, GP	Yes	Yes	Small
2	2015	13	10	WF	Yes	No	Large
e	2015	22	41	GP, CN	Yes	Yes	Large
4	2015	10	12	CM, CN (both period absent)	No	No	Large
5	2015	8	6	PN, CM	No	No	Small
9	2015	7	7	PN, CM	No	No	Large
7	2016	6	J	GP, CM	No	Yes	Small
8	2015	16	16	CN	No	No	Small
6	2016	5	4	PN, CM	Yes	No	Small
10	2016	12	17	WF, OT	No	No	Small
11	2016	11	13	CN, CM	No	No	Small
12	2016	6	6	CN, CM	Yes	No	Small
13	2017	4	4	CN	No	No	Small
14	2017	6	6	PN	No	Yes	Small
15	2017	5	J	PN	Yes	No	Large
16	2017	7	7	PN	No	No	Large
17	2017	7	6	PN	Yes	No	Small
18	2017	14	15	GP, PN	No	No	Small
19	2017	17	14	GP, PN	Yes	No	Small
20	2018	10	13	PN, CN	No	No	Large
21	2018	6	5	GP, CM	No	No	Large
22	2018	15	14	CN, WF	Yes	No	Small
23	2018	8	16	GP, CN	Yes	No	Large
24	2018	8	11	GP, PN	No	No	Small

APPENDIX III - Detailed description of the DementiaNet networks.

АРРЕГ							
25	2018	10	9	PN, PN	No	No	Small
26	2018	22	25	WF, WF	Yes	No	Large
27	2018	9	9	PN	No	No	Small
28	2018	6	7	CN, PN	Yes	No	Small
29	2018	16	16	PN	No	No	Small
30	2018	7	7	PN	No	Yes	Large
31	2018	œ	7	PN	No	Yes	Large
32	2019	12	7	CM, WF	Yes	No	Small
33	2019	œ	7	PN, PN	No	No	Small
34	2019	17	17	PN, CM, PH	No	No	Small
35	2020	16	16	ST, WF	No	No	Large

*Catchment area= area from which the network attracts its population of patients with dementia, defined by geographical size and population distribution and density; large = more than approximately 7,500 persons. GP = general practitioner; PN = practice nurse; CN = community nurse; CM = case manager; OT = occupational therapist; PT = physiotherapist; WF = welfare worker; MM = management or municipality; ST= speech therapist.

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Results of the unconditional growth models and the	e adjusted grow	⁄th models o	f the network ma	aturity score ove	er time of the Demei	ntiaNet networks.
	Model 1: Unc spline growtl	onditional n model	Model 2: Effec collaboration participants a network matu	t of baseline and number t start on urity	Model 3: Effect o collaboration an participants at s network maturit for the deviatior maturity score a	f baseline d number tart on ty adjusted i in network fiter 2 years
Parameter	B (SE)	p-value	B (SE)	p-value	B (SE)	p-value
FIXED EFFECTS						
Intercept						
Network maturity score at start	1.73 (0.08)	<0.001	1.62 (0.06)	<0.001	1.60 (0.06)	<0.001
Collaboration before start			0.69 (0.14)	<0.001	0.73 (0.16)	<0.001
Number of network participants at start			-0.02 (0.01)	0.05	-0.02 (0.01)	0.05
Linear rate of change						
Yearly change in network maturity score	0.32 (0.03)	<0.001	0.30 (0.03)	<0.001	0.35 (0.03)	<0.001
Yearly change deviation of network maturity score after 2 years	-0.31 (0.05)	<0.001	-0.29 (0.05)	<0.001	-0.31 (0.06)	<0.001
Collaboration before start* Yearly change in network maturity score			-0.14 (0.04)	0.007	-0.19 (0.08)	0.03
Collaboration before start* Yearly change deviation of network maturity score after 2 years					0.09 (0.12)	0.47
Number of network participants at start* Yearly change in network maturity score			0.01 (0.004)	0.03	0.01 (0.004)	0.03
RANDOM EFFECTS	variance (SD)		variance (SD)		variance (SD)	
Network maturity at start	0.127 (0.36)		0.049 (0.22)		0.050 (0.22)	
Yearly change in network maturity score	0.006 (0.08)		0.003 (0.05)		0.003 (0.05)	
Within network (residual)	0.063 (0.25)		0.063 (0.25)		0.062 (0.25)	
Covariance	-0.50		0.3		0.24	
GOODNESS-OF-FIT						
Degrees of freedom	134		130		129	
Deviance	94.5		72.73		72.22	
AIC	108.5		94.73		96.22	
BIC	129.2		127.16		131.60	



APPENDIX V – Graph of the unconditional spline growth model of network maturity score

Figure. Graph of the network maturity score over time of the DementiaNet networks (model 1). *Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Bold line indicates the mean*

Results of the unconditional growth models and the	adjusted grow	rth models of	the quality of c	care over time	of the DementiaN	et networks.
	Model 1: Un spline growt	conditional ch model	Model 2: Effe baseline coll Quality of Ca	ect of aboration on ire	Model 3: Effect (collaboration or adjusted for the quality of care a	of baseline n Quality of Care e deviation in after 2 years
Parameter	B (SE)	p-value	B (SE)	p-value	B (SE)	p-value
FIXED EFFECTS						
Intercept						
Quality of care score at start	1.97 (0.12)	<0.001	1.86 (0.12)	<0.001	1.82 (0.13)	<0.001
Collaboration before start			0.65 (0.25)	0.013	0.83 (0.30)	0.007
Linear rate of change						
Yearly change in quality indicator score	0.22 (0.08)	0.003	0.24 (0.08)	0.002	0.29 (0.08)	<0.001
Yearly change deviation of quality of care score after 2 year	-0.21 (0.11)	0.067	-0.19 (0.11)	0.098	-0.28 (0.13)	0.035
Collaboration before start* Yearly change in quality of care score			-0.09 (0.07)	0.227	-0.31 (0.18)	0.100
Collaboration before start* Yearly change					0.33 (0.260)	0.213
ueviation of quality if care score after 2 years						
RANDOM EFFECTS	variance (SD	-	variance (SD)	_	variance (SD)	
Quality of care score at start	0.167 (0.41)		0.123 (0.35)		0.151 (0.39)	
Residual	0.28 (0.53)		0.281 (0.53)		0.265 (0.52)	
GOODNESS-OF-FIT						
Degrees of freedom	114		112		111	
Deviance	223		216.6		215.3	
AIC	233		230.6		231.3	
BIC	247		250.1		253.5	

APPENDIX VI - Table for the results of the quality of care growth models

APPENDIX VII – Graph of the unconditional spline growth model of quality of care



Figure. Graph of the quality of care over time of the DementiaNet network (model 1). *Red lines indicate networks without pre-existing collaboration and blue lines indicate pre-existing collaboration. Bold line indicates the mean.*





Summary and general discussion

SUMMARY

Due to population aging, the number of people with dementia will increase substantially the coming years. A large number of people with dementia are required to live longer at home with more complex healthcare needs, which increases the complexity of primary dementia care. Together with an increased workload and a shortage of healthcare professionals, which is likely to increase even more in the future, this poses a major challenge for primary care.

Especially in later stages of the dementia, involvement of many different primary care professionals is required. However, coordination of care and communication between professionals and informal caregivers is often suboptimal. Improving interprofessional collaboration and communication, and including the informal caregiver and person with dementia, are both prerequisites to enhance the quality and efficiency of care for people with dementia and thereby overcoming fragmentation and the aforementioned challenges primary care faces. In order to strive for integrated dementia care, strategies are needed to improve interprofessional collaboration that can facilitate this process.

We developed such a strategy, called the *DementiaNet* program. This two-year program focused on improving interprofessional collaboration by facilitating network development of medical-, care- and welfare professionals in primary care who jointly provide care to a shared caseload of people with dementia. This thesis aimed to evaluate whether the DementiaNet program is a sustainable strategy to relieve the burden for all involved and overcome the challenges primary care is facing. In three interconnected parts, important aspects were addressed for achieving care integration in the primary dementia care setting: 1) How can we measure integrated (dementia) care?, 2) How can digitalisation support integrated care?, and 3) What are the effects of the DementiaNet program?

In **PART I** we focused on measuring the quality and performance of integrated primary dementia care. In **Chapter 2** we constructed a content-wise valid Minimum DataSet (MDS) with quality indicators (QIs), as the available quality indicator sets did not address the interprofessional context. Using a modified Delphi method, we developed a preliminary indicator set together with stakeholders. Thereafter the relevance and feasibility of the indicators was assessed using a survey. During stakeholder and expert meetings we reduced the preliminary set to 15 QIs to be used for pilot-testing: five for quality of care, three for well-being, four for network-based care, and three as cost-efficiency QIs. The final set was pilot-tested for feasibility by DementiaNet networks. A valid and feasible MDS of quality indicators for primary dementia care was developed, containing innovative QIs

on well-being, network-based care, and cost-efficiency in addition to quality of care Qls. The results showed that the application of the MDS may contribute to development and implementation of integrated care service delivery for primary dementia care.

However, even with the QIs in hand, validated instruments to measure integrated care performance in practice are currently lacking. In **Chapter 3**, we therefore assessed the construct validity of the Rainbow Model of Integrated Care measurement tool (RMIC-MT), for healthcare professionals working in an interprofessional primary dementia care setting. In a cross-sectional study, the RMIC-MT, a 36-item questionnaire covering all domains of the Rainbow Model of Integrated Care (RMIC), was sent out to DementiaNet networks and local networks of primary elderly care professionals. Confirmatory factor analysis was used for the validation of the factor structure of the RMIC-MT. In this chapter we concluded that the tool can be used for evaluating integrated care initiatives in a primary care setting, thereby further contributing to implementation of integrated primary elderly and dementia care.

In **PART II**, we identified how digital tools can facilitate implementation of integrated care, including interprofessional collaboration and caregiver support. Implementation of interprofessional digital communication tools in daily practice frequently fails, and it is often unclear why. That is why in **Chapter 4** we identified generic barriers and facilitators for implementation of interprofessional communication tools, experienced by healthcare professionals and informal caregivers for frail older adults. Qualitative content analysis using individual interviews was used to evaluate three different digital communication tools used by professionals of DementiaNet networks and informal caregivers. The identified barriers and facilitators were related to tool characteristics, context of use, involvement of professionals and informal caregivers. The tools improved users' availability, approachability and involvement. The tools also facilitated care coordination and professionals declared to be better informed about a patients' current situation. However, different work agreements and the large number of digital systems professionals simultaneously use, hampered tool use. Overall, interprofessional digital communication tools can facilitate communication in networks for primary elderly and dementia care. However, integration between digital systems is needed to reduce the number of tools and making it feasible for routine use. On top of that, healthcare organizations and policy makers should actively promote and support the tools' longterm use.

To identify how digital tools can facilitate caregiver support, we developed and pilottested a digital tool to monitor informal caregivers' wellbeing and resilience in **Chapter** **5**. The aim of the tool is to provide timely support, thereby preventing that the informal caregiver gets overburdened, with possibly even crises admissions of the person with dementia as a result. A human-centered design method based on co-creation with informal caregivers and professionals was used to design the 'REMIND' tool, with the defined point of focus to develop a tool that is able to provide insight into the experienced burden of informal caregivers. During co-creation meetings a prototype was created. The REMIND prototype consisted of weekly questions about wellbeing and resilience for informal caregivers and a dashboard with the answers for case managers. Case manager-caregiver duos pilot-tested REMIND and interviews were conducted to determine usability and acceptability. Informal caregivers mentioned that REMIND stimulated self-reflection. Case managers appreciated the tool's ability to gain insight in the actual wellbeing of informal caregivers. Therefore, the REMIND tool tends to increase the level of insight in actual wellbeing of informal caregivers, for both caregivers and case managers. However, a long-term (controlled) follow-up study is required to evaluate REMIND's impact on informal caregiver burden and crisis admissions.

In **PART III** we identified the effects of the DementiaNet program. The first DementiaNet networks started in 2015 and the DementiaNet program has already been evaluated for a small sample of networks that were active for two years. To identify the effects of this network-based approach on a larger scale we first studied the effects on network maturation in 17 interprofessional DementiaNet networks, with a focus on the success and failure factors for network maturation in a longitudinal mixed-methods study in **Chapter 6**. Network maturity increased yearly and important factors for improvement included getting to know each other's expertise, having a capable network leader(s), stable network composition and participation of a general practitioner. These success factors provided better understanding of how network maturity can be achieved and can give guidance to future care integration strategies.

The most important remaining question regarding the DementiaNet program was whether the positive effects in the small network sample could be replicated in a larger sample of networks and most importantly, whether these effects are also able to sustain over time, also after the active program support ended. In **Chapter 7** we therefore evaluated the effects of the DementiaNet program on quality of care, network collaboration and crisis admissions with a follow-up up to six years. Thirty-five DementiaNet networks started between 2015 and 2020 and follow-up ended in 2021. Annually, networks collected data on their quality of care and number of crisis admissions and network collaboration was assessed through semi-structured interviews, which were converted to a network maturity score. Network collaboration and quality of care increased significantly in the first two years. This effect was more pronounced for networks with a newly formed collaboration, since the maturity levels were already higher at baseline in networks with pre-established collaboration. Thereafter, quality of care and network collaboration tended to stabilize.

The DementiaNet program thus improved interprofessional dementia care integration, which persisted after the program ended. This illustrates that a sustainable transition towards network-based integrated dementia care requires sufficient support and time. Future studies should focus on identifying the effects of network-based care on the prevention of crises, other outcomes relevant to patients and caregivers and on the cost-effectiveness of this approach. Organizational and financial reforms should be stimulated to achieve a sustainable transition towards network-based care.

GENERAL DISCUSSION

In this thesis, we showed that DementiaNet facilitates a sustainable transition towards network-based dementia care, thereby relieving the burden for all involved. By addressing questions such as 'What do these results indicate?' and 'What are the necessary next steps for practice, research and education'?, this chapter aims to provide a vision of how network-based care could be a valuable solution for current challenges facing primary care. This vision is formed by a reflection on the three themes of this thesis: how to measure integration of primary dementia care, how to apply digital tools to facilitate integrated care and the effects of the DementiaNet program.

"Our biggest challenge in this new century is to take an idea that seems abstract – sustainable development – and turn it into a reality for all the world's people."

– Kofi Annan

How can we validly measure integration in primary dementia care?

For measuring level of integration in primary dementia care no suitable validated tools were available when DementiaNet started in 2015.¹ However, the Rainbow Model of Integrated Care framework provided us a clear framework that was developed specifically for the primary care setting.² Although time-consuming by taking into account all the RMIC domains in an extensive interview, we were able to obtain a complete overview of networks' current level and process of care integration (**Chapter 6** and **Chapter 7**). To enable feasible and valid measurement of integrated care levels, we performed a construct validation of the RMIC-measurement tool (RMIC-MT) adapted to the elderly care setting in **Chapter 3**.

The RMIC-MT questionnaire showed promising results, however we experienced that professionals had difficulties answering the RMIC-MT. Probably due to the complex formulation of the questions, which could not be changed due to the validated nature of the international RMIC-MT. As a reaction on the questionnaire-based feedback report to the networks, the professionals mentioned they did not recognize the results, because they felt they already had achieved a lot as a network. This made us question whether a survey is suitable or that the integration is better evidenced qualitatively by analysing the networks' narratives (**Chapter 6** and **Chapter 7**). Frequently, professionals mentioned during these interviews that an improvement in collaboration was due to getting to know each other and building trust, which resulted in improved accessibility

of professionals for one another. These improvements were often implicit, and impacted by deeper aspects and therefore hard to extract using a questionnaire.³ This emphasizes the complexity of the integrated dementia care concept and its measurement: it is not a simple practical or clinical concept and therefore difficult to capture with closed or quantifiable questions. Thus, further research should focus on comparing the results of the interview data and the RMIC-MT to identify if similar integration levels are observed using different measurement methods. The RMIC-MT is theory driven approach, valuable in research settings e.g. to compare integration within and between studies, however an easy-to-use, practice-oriented tool is needed for professionals in daily practice. This is a prerequisite for such a tool to become useful to identify areas of improvement on the fly.

Development of a practice-oriented tool was our aim when we constructed our set of quality indicators, the minimum dataset (MDS). Therefore we designed the set in cocreation with professionals and informal caregivers to select the topics most relevant to them.⁴⁻⁶ In parallel to our MDS, national dementia indicators were developed, which was coordinated by the related initiative supported by the Dutch Alzheimer Society called: 'Dementiezorg voor Elkaar' (which means: dementia care for one another). Reassuring is that the independently developed lists turned out to be very similar ⁷, emphasizing the relevance of the represented indicators. However, also after this co-creation process some of these indicators still resulted in missing values when used in daily integrated primary dementia care practice. Especially information on the welfare-oriented indicators e.g. burden of the informal caregiver, which are not part of the information in the electronic patient file of the general practitioner, were difficult to collect. Nevertheless, we experienced that after a few years professionals became more interested in the results of their quality of care and tended to use it as input for their improvement goals. This performance feedback has been proven essential for securing improvements.⁸ Chapter **7** showed that this cyclic work of using Plan-Do-Check-Act cycles was able to improve quality of care and facilitate connectivity and support the transition process towards integrated care.

Professionals ideally should continue measuring their quality of care and care integration, even without a researcher or a research setting, to realize sustained quality of care management. This requires digital tools that are easy-to-use by the networks to gain continuous feedback on their performance. Hereto, we designed the REMIND platform (**Chapter 5**). However, we experienced that it was difficult for professionals to collect the data using this system for various reasons e.g. lack of digital skills, and operational difficulties within the digital tool. Thus, further development of the system is needed.

Since it also is the goal of the Dementia Network Netherlands (In Duch: 'Dementie Netwerk Nederland': DNN), a recently founded network oriented organization, to digitalize the registration of the national dementia indicators, we would highly recommend DNN to use our results as input for further development.

How can digitalization support integrated care?

Pursuing an efficient digitalized future for dementia care is essential, as it can improve efficiency and thereby relieve the pressure on healthcare. The research in this thesis has already shown that digital tools can be important facilitators to care integration. **Chapter 4** showed that implementation of a digital tool is able to facilitate easier and more accessible communication between professionals (improving professional integration) and between professionals and patients/caregivers (improving clinical integration). The REMIND tool in **Chapter 5**, focusing on clinical integration, facilitates proactive care. Pro-activity is paramount, as people with dementia are mostly unable themselves to play an active role in their care coordination. However, these studies made clear that implementation of these tools should not be seen as a goal in itself to reach integrated care (often the marketing strategy of market parties involved), but as a facilitator of proactive interprofessional care in networks where collaboration is already established.

Apart from the abovementioned limitations, REMIND still may grow to be highly beneficial in times of shortage of healthcare professionals, as it clearly highlights whom of the supported informal caregivers and persons with dementia are most in need for further support. When providing timely support to alleviate deterioration in caregivers' wellbeing social or health related crises admission might be prevented.

Acquiring time series data of caregiver's wellbeing, which is enabled by REMIND, could be useful to reveal the dynamics of (over)burdening and thereby identify if small crises are likely to lead to a crisis situation.

Various digital tools described in literature are promising, however implementation remained challenging and so far unsuccessful.^{9, 10} To overcome this, the REMIND tool in **Chapter 5** was developed in co-creation with professionals and informal caregivers in order to create a tool that fitted their wishes and needs. These stakeholders and everyone we presented this idea were enthusiastic, including professionals, informal caregivers, insurance managers, healthcare organization managers, and researchers. Nevertheless, finding case managers and informal caregivers willing to take part in a pilot study still was difficult. It again showed us that it is always difficult to implement a (digital) innovation

in dementia care. The environment in current dementia care is managed tightly (without spare time to get used to new tools), making it less accessible for innovation and making implementation of such tools a slow and challenging process. We did show that the group that used the tool experienced benefit, but needed more time and resources to facilitate implementation at a larger scale.

Another major barrier of digitalization shown in **Chapter 4**, **Chapter 5**, and in literature on digital tools in healthcare is the lack of interoperability of digital tools. REMIND could not yet be connected to a platform also used for other digital tools. This is a result of the fragmented primary care, consisting of numerous small care organizations and general practices all using their own digital systems. Consequently, digital tools are disciplineor condition-specific and vary between organizations as well, resulting in a range of different tools not able to connect with each other, which hinders active use. Thus, care integration requires digital systems that are much more integrated with each other and can be connected on a safe and easy to use overarching digital platform for professionals and informal caregivers. The system and organizational level are in the lead, and should connect with the professional level to identify what is needed.

A relevant future aim would be to develop a shared patient record (possibly the digital patients' health care environment which the government is currently striving for) that can also be used by primary care professionals from different backgrounds and institutions, to improve the data flow and interprofessional communication and collaboration. Favourably, a patient or informal caregiver can be added. This is in line with current priorities set at the regional level, hoping this will accelerate this digital development.

Why did the DementiaNet program successfully facilitate a sustainable transition?

The results from **Chapter 6** and **Chapter 7** add to existing evidence by showing that the short-term benefits of the DementiaNet program, described earlier in a small number of networks ¹¹, can endure the test of time. It is unique that we were able to follow our DementiaNet networks for up six years after they started. Our results positively stand out compared to previous described programs which did not show positive results regarding implementation and sustainability of integrated care initiatives.^{12, 13}

First of all, these positive effects may be attributed to the multifaceted nature of the program. DementiaNet consists of four key elements empowering each other: 1. focus on interprofessional collaboration; 2. leadership; 3. quality improvement and 4.

interprofessional education for joint skill development, which were all described as factors for implementation success.^{8, 14, 15} Since care integration is a complex transition to realize, all these elements are needed, together with a tailor-made approach by connecting to pre-existing circumstances. This approach embraces networks' diversity, which was often overlooked or ignored in previous studies.¹⁶ We did not have a tight protocol as it was unknown what the network trajectories and room for improvement would be. This provided opportunities to facilitate this transition, to see what the networks needed and provide them with the appropriate training and coaching.¹⁷ Second, our program operates bottom-up, which has shown to be most effective to achieve (local) change and to intrinsically motivate professionals.^{18, 19}

Third, frequently programs are too short to effectively implement a new way of working.^{15, 20-22} We showed that much time is needed for a persistent transition towards network integration as time is needed to get to know each other and build trust. Since our follow-up lasted up to six years, we were able to study the long-term effects on the collaboration process and on quality of care. It is crucial that similar projects take these lessons learned into account and provide sufficient flexibility and about two years to establish a transition towards integrated dementia care with a long follow-up.²³ However, most current scientific grants only cover a few years and do not allow to establish these kind of changes in the long term. This current practice needs to become more flexible to enable longer follow-up.

In this study we illustrated that the DementiaNet program helps networks to go through a transition an achieve sustainable change. In order to make such a transition on a network level, theory states that a transition consist of several phases: predevelopment, takeoff, acceleration and stabilization ²⁴ (see Figure 1). Follow-up data of the DementiaNet networks enabled identification of these different phases. At the start of the DementiaNet program in 2015, times for the Dutch primary care setting were turbulent, as financial structures underlying the healthcare system changed dramatically. Among others, community nurses were appointed new additional tasks. This caused uncertainty for primary care professionals resulting in the difficult take-off phase of the first networks. The first positive results of the early-adopting networks introduced the acceleration phase. This acceleration was further stimulated by the urgency felt by professionals to cope with the quickly growing older population with dementia living at home longer. General practitioners were increasingly motivated to participate based on their experienced investment in crisis situations around persons with dementia. Moreover, the program itself kept the acceleration going within the networks by its key elements e.g. leadership, quality improvement cycles, and training, which increased commitment within the networks and supported increase of knowledge and collaboration.



Figure 1. The four phases of complex transition processes, adapted from Rotmans et al. 2001.²⁴

Chapter 7 shows that the plateau phase was reached after two-years, when the formal network training program ended. These results suggest that a certain level of network maturity is sufficient to maintain operational networks delivering a high quality of dementia care. A relevant question is if this plateau would have been higher if the training program would have lasted longer. Since networks with and without pre-existing collaboration reached almost the same plateau in **Chapter 7** it is likely that the two-year program was sufficient. Moreover, research on critical transitions to achieve change in complex systems, showed that the likelihood of a transition to a new stable state increases when a clear tipping point is passed (Figure 1).²⁵⁻²⁷ In our case, the network maturity level between 'defined' and 'controlled' collaboration may be the tipping point for a successful transition towards network-based care, after which networks were able to sustain their collaboration on the clinical, professional and sometimes even organizational level.

What is needed for a large-scale transition?

In sum, this thesis has shown that DementiaNet was able to facilitate a transition on the clinical and professional level (also referred to as micro and meso level), which was also the focus of our bottom-up program. However, involving the organizational and system level (macro level) is required for a large-scale transition.²⁴ Frequently such transitions are not in favour of the ruling and reimbursing parties ²⁴ and therefore take a lot of time.

To achieve structural change in the healthcare setting a more top-down approach may need to be combined with our bottom-up approach. Figure 2 ²⁶ clearly illustrates how the dynamics of transitions on the societal level may work between build-up of bottom-up approaches and the top-down destabilization of current ways of work.²⁸



Figure 2. The X curve of societal change, adapted from Loorbach et al. 2017.²⁶

Currently, top-down destabilization is already ongoing by the existing challenges in primary care: more people with dementia living at home requiring complex care, while there already is a shortage of primary care professionals. In 2021, a report from The Netherlands Scientific Council for Government Policy (WRR) urged the government to take action in order to sustain the accessibility and quality of healthcare in the future.²⁹ The ministry reacted stating that one of their policy pillars will be to stimulate collaboration between informal caregivers and professional organizations to allow healthcare organizations to keep providing the most urgent care.³⁰ Their recent report states that more opportunities for small-scale experiment should be given.²⁹

However, small studies will not allow for realizing large-scale sustainable transitions in the complete healthcare system. Organizational and system support, especially financially, is needed for large-scale roll-out.^{22, 31, 32} It is now the task of the government and large scale institutions (e.g. insurance companies) to react to these bottom-up approaches, such as DementiaNet, as it is in the system's interest that the healthcare system becomes more sustainable as soon as possible.^{32, 33} Therefore, researchers have the responsibility to make the effects of their studies known to policy makers. We have shown that

network-based care on micro- and meso-level may be a valuable solution for the current primary dementia care challenges. As such it may add value to the quadruple aim as it improves patient's health and experiences, improves population health and improves work satisfaction.³⁴ Moreover, additional research we carried out with the research group headed by health economist prof. Patrick Jeurissen supports our hypothesis of cost-effectiveness of DementiaNet by reducing hospital admissions with 20%, while only increasing primary care costs with 10%, as based on insurance registry date (paper under review). Consequently, subsequent top-down support can result in more efficient dementia care at a large scale.^{32, 33}

Change is also needed in the reimbursement of daily primary care. Structural funding for network-based working, such as multidisciplinary meetings, is required ^{22, 31, 32}, but still lacking. As a result, professionals have to devote their own (scarcely) available time to these multidisciplinary meetings, which hampers large-scale implementation. Currently nor the ministry, municipalities nor healthcare insurance companies have suitable instruments to support DementiaNet network implementation, though they are enthusiastic on the results realized (conclusions confirmed in personal meetings with the regional health insurance managers and ZonMw). That the nature of such changes improving quality and efficiency of care is not self-evident, was illustrated by recent reforms in the reimbursement of birth care in the Netherlands. Recently, such reforms were proposed by providing an integrated financing system stimulating professionals in primary care and secondary birth care to collaborate. However, it immediately resulted in professional protests based on fear of loss of autonomy of the primary care professionals.^{35, 36} We would advise the government and or health insurance companies to invest more time and efforts in identifying effective financial compensation systems for upscaling health care innovations with proven cost-effectiveness, especially in domains of great societal relevance and urgency such as dementia care.

What can we already do tomorrow?

The abovementioned transitions on policy level are lying beyond our power, being researchers and (primary) care professionals. What we can do is focus on a sustainable change towards network-based primary (dementia) care by stimulating adjustments in educational curricula of all healthcare education programs. For example, by empathizing the importance of collaboration to future professionals and improving their knowledge about the expertise of other professionals and by teaching effective ways of interprofessional collaboration.^{37, 38} Interprofessional working should become a basic skill

to be trained instead of a skill taken for granted. This may enable all future primary care professionals to be sufficiently able to communicate and collaborate, including a shift from reactive to proactive working.

So far, the results regarding cost-effectiveness of integrated care programs in general are mixed or of low quality ³⁹⁻⁴², although some studies did find a reduction in the number of emergency room visits after implementing an integrated care approach.^{43, 44} As these outcomes are highly important for system change, in further research we should focus on the outcome 'crisis situations', as these are costly and rising in number. **Chapter 7** highlighted the importance of identifying strategies to objectively measure crisis situations as an outcome. This is a challenge since many context-specific variables influence crises outcomes, such as the unpredictable and heterogeneous causal factors, differential behavioural effects of such events, differences in crisis severity and in the effects on wellbeing and (over)burden of the informal caregivers. Further use of the REMIND tool in these networks could contribute to gain insight in the number of crises and predicting factors.

Although there is still a field of research left unexplored, the eight years of DementiaNet research and development provided us with a large amount of data, insights, and positive results. The key elements of network formation, leadership, interprofessional training and quality improvement cycles proved to be highly successful for establishing an interprofessional way of working and a sustainable transition to network-based care. Moreover, these generalist elements transcend the primary dementia care setting for example to elderly care in general, and may make this network innovation also applicable to other chronic (complex) conditions and in other countries or healthcare structures.

CONCLUSION

In this thesis, we found that network-based care implementation enabled a sustainable transition towards an integrated way of working within the primary dementia care setting. We developed feasible and valid (digital) tools to facilitate this transition by improving communication amongst professionals and by enabling networks to reflect on their current care integration and quality of care. Though, collaboration between primary care professionals and informal caregivers sounds simple and self-evident, much time and effort is needed to realize it in the currently fragmented dementia care. Professionals need to know each other, their skills and competencies, build trust and agree on the leading targets per patient. We have shown in our research that the DementiaNet program provided the necessary training, proved effectiveness and by linking a series
of project parts, allowed sufficient time for this to evolve. To enable a larger roll-out of the program, transition support at the macro level is required. Reforms in the current funding of dementia care are required to enable network-based dementia care, which ultimately can facilitate that all people receive integrated dementia care close to their homes when needed.

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Nederlandse samenvatting

NEDERLANDSE SAMENVATTING

Door het steeds ouder worden van de bevolking zal het aantal mensen met dementie de komende jaren fors stijgen. Een groot aantal mensen met dementie is genoodzaakt om langer thuis te blijven wonen, met een steeds complexere zorgvraag. Dit zorgt ook voor een toename van de complexiteit van de eerstelijns dementiezorg. Samen met de verhoogde werkdruk en het tekort aan personeel, wat alleen maar verder zal stijgen de komende jaren, zorgt dit voor een grote uitdaging voor de eerstelijns zorg.

Met name in een vergevorderd stadium van dementie zijn er veel verschillende eerstelijns professionals betrokken vanuit medische, zorg- en welzijnsdisciplines. Echter is coördinatie van zorg en communicatie tussen deze professionals en met mantelzorgers vaak suboptimaal. Het verbeteren van interprofessionele samenwerking en communicatie, en het betrekken van de mantelzorger en persoon met dementie zijn twee belangrijke voorwaarden om de kwaliteit en efficiëntie van zorg voor mensen met dementie te verbeteren. Daarnaast kan het ook bijdragen aan het verminderen van fragmentatie van zorg om zo beter om te kunnen gaan met de huidige uitdagingen in de eerstelijnszorg. Om geïntegreerde dementiezorg te bereiken zijn er strategieën nodig om interprofessionele samenwerking te faciliteren.

Wij hebben een dergelijke strategie ontwikkelend, het DementieNet programma. Dit tweejarige programma richt zich op het verbeteren van interprofessionele samenwerking door het faciliteren van netwerk ontwikkeling van medische, zorg- en welzijnsprofessionals in de eerste lijn die zorg leveren aan een gezamenlijke groep mensen met dementie. Dit proefschrift heeft als doel om te evalueren of het DementieNet programma een duurzame strategie is om de last voor alle mensen die erbij betrokken zijn te verlichten en om de eerdergenoemde uitdagingen in de eerstelijnszorg aan te kunnen nu en in de toekomst. In drie samenhangede proefschrift delen zijn belangrijke aspecten om geïntegreerde zorg in de eerste lijn te bereiken behandeld: 1) Hoe meten we geïntegreerde (dementie) zorg?, 2) Hoe kan digitalisatie integratie van zorg ondersteunen?, en 3) Wat zijn de uitkomsten van het DementieNet programma?

In **DEEL I** lag de focus op het meten van kwaliteit en uitvoering van geïntegreerde eerstelijns dementiezorg. In **Hoofdstuk 2** hebben we een, op de inhoud gevalideerde, minimum dataset (MDS) opgezet van kwaliteitsindicatoren, omdat de beschikbare sets met kwaliteitsindicatoren geen rekening houden met de interprofessionele context. Door gebruik te maken van een aangepaste Delphi methode hebben we samen met belanghebbenden een voorlopige set kwaliteitsindicatoren opgesteld. Vervolgens

is de relevantie en haalbaarheid van de indicatoren beoordeeld door middel van een vragenlijst. Tijdens bijeenkomsten met belanghebbenden en experts is de set gereduceerd tot 15 kwaliteitsindicatoren die we voor een pilot test hebben gebruikt: vijf indicatoren voor kwaliteit van zorg, drie voor welzijn, vier voor netwerkzorg en drie voor kosteneffectiviteit. Deze uiteindelijke set werd door een aantal DementieNet netwerken getest op haalbaarheid. De resultaten lieten zien dat de MDS valide en haalbaar is en dat het toepassen van de MDS kan bijdragen aan de ontwikkeling en implementatie voor het leveren van geïntegreerde eerstelijns dementiezorg.

Echter, met deze kwaliteitsindicatoren in hand missen er nog steeds valide instrumenten om het niveau van geïntegreerde zorg in de praktijk te meten. In **Hoofdstuk 3** hebben we daarom de constructvaliditeit beoordeeld van het Regenboogmodel voor Geïntegreerde Zorg meetinstrument (RMIC-MT), voor zorgverleners die werken in een interprofessionele eerstelijns dementiezorg setting.

In een cross-sectionele studie werd de RMIC-MT, een 36-item vragenlijst die gaat over alle domeinen van het Regenboogmodel voor Geïntegreerde Zorg, uitgestuurd naar DementieNet netwerken en andere lokale netwerken van eerstelijns ouderenzorg professionals. Bevestigende factoranalyse ("confirmatory factor analysis") werd uitgevoerd voor de validatie van de factorstructuur van de RMIC-MT. De resultaten lieten zien dat de tool gebruikt kan worden voor het evalueren van geïntegreerde zorginitiatieven in de eerstelijnszorg en dat het daarmee verder kan bijdragen aan de implementatie van geïntegreerde eerstelijns ouderen- en dementiezorg.

In **DEEL II** hebben we onderzocht hoe digitale tools geïntegreerde zorgimplementatie kunnen faciliteren, door te focussen op interprofessionele samenwerking en mantelzorg ondersteuning. Implementatie van interprofessionele digitale communicatietools in de dagelijkste praktijk is vaak niet succesvol en het is nog onbekend waardoor dit komt. Daarom hebben we in **Hoofdstuk 4** geïdentificeerd wat de belemmerende en faciliterende factoren zijn voor de implementatie van interprofessionele communicatie tools, zoals ervaren door professionals en mantelzorgers. Kwalitatieve inhoudsanalyse van individuele interviews werd uitgevoerd voor het evalueren van drie verschillende digitale communicatie tools die gebruikt werden door DementieNet netwerken en mantelzorgers. Belemmerende en faciliterende factoren die geïdentificeerd werden, waren gerelateerd aan de eigenschappen van de tool, de gebruikerscontext, betrokkenheid van professionals en mantelzorgers. De tools verbeterden de bereikbaarheid, benaderbaarheid en gebruikersbetrokkenheid. De tools faciliteerden ook zorgcoördinatie

en professionals gaven aan beter op de hoogte te zijn van de huidige situatie van patiënten. Echter, het grote aantal digitale systemen dat professionals gelijktijdig moeten gebruiken en de verschillende werkafspraken belemmerden het gebruik van de tool. Interprofessionele digitale communicatie tools faciliteren communicatie in netwerken van eerstelijns ouderen- en dementiezorg. Echter, integratie tussen de digitale systemen is nodig om het aantal tools die professionals moeten gebruiken te verminderen en interprofessionele tools bruikbaar te maken voor dagelijks gebruik. Aanvullend is het nodig dat zorgorganisaties en beleidsmakers actief het gebruik van deze tools promoten en ondersteunen.

Om te identificeren hoe digitale tools mantelzorgers kunnen ondersteunen, hebben we een digitale tool ontwikkeld voor het monitoren van mantelzorger welzijn en veerkracht in **Hoofdstuk 5**. Het doel van deze tool is om tijdig ondersteuning te kunnen bieden om overbelasting bij mantelzorgers te voorkomen en daarmee mogelijk zelfs crisisopnames van de persoon met dementie te voorkomen. Door middel van een mensgerichte onderzoeksmethode is met behulp van co-creatie tussen mantelzorgers en professionals de REMIND tool ontwikkeld met als uiteindelijk doel inzicht te geven in de ervaren belasting van mantelzorgers. Tijdens co-creatie sessies is een prototype ontwikkeld. Het REMIND prototype bestond uit wekelijkse vragen over welzijn en veerkracht van de mantelzorger en een dashboard met antwoorden voor de casemanager. Duo's van casemanagers en mantelzorgers hebben REMIND getest tijdens een pilot en interviews werden uitgevoerd om de bruikbaarheid en acceptatie te beoordelen. Mantelzorgers gaven aan dat REMIND hen stimuleerde om te reflecteren op hun zorgtaken en hoe het met henzelf ging. Casemanagers waardeerden de tool omdat het hen meer inzicht gaf in het welzijn van mantelzorgers. REMIND is daarom in staat om het zicht op het welzijn van mantelzorgers te verbeteren, voor zowel mantelzorgers zelf als voor de casemanager. Echter er is een lange termijn (gecontroleerde) follow-up studie nodig om de impact van REMIND op mantelzorger belasting en crisisopnames te beoordelen.

Ten slotte hebben we in **DEEL III** onderzocht wat het effect is van het DementieNet programma. De eerste DementieNet netwerken zijn gestart in 2015 en het DementieNet programma is al geëvalueerd in een kleine groep van netwerken dat twee jaar actief was. Om te identificeren wat de effecten van deze netwerkzorg aanpak zijn op een grotere schaal hebben we eerst bestudeerd wat de effecten waren op netwerkmaturiteit bij 17 interprofessionele DementieNet netwerken. In **Hoofdstuk 6** hebben we specifiek gefocust op succes- en faalfactoren voor netwerkmaturiteit in een longitudinale mixed-methods studie. Netwerkmaturiteit verbeterde jaarlijks en belangrijke factoren die leidde

tot verbetering waren het leren kennen van elkaar en elkaars expertise, het hebben van (een) capabele netwerkleider(s), een stabiele netwerksamenwerking en deelname van een actieve huisarts. Deze succesfactoren zorgden voor het beter begrijpen van hoe netwerkmaturiteit bereikt kan worden en gaven richting voor toekomstige integratiestrategieën.

De belangrijkste overgebleven vraag is of de positieve effecten van het DementieNet programma in de kleine steekproef van netwerken ook te zien zijn in een grotere groep van netwerken. En nog belangrijker, of deze effecten ook voortduren nadat het tweejarige ondersteuningsprogramma stopt. In **Hoofdstuk 7** hebben we daarom het effect van het DementieNet programma op kwaliteit van zorg, netwerksamenwerking en crisisopnames onderzocht met een zesjarige follow-up periode. Vijfendertig netwerken zijn gestart tussen 2015 en 2020 en follow-up eindigde in 2021. Jaarlijks hebben netwerken data verzameld over hun kwaliteit van zorg. Netwerksamenwerking werd beoordeeld door een semigestructureerd interview dat daarna werd omgezet naar een score voor netwerkmaturiteit. Netwerksamenwerking en kwaliteit van zorg verbeterde significant in de eerste twee jaar. Deze scores waren bij de start al hoger voor netwerken die al samenwerkten, maar netwerken met een nieuw gevormde samenwerking stegen sterker in deze eerste periode. Daarna stabiliseerde de kwaliteit van zorg en netwerksamenwerking.

Concluderend kan er gesteld worden dat het DementieNet programma de integratie van dementiezorg heeft verbeterd. Een effect dat voortduurde ook nadat het ondersteuningsprogramma stopte. Dit laat zien dat er voor een duurzame transitie naar geïntegreerde dementiezorg voldoende support en tijd nodig is. Vervolgstudies zijn nodig om te identificeren wat het effect van netwerkzorg is op het voorkomen van crisissituaties, op andere patiëntgerelateerde uitkomsten en op de kosteneffectiviteit van deze aanpak. Ten slotte zijn er ook op organisatorisch en financieel gebied hervormingen nodig om een duurzame transitie naar geïntegreerde dementiezorg te bewerkstelligen.





APPENDICES

Dankwoord

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PhD portfolio

Research data management

Radboudumc Alzheimer Center series

Dankwoord

Als er iets is wat dit proefschrift laat zien is dat je met een sterk netwerk veel positieve resultaten kan behalen. Graag wil ik daarom dit dankwoord gebruiken om mijn eigen netwerk heel erg te bedanken voor alle hulp en ondersteuning. Dit proefschrift had niet tot stand kunnen komen zonder jullie.

Als eerste wil ik mijn promotieteam bedanken. **Marcel**, bedankt voor je betrokkenheid, snelle acties en scherpe blik! Jouw adviezen project inhoudelijk en over mijn PhD-traject in het algemeen waren heel waardevol. Marieke en Minke, jullie waren echt een top copromotor duo. Ik kon altijd bij jullie terecht met inhoudelijke of praktische vragen. Bedankt voor de vrijheid die jullie mij gegeven hebben om zelf na te denken over leuke zij-projecten. En vooral bedankt voor jullie enthousiasme! In zo'n fijn team zitten heeft het werken aan dit proefschrift echt ontzettend leuk gemaakt. **Marieke**, ontzettend fijn dat jij me vanaf het eerste moment zo goed op weg hebt geholpen met mijn promotietraject. Ik heb veel van je mogen leren en er zijn veel bomen gespaard bij het drukken van dit proefschrift door jouw bondige schrijfstijl. Ik hoop nog veel van je te blijven leren. **Minke**, bedankt voor je enthousiasme, interesse, gezelligheid en goede adviezen. Ik heb echt ontzettend veel communicatie skills bijgeleerd van jou. Leuk dat ik met je mag blijven werken en je 'dat meisje met het rode haar' zelfs hebt aangenomen bij jouw lectoraat bij de HAN.

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In het bijzonder wil ik graag de volgende (oud) promovendi noemen: **Rianne** en **Marit**, bedankt dat jullie mij hebben aangestoken met jullie liefde voor planten door ons gezellige groene 'jungle' kantoor. **Carlijn**, **Jana** en **Lara** bedankt voor ons leuke uitstapje naar Dublin, en de memorabele terugreis die toch nog heel geslaagd afliep! **Thea**, bedankt voor het meedenken en de leuke/goede gesprekken tijdens onze digitale dagstart. **Toine**, bedankt voor de leuke samenwerking, interesse en gezelligheid! En natuurlijk de roadtrip naar Denemarken met een hele geslaagde duo-presentatie! **Marjolein**, bedankt voor de gezelligheid tijdens ons leuke (en vermoeiende) congres bezoek in Londen. We hebben toch wel bijna alle hotspots weten te bezoeken naast alle conferentie sessies.

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Lieve **Myrthe**, als er iemand is die mij helemaal snapt qua studie interesse was jij het wel! Naast een hele sterke vriendinnen band hebben we ook een gezamenlijke interesse in de ouderenzorg. Dat jij naast me staat als paranimf vind ik echt ontzettend fijn! Bedankt voor je jarenlange vriendschap met veel gezelligheid, lachbuien, gekke acties, hysterie, en ontelbare theetjes! Wie weet dat er na deze PhD eindelijk tijd is om onze serie af te kijken.

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Lieve Familie van Leuteren bedankt voor alle Twentse gezelligheid, warmte en interesse.

Lieve ome **Joop** en tante **Annette**, bedankt voor jullie gezelligheid, gevatheid en enorme interesse.

Lieve **Bart** en **Geert** en **Roeline** bedankt voor jullie broederlijke/schoonzus steun en soms gezonde desinteresse in mijn werk maar genoeg interesse in alle andere aspecten van het leven.

Lieve **papa** en **mama**, bedankt voor al jullie liefde, steun en zorg. Dankzij jullie heb ik de mogelijkheid gehad om hier terecht te komen.

Lieve **Ruud**, dat ik tijdens deze PhD periode jou heb leren kennen is echt het beste wat me in deze afgelopen jaren is overkomen! Je hebt het grootste deel van mijn promotie meegemaakt en ik heb echt ontzettend veel steun aan je gehad. Als ik er weer eens klaar mee was, dan was jij degene die me weer motiveerde om aan de slag te gaan. En ik heb de kunst mooi kunnen afkijken bij jou. Bedankt voor al je liefde, steun, zorg, humor en gezelligheid! Fantastisch dat de promotie stress nu plaats mag maken voor baby spullen en een trouwerij. Ik heb ontzettend veel zin in al onze avonturen!

About the author



Dorien Oostra was born on June 10, 1994 in Dordrecht (The Netherlands) and grew up in Papendrecht. She completed her preuniversity education at CSG de Lage Waard in 2012 and pursued her education at the Wageningen University studying Nutrition & Health. During her Bachelor she became interested in the health of older adults. This specific interest was further stimulated by various side jobs in elderly care and nursing homes. She finished her bachelor with a thesis focused on beneficial physical exercise forms for older adults. During her Masters Nutrition & Health she specialised in Epidemiology &

Public health, interested in how to improve health on a population level. During her Master thesis she combined her interest in older adults with her interest in e-health, working on a research project to prevent undernutrition in older adults by using a digital tool. She finished her Masters with a five-month internship abroad in the United States of America where she was an intern at the Penn State Cancer Institute in Hershey, Pennsylvania. During this internship she assisted in developing an e-health tool focused on nutrition. She received her Nutrition & Health Master's degree in February 2018. In April 2018 she started her PhD research at the Department of Geriatric Medicine at the Radboudumc to work on the DementiaNet project, under the supervision of her promotor prof. dr. Marcel Olde Rikkert and copromotors dr. Marieke Perry and dr. Minke Nieuwboer. The DementiaNet project, focusing on interprofessional collaboration in the primary care setting, matched many of her interests in older adults, e-health tools, and improving population health. As of March 2022 she combined her PhD work with a position as researcher at the HAN University of Applied Sciences with a focus on interprofessional collaboration. Since October 2022 she combines her position at the HAN with a position as post-doctoral researcher at the Department of Geriatric Medicine at the Radboudumc.

List of publications

Publications in this thesis

Oostra D.L., Fierkens C., Alewijnse M.E., Olde Rikkert M.G., Nieuwboer M.S., Perry M. (2022). Implementation of interprofessional digital communication tools in primary care for frail older adults: An interview study. *Journal of Interprofessional Care*, 1-9.

Oostra D.L., Harmsen A., Nieuwboer M.S., Rikkert M.G.O., Perry M. (2021). Care Integration in Primary Dementia Care Networks: A Longitudinal Mixed-Methods Study. *International Journal of Integrated Care*, *21*(4).

Oostra D.L., Nieuwboer M.S., Rikkert M.G.O., Perry M. (2020). Development and pilot testing of quality improvement indicators for integrated primary dementia care. *BMJ Open Quality*, *9*(2), e000916.

Submitted for publication

Oostra D.L., Vos W., Olde Rikkert M.G.M., Nieuwboer M.S., Perry M. Digital resilience monitoring of informal caregivers of persons with dementia: a promising concept for early detection of overburden. Under review.

Oostra D.L., Nieuwboer M.S., Janssen J.H.M., Olde Rikkert M.G.M., Valentijn P.P., Perry M.

Construct validation of the Rainbow Model of Integrated Care Measurement Tool in Dutch primary care for older adults. Under review.

Oostra D.L., Nieuwboer M.S., Melis R.J.F., Remers T.E.P., Olde Rikkert M.G.M., Perry M. DementiaNet facilitates a sustainable transition towards integrated primary dementia care: a long-term evaluation. Submitted.

Publications not included in this thesis

Oostra D.L., Burse N.R., Wolf L.J., Schleicher E., Mama S.K., Bluethmann S., Schmitz K., Winkels R.M. (2021). Understanding Nutritional Problems of Metastatic Breast Cancer Patients: Opportunities for Supportive Care Through eHealth. *Cancer Nursing*, *44*(2), 154-162.

PhD portfolio

Name PhD candidate: D.L. Oostra	PhD period : 01-04-2018 – 30-09-2022
Department: Geriatric Medicine	Promotor: prof. dr. M.G.M. Olde Rikkert
Graduate School: Radboud Institute	Copromotors: dr. M. Perry,
for Health Sciences	dr. M.S. Nieuwboer

		Year(s)	Hours		
	TRAINING ACTIVITIES				
a.	Courses				
-	Introduction day Radboudumc	2018	6		
-	Graduate School specific introductory course RIHS	2018	15		
-	eBROK course	2018	26		
-	Introductie cursus kwalitatief onderzoek	2018	84		
-	How to write a medical scientific paper	2018	4		
-	Designing a PhD research project	2018	84		
-	Management voor Promovendi	2018	45		
-	Education in a nutshell	2019	28		
-	Scientific Writing for PhD candidates	2019	84		
-	The Art of Presenting Science	2019	33		
-	Writing a Conference Abstract	2019	14		
-	Design and illustration	2019	26		
-	Scientific Integrity course	2020	20		
-	Effective writing strategies	2020	75		
-	Grant writing	2021	28		
-	Loopbaanmanagement voor Promovendi	2021	28		
-	R course	2021	14		
-	Art of finishing up	2021	10		
b.	Seminars & lectures				
-	Research Integrity Rounds	2018 - 2022	8		
-	Radboud Alzheimer Center sessies	2018 - 2021	10		
-	Workshop on Growth Models	2019	8		
с.	Symposia & congresses				
-	DementiaLab (Dutch Design Week) in Eindhoven, the	2019	16		
	Netherlands				
	Poster presentation: REMIND: Resilience Monitor for Informal				
	caregivers for people with Dementia				

-	Alzheimer Europe in The Hague, the Netherlands.	2019	16
	Oral presentation: Maturity of integrated care in primary		
	dementia care networks over time, a longitudinal mixed-		
	methods study.		
-	Alzheimer's Association International Conference (AAIC),	2020	2
	Online. Poster presentation: Resilience Monitor for Informal		
	caregivers in Dementia (REMIND).		
-	Alzheimer Europe, Online.	2020	2
	Poster presentation: Development of a digital resilience monitor		
	for informal caregivers of persons with dementia to prevent		
	crises.		
-	Jaarevent Deltaplan Dementie, Online.	2020	4
	Oral presentation: De Mantelzorger Voorop.		
-	International Conference on Integrated Care (ICIC), Online.	2021	5
	Oral presentation: Evaluation of a digital resilience		
	monitor for informal caregivers of persons with dementia to		
	prevent crisis: a pilot study.		
	Oral presentation: Network-based primary care and crisis		
	admissions of persons with dementia.		
-	WONCA, Online.	2021	2
	Oral presentation: Network-based primary care decreases the		
	number of crisis admissions of persons with dementia.		
-	Nederlands Geheugenpoli Netwerk congres, Utrecht, the	2021	4
	Netherlands.		
	Oral presentation: Netwerkzorg effectieve manier voor ZSD		
	implementatie?		
-	Vilans Zoek het Uit Festival, Nieuwegein, the Netherlands.	2021	5
	Oral presentation: Veerkrachtmonitor (REMIND) voor		
	mantelzorgers van personen met dementie.		
-	DementieNet afsluitende symposium, Nijmegen, the	2022	4
	Netherlands		
	Oral presentation: De lange termijn resultaten van DementieNet.		
-	 Oral presentation: Netwerkzorg effectieve manier voor ZSD implementatie? Vilans Zoek het Uit Festival, Nieuwegein, the Netherlands. Oral presentation: Veerkrachtmonitor (REMIND) voor mantelzorgers van personen met dementie. DementieNet afsluitende symposium, Nijmegen, the Netherlands Oral presentation: De lange termijn resultaten van DementieNet. 	2021 2022	5

-	International Conference on Integrated Care (ICIC), Odense,	2022	24
	Denmark.		
	Oral presentation: Integrated primary dementia care increases		
	collaboration, quality of care and prevents crisis admissions: the		
	DementiaNet longitudinal multiple case study.		
	Poster presentation: The Rainbow Model of Integrated		
	Care Measurement Tool: validation for the primary elderly care		
	setting		
-	European Geriatric Medicine Society (EUGMS), Londen,	2022	20
	United Kingdom.		
	Oral presentation: network-based care facilitates a sustainable		
	transition towards integrated primary dementia care: the		
	DementiaNet cohort study		
d.	Other		
-	Chair of the department's Quality lunch	2018 - 2021	40
-	Participated in weekly junior epidemiologist meetings and	2019 - 2021	210
	journal clubs		
-	Chair Mix & Match meeting of Alzheimer Nederland	2022	14
	TEACHING ACTIVITIES		
e.	Lecturing		
-	Teaching activities for Medical students (CK09)	2019 - 2021	-
-	Meet your PhD (3x each)	2019 - 2021	-
f.	Supervision of internships / other		
-	2 Health & Society 2 nd year master students	2018 - 2021	-
-	10 Medical master students	2018 -2021	-
-	Grant proposal	2019 - 2020	-
-	1 Biomedical science 2 nd year master student	2020	-
-	1 Biomedical science 3 rd year bachelor student	2021	-
Tot	al		1018

Research data management

The data of the studies in this thesis is obtained and stored in accordance with the Findable, Accessible, Interoperable and Reusable (FAIR) principles.

Ethical approval

The study protocols were all reviewed by the local ethical committee of the Radboudumc, and they declared that formal judgment was not required according to the Dutch law.

DementieNet

For the data collection of the DementieNet study and sub studies (Chapter 2, 4, 6, 7), for all forms of data collection informed consent was obtained from the participants prior to the data-collection (e.g. interviews, and questionnaires). Informed consent paper forms are al filed and securely stored at the department of Geriatrics and upon finalizing the projects will go to an external archive where the data will be stored for 15 years. Digital informed consent forms will be archived on the K-drive of the department of Geriatrics. Participants of the network collected data regarding their own caseload in a registration file. Informed consent was not necessary, since we only received anonymised data.

The registration files were than stored at the department server. Audio files and questionnaire data is saved at the department server as well. The privacy of the networks in this study is warranted by use of encrypted and unique network codes. This code correspondents with the code on the data files. The key file was stored separately from the study data.

For the quantitative data statistical analyses were performed in SPSS and R. Necessary datafiles and syntaxes to replicate the study are saved together at the department server: K:\Afgesloten Projecten\DementieNet (Dorien Oostra).

For the qualitative data analysis were performed using Atlas.ti files and associated codebooks with categories and themes are saved together at the department server: K:\ Afgesloten Projecten\DementieNet (Dorien Oostra).

The data will be saved for 15 years after termination of the study. Data is accessible for reuse upon reasonable request via the principle investigator, dr. Marieke Perry (Marieke. Perry@radboudumc.nl). All papers are or will be published open access.

RMIC

Before the participants started with the RMIC-MT questionnaire of Chapter 3, they checked the box for informed consent. Since we performed this study in collaboration with dr. Pim Valentijn the data is stored at our department server and his secured server.

Statistical analyses were performed in R. Necessary datafiles and syntaxes to replicate the study are saved together at the department server: K:\Afgesloten Projecten\DementieNet (Dorien Oostra).

The data will be saved for 15 years after termination of the study. Data is accessible for reuse upon reasonable request via the principle investigator, dr. Marieke Perry (Marieke.Perry@radboudumc.nl) or corresponding author, dr. Pim Valentijn (valentijn@ essenburgh.com). The paper will be published open access.

REMIND

Participants of the REMIND tool in Chapter 5 gave written informed consent prior to starting to use the tool. Case managers gave written or digital consent. Informed consent paper forms are al filed and securely stored at the department of Geriatrics and upon finalizing the projects will go to an external archive where the data will be stored for 15 years. Digital informed consent forms will be archived on the K-drive of the department of Geriatrics. Informal caregivers checked the box in their first questionnaire as their informed consent.

The audio files of the interviews are stored at our department server. The data analysis were performed using Atlas.ti files and associated codebooks with categories and themes are saved together at the department server: K:\Afgesloten Projecten\DementieNet (Dorien Oostra).

This study is still ongoing. After termination of the study the data will be saved for 15 years. Data is accessible for reuse upon reasonable request via the principle investigator, dr. Marieke Perry (Marieke.Perry@radboudumc.nl). The paper will be published open access.

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Van Corven, C (2022). Empowerment for people living with dementia.

Linden, R (2022). "Synaptic loss in Alzheimer's disease: From genes to mechanisms"

- Maasakkers, C.M. (2021). Sitting brains won't stand Sedentary behaviour, brain health, and cognitive function in older adults.
- Tengeler, A (2020) "Mind the Microbes. The impact of the gut microbiota on brain structure and function in mice"
- Thomas, J (2020). Slow waves Assessing sleep and detrimental effects of sleep disruption on brain amyloid-β and cognitive function in shift workers
- Boumans, R (2020). Feasibility and effectiveness of social robots in acquiring patient reported outcomes from older adults.
- Sanders, M (2020). NeuroExercise: The effects of exercise on cognition, central and cerebral hemodynamics in mild cognitive impairment.
- Heus, de R (2020). The ups and downs of blood pressure variation in cognitive impairment and dementia.
- Van Waalwijk van Doorn, L.J.C. (2020). Cerebrospinal fluid biomarker assays for Alzheimer's disease: standardization, validation and analysis of confounders
- Gerritsen, A (2020). The course and clinical aspects in young-onset dementia. Results of the Needs in Young-onset Dementia study
- Tilburgs, B (2020). Advance care planning in dementia; Development and evaluation of an educational intervention in primary care.
- Nieuwboer, M. (2019). Interprofessional communication and clinical leadership in the development of network-based primary care.
- Smeets, C. (2019). Psychopharmacological treatment of neuropsychiatric symptoms: proper prescription in perspective.
- Mariani, E. (2019). Let Me Participate: Using shared decision-making to involve persons with dementia in care planning in long-term care
- Haaksma, M. (2019). Different but the same, unravelling the progression of dementia
- Karssemeijer, E (2019). Brain in Motion: Combined cognitive and physical exercise training in people with dementia.
- Borsje, P. (2019). Dementia related problems in primary care of greatest concern. The occurrence and course of neuropsychiatric symptoms in people with dementia and psychological distress in their informal caregivers.
- Appelhof, B (2019). The management of neuropsychiatric symptoms in people with young-onset dementia. Improving specialized long-term care.
- Ooms, S.J. (2018). Sleep well, age well? Assessing sleep disruption as a player in Alzheimer's disease pathogenesis.

- Arnoldussen, I. A.C. (2018). Adiposity and the Brain. The adiposity-brain-axis in mice and men
- Jong, D.L.K. de (2018). Regulation of cerebral perfusion in Alzheimer's disease: from seconds to months.
- Donkers, H.W. (2018). Social Participation Dilemma's in dementia.
- Richters, A. (2018). Network-based care for people with dementia: a complex transition.
- Spek, K. van der (2018). Appropriate psychotropic drug use in institutionalized people with dementia.

The PROPER-study

- Wiesmann, M. (2017). Vascular risk factors and Alzheimer's disease.
- Rijpma, A. (2017). Multi-nutrient interventions and brain metabolism in Alzheimer's disease: a spectrum of effects.
- Elsen, G. van den (2016). Tetrahydrocannabinol in the treatment of neuropsychiatric symptoms in dementia.
- Vermeij, A. (2016). Cognitive plasticity in normal aging and mild cognitive impairment: Shedding light on prefrontal activation.
- Müller, M. (2016). Footprints of Alzheimer's disease. Exploring proteins and microRNAs as biomarkers for differential diagnosis.
- Bruggink, K.A. (2016). Amyloid-β and amyloid associated proteins in the pathology and diagnosis of Alzheimer's disease.
- Aalbers, T. (2016). eHealth in the primary prevention of cognitive decline; The Brain Aging Monitor study.
- Maaden, T. van der (2016). Improving discomfort in nursing home residents with dementia and pneumonia. Development, implementation and evaluation of a practice guideline for optimal symptom relief.
- Millenaar, J. (2016). Young onset dementia, towards a better understanding of care needs and experiences.
- Döpp, C.M.E. (2015). Making the jump-The translation of research evidence into clinical occupational therapy practice.
- Herbert, M. (2014). Facing uncertain diagnosis: the use of CSF biomarkers for the differential diagnosis of neurodegenerative diseases.
- Ven, G. van de (2014). Effectiveness and costs of Dementia Care Mapping intervention in Dutch nursing homes
- Aisha Sadie Sade Meel-vanden Abeelen (2014). methodological and clinical aspects of cerebral autoregulation and haemodynamics
- Bakker, C. (2013). Young onset dementia: care needs & service provision.

- Meeuwsen, E.J. (2013). Towards efficient dementia care : a comparison of memory clinics and general practitioners.
- Spijker, G.J.A.A (2013). Systematic care for caregivers of people with dementia in community mental health services.
- Janssen, D. (2013). The role of nutrition in Alzheimer's disease : a study in transgenic mouse models for Alzheimer's disease and vascular disorders.
- Zerbi, V. (2013). Impact of nutrition on brain structure and function : a magnetic resonance imaging approach in Alzheimer mouse models.
- Voight-Radloff, S. (2012). Cross-national transfer of community occupational therapy in dementia.
- Spies, P.E. (2012). The reflection of Alzheimer disease in CSF.
- Joosten-Weyn Banning, E.W.A. (2012). Learning to live with Mild Cognitive Impairment: development and evaluation of a psychological intervention for patients with Mild Cognitive Impairment and their significant others.
- Vasse, E. (2012). A stepwise process for developing and implementing quality indicators to improve psychosocial dementia care in European countries.
- Slats, D. (2012). CSF biomarkers of Alzheimer's disease; serial sampling analysis and the study of circadian rhythmicity.
- Leontjevas, R. (2012). Act in case of Depression! Validation and effectiveness of a multidisciplinary depression care program in nursing homes.
- Schölzel-Dorenbos, C.J.M. (2011). Quality of life in dementia: From concept to practice
- Bruinsma, I.B. (2011). Amyloidogenic proteins in Alzheimer's disease and Parkinson's disease: interaction with chaperones and inflammation
- Perry, M. (2011). Development and evaluation of a Dementia Training Programme for Primary care
- Derksen, E.W.C. (2011). Diagnostic disclosure: a basic intervention in dementia care
- Wetzels, R.B. (2011). Neuropsychiatric symptoms in institutionalized residents with dementia: Course and interplay with cognition, quality of life and psychotropic drug use.
- Dado- Van Beek, H.E.A. (2010). The regulation of cerebral perfusion in patients with Alzheimer's disease
- Jong, D. de (2010). Anti-inflammatory therapy and cerebrospinal fluid diagnosis in Alzheimer's disease
- Persoon, J.W.B. (2010). Development and validation of the Nurses' Observation Scale for Cognitive Abilities – NOSCA

- Meulenbroek, O.V. (2010). Neural correlates of episodic memory in healthy aging and Alzheimer's disease
- Zuidema, S.U. (2008). Neuropsychiatric symptoms in Dutch nursing home patients with dementiaGraff, M.J.L. (2008). Effectiveness and efficiency of community occupational therapy for older people with dementia and the caregivers
- Claassen, J.A.H.R. (2008). Cerebral hemodynamics in aging: the interplay between blood pressure, cerebral perfusion, and dementia
- Wilhelmus, M.M.M. (2006). Small heat shock proteins and apolipoprotein E in Alzheimer's disease
- Van Horssen, J. (2005). Heparan sulfate proteoglycans and vascular pathology in Alzheimer's disease

