Hitting the TARGET in primary care

Citation for published version (APA):

Smeets, R. G. M. (2023). *Hitting the TARGET in primary care: working towards integrated and person-centred care*. [Doctoral Thesis, Maastricht University]. Maastricht University. https://doi.org/10.26481/dis.20230113rs

Document status and date:
Published: 01/01/2023

DOI:
10.26481/dis.20230113rs

Document Version:
Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

Link to publication

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Hitting the TARGET in primary care

Working towards integrated and person-centred care

Rowan G. M. Smeets

The research presented in this dissertation was conducted at the Care and Public Health Research Institute (CAPHRI), department of Health Services Research, Maastricht University. CAPHRI participates in the Netherlands School of Public Health and Care Research (CaRe), which has been acknowledged by the Royal Academy of Science (KNAW). This research was conducted within the Living Lab for Sustainable Care (AWDZ). This research was funded by care group Dokter Drenthe (formerly known as Huisartsenzorg Drenthe) and healthcare insurance company Zilveren Kruis (Stichting Achmea Gezondheidszorg).

Cover and chapter design: Paul-Jean Jessen (design); Thijs Offermans (lay-out)
Lay-out: Tiny Wouters-Lenssen
Printing: Ridderprint I www.ridderprint.nl

ISBN: 978-94-6469-148-1

Hitting the TARGET in primary care

Working towards integrated and person-centred care

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de Universiteit Maastricht,
op gezag van de Rector Magnificus, Prof. dr. Pamela Habibović,
volgens het besluit van het College van Decanen,
in het openbaar te verdedigen op
vrijdag 13 januari 2023 om 16.00 uur

door

Rowan Goswina Monique Smeets

Promotor

Prof. dr. D. Ruwaard

Copromotores

Dr. A.M.J. Elissen
Dr. M.E.A.L. Kroese

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Table of contents

Chapter 1

General introduction

Rowan G.M. Smeets

While innovations to improve chronic care management come and go, it seems crystal clear that conditions such as diabetes, chronic obstructive pulmonary disease (COPD) and cancer are here to stay[1]. After all, technologies to increase longevity and quality of life continue to evolve, accompanied with increasingly unhealthy lifestyles[1,2]. As a consequence, chronic conditions are more common, not only among the oldest people - who keep getting older – but also among younger and middle-aged people[3]. In 2019, more than 35% of people living in the European Union had a long-standing illness or health problem[3,4]. Multimorbidity, referred to as having multiple conditions at the same time, is often framed as 'the norm rather than the exception', with recent studies showing that at least 30 to 40% of European adults aged 50 or over have multimorbidity[5,6].

The consequences of the alarming numbers of chronic diseases are countless and range from threatening patients' quality of life and increasing professionals' work pressure on the individual level, to increasing costs for healthcare systems and society as a whole[7]. This has led to a reconsideration of the current dominant approach to managing chronic diseases in many countries, via disease management programs. While these programs have earned their stripes over the years, the fundamental single-disease focus and standardization is at odds with the increasingly diverse and (socially) complex needs of chronically ill, particularly those with multimorbidity[8-14]. Promising new care models were introduced, often developed in the US, and gradually spread throughout the world[15,16]. Amongst others, these models are designed around the ideas of integrated, person-centred care, with the allocation of patients to subgroups with similar needs (i.e. segmentation) as a starting point[15,16]. But it remains largely unclear how such a new care model should be successfully designed and implemented in Dutch primary care.

This dissertation is about person-centred, integrated care for people with chronic conditions, and – as part of that overarching aim – presents the development and first implementation of the TARGET program. TARGET aims for “Targeting Advanced Resources in General practice to create Efficient, Tailored and holistic care for chronically ill patients”. Primary care group 'Dokter Drenthe', (formerly known as 'Huisartsenzorg Drenthe') commissioned the study in 2016. In this first chapter, the context in which TARGET was developed and implemented is described, even as the traditional but changing management approaches to chronic illness. The chapter ends with the aims and outline of this dissertation.

Chronic disease

While the COVID-19 pandemic has again directed our attention to the risks and impact of communicable diseases, non-communicable, chronic diseases are usually higher on the political agenda of developed, western countries[17,18]. There is no universal agreement about the exact definition and breadth of the term ‘chronic disease’, but it is generally described as a condition that lasts for longer periods of time and needs endured medical attention[19]. The World Health Organization (WHO) concluded that non-communicable diseases are the leading cause of death worldwide, being responsible for 71% of deaths in 2016[20]. Four major types of chronic conditions contribute in particular to the total number of deaths: cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes[20]. Also neurocognitive and mental chronic conditions are growing in prevalence and strongly impacting quality of life and longevity[21,22]. Amongst others, dementia entered the top-10 list of causes of deaths worldwide in 2019 and depression – with 264 million people affected globally – is considered by the WHO as one of the main causes of disability[21,22].

Research shows how the increase in chronic conditions is not only attributable to what the WHO describes as ‘non-modifiable risk factors’, i.e. age and heredity, but also to ‘modifiable risk factors’[23,24]. The latter group of factors traditionally includes an unhealthy diet, physical inactivity and tobacco use, and is expanded with new insights into important risk factors like alcohol consumption, but also living circumstances like the socioeconomic status (SES) of the neighbourhood and air pollution[23-26]. As countries develop and go through a process of so-called westernization, these modifiable risk factors start playing a larger role, while former risks for health in developing countries, i.e. poor water, sanitation and undernutrition, are reduced[27]. Not surprisingly, researchers and policy makers therefore advocate a strong, universally accessible system of care having sufficient resources for prevention and behavioural health to address those modifiable factors as early as possible[24,25,27].

Healthcare consumption

Most people with chronic conditions use care on a regular basis and on average more than the general population[28]. In the Netherlands, 89% of people who are chronically ill, compared to 69% of the general population (including people with chronic conditions), received care from their general practitioner (GP) in 2018. A medical specialist was consulted by 75% of chronically ill in 2018, in contrast with 44% of the (adult) general population[28]. Statistics about the average care consumption and healthcare costs of chronically ill should however be interpreted with caution, as care use and costs are highly unequally divided amongst patients. In a first explorative study[29] that was conducted in the context of the TARGET program, it was found that amongst the population with chronic conditions (n=97.175), three subgroups with a different level of care use can be distinguished: low, moderate and high (see Figure 1.1). While each subgroup is responsible for exactly one-third of the total care consumption, the low care use-subgroup includes almost two-third of the people who on average have

6 consultations per year. In sharp contrast, the high care use-subgroup only includes 12.3% of patients who on average have 30 consultations per year.

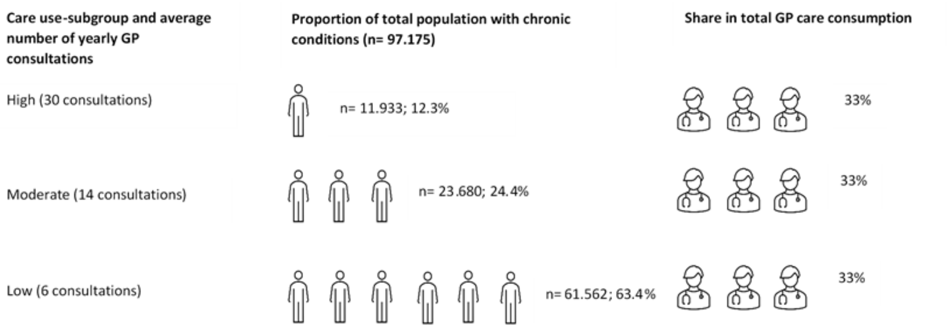

Figure 1.1 Three subgroups of people with chronic conditions, as identified by Hameleers, et al.[29]

Not only the average care consumption differs between the subgroups, but also the prevalence of demographic and health-related characteristics: the high care use-subgroup includes more people of higher age, women and people with multimorbidity. In particular the high care use-subgroup, also called the high-need, high-cost (HNHC) subgroup or frequent attenders in international research, is seen as an interesting subgroup because of the large impact on healthcare costs and work pressure[15,30-32]. Studies on HNHC patients are mainly done in the US and while this calls for caution in generalizing results to a Dutch setting, it also serves as an inspiration for other countries and care settings. For instance, the taxonomy suggested in the report of the National Academy of Medicine on high-need patients shows that while HNHC patients may have a high care need in common, a second division in six different HNHC subgroups is relevant: children with complex needs, non-elderly disabled, multiple chronic, major complex chronic, frail elderly, and advancing illness[15]. While these subgroups can be identified by using merely clinical data, a behavioural and social assessment is subsequently needed "to determine the specific type of services that are required."[15]

Chronic care management, the traditional way

In the Alma-Ata conference on primary health care held in 1978, primary care was discussed as "the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and [it] constitutes the first element of a continuing health care process."[33] In the Netherlands, as in other western countries with a strongly developed primary care system, primary care plays an important, coordinating role in the care for chronically ill[34]. Due to the increasing number of chronically ill patients in combination with workforce shortages in large parts of the Western world, efficient teamwork and task delegation has become more important in primary care[35-37]. In the Netherlands for instance, more GPs currently prefer to work in a practice with several GPs and the number of solo-practices has decreased steadily over time, from 44% in 2012 to 35% of total practices in 2018[38]. In 2000, the 'somatic practice nurse' was introduced in Dutch general practice to take over parts of the standardized care for people with common chronic conditions[39]. The 'mental health practice nurse' is a second type of practice nurse, introduced in 2008, in reaction to the growing demands for mental and psychosocial care[39]. This practice nurse offers easily accessible care to patients who may otherwise unnecessarily use more expensive specialized mental care[39].

Almost thirty years ago, the United States was the frontrunner in developing disease management programs[40]. These were intended for groups of people having the same chronic condition and should enable delivery of "a standardized, coordinated set of evidence-based interventions"[40]. The Netherlands, as other European countries, followed the American example and started designing these programs: first for diabetes type 2 and later for common chronic conditions like COPD and cardiovascular diseases, and patient groups with specific needs (e.g. elderly)[41]. In order to stimulate multidisciplinary cooperation (within primary care), a bundled payment system was introduced in the Netherlands to purchase, deliver and claim the expenses of the 'standard' care for a specific chronic illness as one product, instead of several individual ones[41,42]. Bundled payment agreements need to be negotiated with the health insurer, and to strengthen primary care professionals' negotiating position, the 'care group' was introduced in the Netherlands, which has clear similarities with the American accountable care organizations (ACOs). Care groups unite care professionals, often mostly GPs, and are responsible for coordinating and delivering chronic care to a specific patient population living in a specific region[41,42].

Shortcomings of disease-specific care management

Many studies found evidence that disease management programs improve different lifestyle (e.g. smoking, physical activity) and short-term health indicators such as blood sugar levels, in chronically ill patients[9,43,44]. But substantial costs reductions are not convincing[9,45,46]. The bundled-payment approach in the Netherlands has resulted into improved coordination of care and collaboration between professionals[47]. However, chronically ill with complex needs, as compared to patients with single and simple conditions, still receive suboptimal care[48]. The guidelines underpinning each DMP do not sufficiently take into account multimorbidity. Collaboration within care groups commonly remains limited to professionals working in primary care, while people with complex needs often require care from disciplines across multiple sectors, within and beyond the boundaries of the health system[48]. Hence, various inefficiencies in the care system still exist, ranging from insufficient attention for patient needs and preferences, a lack of attention to comorbidities and poor care coordination between professionals working in different settings to limited continuity of care over time[48-50].

Movement to integrated care

In 2015, the WHO published a report about how care systems should be transformed in order to deal with the alarming epidemiological challenges and remove the inefficiencies in the current system of care. They stated: “unless a people-centred and integrated health services approach is adopted, health care will become increasingly fragmented, inefficient and unsustainable.”[51] Simply described, integrated care means that care is well coordinated across different settings and providers[16]. Healthcare managers and policy makers have developed and implemented a range of strategies to improve integration of services over the years[51-53]. These strategies can be, based on the work of Singer and colleagues, classified as either related to organizational features, social features or activities within a health system[54,55]. Examples of organizational integration efforts are interoperable information systems and the composition of leadership teams[54,55]. Social integration is more difficult to directly influence and refers to sharing a common culture, value, norms and teamwork amongst professionals[54,55]. Integration in terms of activities may refer to the use of shared care plans[54,55]. To design care as truly integrated, there should be a focus on the needs of both the individual person and (sub)populations. This means taking a person-centred and population health management approach, respectively[16,55]. The first concept refers to attention for ‘the person behind the patient’ and acknowledgement of patients as co-creators of health and care[55-58]. Health and well-being is more than ‘the absence of disease’ and is influenced by a range of biopsychosocial factors[26,59,60]. Therefore, a comprehensive insight into the needs of a patient is a first step towards (in a shared way) determining the type and level of integrated care that is needed[55,61]. Yet, designing integrated care paths and models for each individual patient would be costly and above all unnecessary, as similarities exist between patients in terms of their biopsychosocial characteristics and needs. Creating subgroups of patients, i.e. population segmentation, is a powerful population health management strategy to increase insight into what types of subgroups exist within a population and what needs they have[16,55,62-64]. Doing so helps to arrange services, from a local to (inter)national level, in such a way that there is a proper match with the demands and preferences of subgroups[16,55,62-64]. To address the varying needs of all population subgroups, including the growing subgroup with primarily social needs “the scope of integrated care needs to be expanded to bridge the gaps not only within the health system, but also between the health and social systems, among others.”[65]

A well-known example of a simple segmentation approach, is the Triangle of Kaiser Permanente, an American non-profit health maintenance organisation[66,67]. The triangle divides the population with chronic conditions into three subgroups with a different type of required care strategy, based on the complexity and level of care needs of each subgroup. At the top, the relatively low number of highly complex patients would need intensive case management. Care management strategies are most suitable for patients who are identified as 'high-risk', the middle level. At the bottom level, where 70 to 80% of people with chronic conditions can be found, self-care support is the preferred care strategy. Prevention plays a role across all subgroups[66,67].

Figure 1.2 The Kaiser Permanente Triangle[66,67].

Integrated care evidence

Integrated, person-centred innovations are generally aimed at improving patient experience, population health and the work life of professionals, while simultaneously lowering costs, described as the Quadruple Aim[68]. While it seems plausible that integrated care would lead to improved Quadruple Aim outcomes – by for example removing inefficiencies and increasing attention for what patients need – the evidence for integrated care is still limited[53,69]. This can partly be explained by the fact that integrated care interventions are often complex and multicomponent interventions, implemented in dynamic, real-life settings[53,69]. As a consequence, using experimental designs to evaluate integrated care is problematic: amongst others, it is extremely difficult to remove all factors possibly disturbing the relation between the intervention and the outcome, which limits the strength to prove that integrated care is effective[70,71]. Furthermore, a dominant focus on the outcomes of integrated care, may neglect attention for 'how, why, and under what circumstances' such complex programs work. Answering those questions – which is central to 'realist evaluation' – during an implementation study leads to valuable insights and lessons for improving integrated care, and transferring programs to other settings or populations[70-73].

Dutch TARGET initiative

Primary care group Dokter Drenthe commissioned this research to work towards the TARGET program[74,75]. This care group is located in the northern province of the Netherlands, called Drenthe. In this predominantly rural area, the number of people aged 65 and over – who often have chronic conditions – will grow, from 24% in 2020 to 33% in 2040[76]. The number of people between 15 and 65 years will decrease in the same period from 61% to 52%[76]. Hence, the potential workforce shrinks and together with the fact that many GPs leave the region to work elsewhere, Drenthe faces problems to recruit sufficient numbers of GPs[35,77]. Within this alarming context, Dokter Drenthe considered the current design of care for chronically ill as unsustainable: affiliated professionals reported a high work pressure and the growing number of disease management programs were considered unsuited to meet the actual demands of patients. In response to these challenges, Dokter Drenthe wanted to develop an integrated care program in a robust way: based on scientific insights, but above all relevant and feasible for daily practice[75] .To this end, Dokter Drenthe cooperated with the University of Maastricht (UM), department of Health Services Research, but also established two steering groups. Those steering groups discussed the research insights with the researchers of the UM on a regular basis, and advised on the content of the program as well as on the required preconditions in terms of policy and research. One steering group, with ‘internal’ stakeholders, included primary care professionals (predominantly GPs and practice nurses) working in the region covered by Dokter Drenthe. The second steering group, with ‘external’ stakeholders, included amongst others Dutch primary care expertise organisations (e.g. InEen), other primary care groups with interest in integrated care, and the dominant health insurer in the northern region of the Netherlands (i.e. Zilveren Kruis).

Aim and outline of the dissertation

The overall aim of this dissertation is to provide new insights into person-centred, integrated care for people with chronic conditions. To do so, we have, in cooperation with care group Dokter Drenthe, formulated two overarching objectives:

1. To increase insight into how an integrated, person-centred program for people with chronic conditions should be designed, taking into account the needs of this patient population as well as the organizational innovations needed to accommodate those needs.
2. To translate those insights into the TARGET integrated care program, prepare the implementation of this program and gather first implementation insights.

Corresponding with these two objectives, this dissertation is divided into two parts. **Part I** is named 'Assessing the needs for and organizational building blocks of the TARGET integrated care program' and includes chapter 2 and 3. **Chapter 2** is a quantitative study providing insights into the diverse subgroups of HNHC patients with chronic conditions that can be identified in primary care. **Chapter 3** presents a qualitative study in which primary care professionals are interviewed about the organisational solutions to overcome the barriers to person-centred, integrated primary care.

Part II is named 'Towards a first implementation of the TARGET program in Dutch primary care' and includes chapter 4 to 6. **Chapter 4** is a methodological study to prepare the TARGET implementation by presenting the hypothesized functioning of the TARGET using a realist evaluation approach. **Chapter 5** is about the translation and validation of the Patient-Centered Assessment Method (PCAM), a biopsychosocial assessment tool used in the context of the TARGET program. **Chapter 6** shows the results of the pilot study of TARGET, which was aimed at determining the feasibility and acceptability of the program and gathering first insights into the preconditions for successful implementation. The last chapter (**Chapter 7**) provides the main findings of the current dissertation, including a reflection on the theoretical and methodological considerations. Based on this, we provide recommendations to move forward in practice, policy, as well as in research.

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Part I

Assessing the needs for and organizational building blocks of the TARGET integrated care program

Chapter 2

Identifying subgroups of high-need, high cost, chronically ill patients in primary care: A latent class analysis

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PLos One2020;15(1): e0228103

Abstract

Introduction

Segmentation of the high-need, high-cost (HNHC) population is required for reorganizing care to accommodate person-centered, integrated care delivery. Therefore, we aimed to identify and characterize relevant subgroups of the HNHC population in primary care by using demographic, biomedical, and socioeconomic patient characteristics.

Methods

This was a retrospective cohort study within a Dutch primary care group, with a follow-up period from September 1, 2014 to August 31, 2017. Chronically ill patients were included in the HNHC population if they belonged to the top 10% of care utilizers and/or suffered from multimorbidity and had an above-average care utilization. In a latent class analysis, forty-one patient characteristics were initially used as potential indicators of heterogeneity in HNHC patients' needs.

Results

Patient data from 12 602 HNHC patients was used. A 4-class model was considered statistically and clinically superior. The classes were named according to the characteristics that were most dominantly present and distinctive between the classes (i.e. mainly age, household position, and source of income). Class 1 ('older adults living with partner') included 39.3% of patients, class 2 ('older adults living alone') included 25.5% of patients, class 3 ('middle-aged, employed adults with family') included 23.3% of patients, and class 4 ('middle-aged adults with social welfare dependency') included 11.9% of patients. Diabetes was the most common condition in all classes; the second most prevalent condition differed between osteoarthritis in class 1 (21.7%) and 2 (23.8%), asthma in class 3 (25.3%), and mood disorders in class 4 (23.1%). Furthermore, while (GP) care utilization increased during the follow-up period in the classes of older adults, it remained relatively stable in the middle-aged classes.

Conclusions

Although the HNHC population is heterogeneous, distinct subgroups with relatively homogeneous patterns of mainly demographic and socioeconomic characteristics can be identified. This calls for tailoring care and increased attention for social determinants of health.

Introduction

Due to increasing numbers of chronically ill patients, in particular with multimorbidity, and rising health care costs, Western health care systems are faced with challenges to deliver high-quality, person-centered, and sustainable care[1-3]. In response to these developments, accountable care organizations (ACOs) were introduced in the United States several years ago[4-6]. Within ACOs, a value-based payment system is designed to incentivize providers to share accountability for the quality and cost of care for a defined population[6-8]. Likewise, more than a decade ago, 'care groups' were first introduced in Dutch primary care. In line with the ACOs, care groups unite providers, mostly general practitioners (GPs), with shared responsibility for all assigned patients receiving care for a specific chronic condition from a value-based bundled payment approach[5,9]. These initiatives show that, similar to the US, the Netherlands aims to achieve more value-based care.

If health systems aim to increase the value of delivered care, it is crucial to focus on the population with the highest care use as they offer the largest potential for achieving improved value[10,11]. This population with a disproportionately high care use is also referred to as the high-need, high-cost (HNHC) population[10,12]. The identification of the HNHC population, as a subgroup of the total population, is embedded in the approach of population segmentation, which is defined as the division of a specific population into homogeneous subgroups with distinct needs and (health) characteristics[13-15]. A closely related concept in which principles of segmentation are applied, pertains to the concept of 'population (health) management' (PM),[16] as a way to promote 'population health'[17,18]. Within population health, the focus is on the health outcomes of subgroups rather than individuals, by taking into account a large variety of determinants of health (i.e. physical, mental, social)[17,18]. PM strategies generally aim to improve health needs of defined subgroups along 'the continuum of health and well-being', and aim to integrate services across multiple domains[16]. As such, PM strategies can be used to tailor interventions to the care needs of specific subgroups of patients, which is assumed to lead towards improving individual patients', and providers' experiences as well as population outcomes and cost (Quadruple Aim[19]).

With the growing availability of digital patient data, studies have identified common biomedical characteristics of the HNHC population, such as the high prevalence of (co-occurring) chronic conditions and mental illness[20,21]. At the same time, studies have suggested that the HNHC population is diverse, not only in terms of patients' biomedical but also in their demographic and socioeconomic profiles[10,20,21]. These findings underline the importance of social determinants of health within the HNHC population. Yet, population segmentation studies have predominantly focused on specific populations, such as older adults[22-24] and Medicaid beneficiaries[25], and mainly characterized the identified patient subgroups by their biomedical characteristics (i.e., chronic diagnoses) [22-27]. Therefore, the main aim of this study was to identify and characterize, by means of latent class analysis (LCA), clinically relevant subgroups of the HNHC population in primary care, defined by demographic, biomedical, and socioeconomic patient characteristics as well as care utilization.

Materials and methods

Setting

This retrospective cohort study was conducted at a (primary) care group in the northern region of the Netherlands, covering 130 general practices. This care group was founded in 2009 and currently has bundled payment contracts with health insurers for the delivery of several disease management programs, including for patients with type 2 diabetes mellitus, COPD, and cardiovascular risks.

As this study used retrospective data and did not intervene into people's life or impose rules, no formal ethical approval was required (project number 164111), in line with the Dutch Medical Research (Human Subjects) Act.

Data sources

All general practices connected to the care group were invited to extract and provide individual-level patient data from their electronic health records (EHRs). The EHR data covered 4.5 years: baseline was on September 1, 2014; the follow-up period covered three years (from September 1, 2014 to August 31, 2017). Furthermore, the EHR data were linked on the individual patient level to socioeconomic data (e.g., source of income) and health care claims data (e.g., pharmaceutical costs). Socioeconomic data were retrieved from Statistics Netherlands, which is involved in the collection, preparation, and publication of statistics on behalf of the Dutch government, science and commercial sector[28]. Claims data were retrieved from the health care information center 'Vektis', which collects and manages all claims under the Dutch Healthcare Insurance Act[29]. To ensure data confidentiality and safety, a third trusted party was involved in the provision of a pseudonymized version of the data set to the researchers.

Participants

We selected a cohort of chronically ill patients, limited to those with a full EHR registration over the 4.5-year research period. Patients were considered chronically ill if they had registered at least one GP consultation in the 1.5 years before baseline related to one of 28 conditions defined as chronic (see Table 2.1)[30,31]. Chronically ill patients were included in the HNHC population ifthey belonged to the top 10% of care utilizers (over follow-up period) and/or suffered from multimorbidity and had an above-average care utilization (over follow-up period). The first criterion was applied as this is one of the commonly used thresholds for identifying HNHC patients according to previous studies[20,32,33]. The second criterion was applied because multimorbidity brings along a challenging complexity to the organization of care, especially in light of the current single-disease management programs for single chronic conditions[2,3]. Furthermore, care utilization was measured as the total number of GP consultations weighted by the required time investment per type of consultation (i.e. 0.5 for telephone or e-mail consultation, 1.0 for regular consultation, 2.0 for extended regular consultation, 1.5 for home visit, 2.5 for extended home visit), determined by the Netherlands Institute for Health Services Research[34]. As the weighting factors based on time investment are related to costs[35], the patients selected for this study can be considered high-need, high-cost in primary care.

Table 2.1 Baseline characteristics of the HNHC population (n=12 602).

Patient characteristics	n (%)	Missing, n (%)
Demographic characteristics		
Sex		0
Male	4495 (35.67)	
Female	8107 (64.33)	
Age, mean (SD)[a]	67.55 (14.80)	0
Household position		0
Child living at home	141 (1.12)	
Single adult	3773 (29.94)	
Partner with children at home	1515 (12.02)	
Partner without children at home	6245 (49.56)	
Single parent	403 (3.20)	
Member of collective household	371 (2.94)	
Other	154 (1.22)	
Age of children living at parental home		0
≤12	388 (3.08)	
>12	1752 (13.90)	
No children living at home	10 462 (83.02)	
Biomedical characteristics		
Type of chronic condition(s)		0
Only physical	10 060 (79.83)	
Only mental	436 (3.46)	
Combination of both	2106 (16.71)	
Number of chronic conditions, mean (SD)	2.23 (0.93)	0

Table 2.1 (continued)

Patient characteristics	n (%)	Missing, n (%)
Prevalence of 28 chronic conditions		0
Chronic alcohol abuse	163 (1.29)	
Endocardial conditions, valvular conditions	298 (2.36)	
Congenital cardiovascular anomaly	25 (0.20)	
HIV/AIDS	9 (0.07)	
Anxiety disorders	649 (5.15)	
Asthma	2142 (17.00)	
Stroke (including TIA)	986 (7.82)	
Chronic obstructive pulmonary disease (COPD)	2218 (17.60)	
Chronic back or neck disorder	2033 (16.13)	
Coronary heart diseases	1725 (13.69)	
Dementia including Alzheimer's	172 (1.36)	
Diabetes mellitus	4925 (39.08)	
Epilepsy	181 (1.44)	
Hearing disorders	679 (5.39)	
Visual disorders	1694 (13.44)	
Heart failure	659 (5.23)	
Heart arrhythmia	1446 (11.47)	
Cancer	2032 (16.12)	
Migraine	395 (3.13)	
Osteoporosis	737 (5.85)	
Burnout	452 (3.59)	
Osteoarthritis	2360 (18.73)	
Personality disorders	120 (0.95)	
Rheumatoid arthritis	433 (3.44)	
Schizophrenia	53 (0.42)	
Mood disorders	1380 (10.95)	
Mental retardation	48 (0.38)	
Parkinson's disease	136 (1.08)	
Socioeconomic characteristics		
Housing situation		12 (0.10)
Owner-occupied	6777 (53.78)	
Rented[b]	5813 (46.13)	
Source of income		0
Paid work[c]	1974 (15.66)	
Social welfare or unemployment benefits	1838 (14.58)	
Pension benefits	8156 (64.72)	
Without income[d]	634 (5.03)	
Number of people in a household with an individual income		26 (0.21)
1	4594 (36.45)	
>1	7982 (63.34)	
Household dependence on social security payments, mean (SD)	11.63 (25.44)	346 (2.75)
Paid interest over debts, mean (SD)	48.89 (782.63)	20 (0.16)
Care utilization		
Pharmaceutical costs		16 (0.13)
≤€500	4773 (37.87)	
>€500 and ≤€1500	5122 (40.64)	
>€1500	2691 (21.35)	
GP care utilization before baseline, mean (SD)	29.97 (18.50)	0

[a] For continuous variables, mean (SD) is reported; [b] Includes members of collective households; [c] Includes employees, entrepreneurs, and managers; [d] Includes students with and without individual income.

Variables

Forty-one patient characteristics were initially used as potential indicators of heterogeneity in HNHC patients' needs in the LCA. These characteristics were included based on scientific studies describing these characteristics as relevant in relation to (high) care utilization[12,36]. Demographic characteristics were measured at baseline and included patients' sex, age (in years), household position (child living at home, single adult, partner with children at home, partner without children at home, single parent, member of a collective household, other), and age of children living at parental home (≤12 years, >12 years (i.e. the age that they generally leave elementary school), no children living at home). Biomedical characteristics were also measured at baseline and included patients' chronic disease diagnoses based on GP care use related to the chronic disease in the 1.5 years before baseline, type of chronic condition(s) (only physical, only mental, or a combination of both), and number of chronic conditions (1 to 28). All socioeconomic characteristics, except for source of income, were measured over the year 2014 and included patients' (household) housing situation (owner-occupied, rented), number of people in a household with an individual income (1, >1), household dependence on social security payments as proportion of gross household income (0% to 100%), and paid interest over debts (in euros, excluding mortgage or debts related to renovating personal property). Source of income (paid work, social welfare or unemployment benefits, pension benefits, without income) was measured at baseline. Care utilization characteristics included GP care utilization on baseline (number of registred GP consultations) and patients' pharmaceutical costs (≤€500, >€500 and ≤€1500, >€1500) which were measured over 2014.

Data analysis

Data were validated and checked for outliers and missing values. We employed LCA, which is a sophisticated analysis technique to capture heterogeneity in the HNHC population's needs by the smallest number of unobserved homogeneous classes[37]. Furthermore, LCA is a person-oriented analysis technique[37] which aims to identify classes of individuals with similar patterns of, in the current study, (correlated) personal factors relevant to health care utilization. Initially, the LCA was run using all 41 patient characteristics (see Table 2.1) in order to explore the potential to identify clinically relevant subgroups. Furthermore, the analysis was conducted with a maximum likelihood estimator with robust standard errors (MLR). Missing values were handled by the default option in the Mplus software (version 8.1). To test whether the missing values were completely at random (MCAR), a MCAR Pearson-Chi Square and Likelihood Ratio Chi-Square test ($P<.05$) was computed. Additionally, the number of random starts values was increased several times to prevent problems related to nonconvergence or local maxima[38]. By stepwise increasing the number of classes, starting with a 1-class model, and comparing various statistical indicators and clinical relevance, we decided on the final model. Statistical indicators for model fit included the Akaike Information Criterion (AIC),[39,40] Bayesian Information Criterion (BIC),[41] bootstrapped likelihood ratio test (BLRT),[42] and entropy score. Lower values on AIC and BIC indicated better model fit; significant p-values on the BLRT showed dominance of the k class model, compared to the k-1 class model. The entropy score gave an indication of classification certainty, using a cutoff score of at least 0.8, indicating high classification certainty[38]. The BIC and BLRT were considered most important in deciding on the best model as these outperform other statistical indicators[43].

Besides statistical indicators, clinical relevance of the model was a key factor, as the model should support daily clinical practice[15]. Also, the size of the classes within the model was taken into account (also reffered to as substantiality)[15]. A model with classes including at least 10% of HNHC population was considered substantial to counterbalance efforts to tailor interventions in daily practice. Although we aimed to maintain the largest variety of patient characteristics, the model was made more parsimonious after identifying a clinically relevant model. Thus, we removed any variables that did not contribute to the division in clinically relevant classes, significantly deteriorated the model fit, and/or were regarded as being of less added value based on internal clinical insight. Patients in each class of the final model were described in terms of the probability of having a given patient characteristic. In line with previous studies using LCA, probabilities of 70% to 100% were considered high, probabilities of 40% to 69% moderate, and probabilities of less than 40% low[44,45]. The continuous variables were described by their estimated mean (SE). Furthermore, each class was described in their top five of chronic conditions at baseline and mean GP care utilization (i.e. mean number of weighted GP consultations) over the follow-up period.

Results

Baseline characteristics

A total of 63 general practices (48.5%) participated. The complete data set included individual-level data from 58 551 chronically ill patients, of whom 12 602 patients (21.5%) met the inclusion criteria for the study (i.e., were considered HNHC). Baseline characteristics of the HNHC population, including number (%) of missing values per characteristic, are shown in Table 2.1. Patients’ mean (SD) GP care utilization over the follow-up period was 66.9 contacts (33.3).

Latent class analysis

A 4-class model was considered statistically and clinically superior. The 4-class model had a low value on BIC, a significant BLRT (*P*<.001), high entropy score (0.973), and each class was sufficiently substantial by including at least 10% of the HNHC population (see Table 2.2). Although the 5-class model was statistically superior to the 4-class model, it included two classes with less than 10% of the HNHC population and resulted in less relevant and distinct classes compared to the 4-class model. More specifically, a 5-class model largely maintained three of the four classes of the 4-class model and subdivided the fourth and smallest class of the 4-class model into two smaller classes which were relatively indistinct from each other (Table 2.2).

Table 2.2 Statistical indicators and relative class sizes for models with increasing numbers of latent classes.

	1-class model	2-class model	3-class model	4-class model	5-class model
Loglikelihood	-183,726.630	-172,407.886	-164,350.740	-159,286.403	-154,427.535
AIC[a]	367,493.259	344,893.772	328,817.480	318,726.806	309,047.071
BIC[b]	367,642.092	345,183.995	329,249.094	319,299.810	309,761.466
Entropy	n/a	0.981	0.974	0.973	0.977
BLRT[c]	n/a	*P*<.001	*P*<.001	*P*<.001	*P*<.001
Relative class size	n/a	86.62/13.38	64.51/23.58/ 11.90	39.30/25.51/ 23.31/11.87	38.18/25.31/18.48/ 9.21/8.82

[a]AIC refers to Akaike Information Criterion; [b]BIC refers to Bayesian Information Criterion; [c]BLRT refers to bootstrapped likelihood ratio test.

Table 2.3 shows the final model, which includes nine of the initially used 41 patient characteristics and the probabilities of having each patient characteristic, given class membership (see also Figure 2.1). This means that the following variables were excluded in the final LCA due to less statistical relevance: age of children living at parental home, number of chronic conditions, prevalence of 28 chronic conditions, paid interest over debts, GP care utilization on baseline. The MCAR Pearson-Chi Square and Likelihood Ratio Chi-Square test showed that values were missing completely at random (*P*<0.001). As the entropy score was high, we report the final class counts and proportions for the latent classes that are based on their most likely latent class membership. Class 1 (n=4953; 39.3%) had a mean (SE) age of 74.5 years (0.10), had a high probability (0.91) of having a partner but no children at home, and a high probability (0.98) of receiving pension benefits. Based on these dominant characteristics, class 1 was named 'older adults living with partner'. Class 2 (n=3215; 25.5%) had a mean (SE) age of 78.8 years (0.15), had a high probability (0.92) of being single, and a high probability (0.99) of receiving pension benefits. Based on these dominant characteristics, class 2 was named 'older adults living alone'. Class 3 (n=2938; 23.3%) had a mean (SE) age of 51.0 years (0.24) and had a high probability of having a partner with or without children at home (0.82). In terms of socioeconomic status, members of class 3 had a moderate probability

(0.62) of having paid work. Based on these dominant characteristics, class 3 was named ‘middle-aged, employed adults with family’. Class 4 (n=1496; 11.9%) had a mean (SE) age of 52.2 years (0.32). With regard to household position, members of class 4 had a low probability (0.34) of being single and a low probability (0.33) of having a partner but no children at home. In terms of socioeconomic status, members of class 4 had a high probability (0.84) of receiving social welfare or unemployment benefits. Based on these dominant characteristics, class 4 was named ‘middle-aged adults with social welfare dependency’. See also Appendix 2A for a description of typical qualitative personas who characterize the four classes.

Table 2.3 Probabilities of having the (categorical) patient characteristic, given class membership, for each class within the final 4-class model.

Patient characteristics	Probability (SE)			
	Class 1 (n=4953)	Class 2 (n=3215)	Class 3 (n=2938)	Class 4 (n=1496)
Demographic characteristics				
Sex				
Male	0.481 (0.01)	0.202 (0.01)	0.290 (0.01)	0.404 (0.01)
Female	0.519 (0.01)	0.798 (0.01)	0.710 (0.01)	0.596 (0.01)
Age, mean (SE)[a]	**74.47 (0.10)**	**78.78 (0.15)**	**51.01 (0.24)**	**52.22 (0.32)**
Household position				
Child living at home	0.001 (0.00)	0.000 (0.00)	0.034 (0.00)	0.027 (0.00)
Single adult	0.010 (0.00)	**0.917 (0.08)**	0.092 (0.01)	**0.341 (0.01)**
Partner with children at home	0.034 (0.00)	0.000 (0.00)	**0.391 (0.01)**	0.144 (0.01)
Partner without children at home	**0.905 (0.01)**	0.000 (0.00)	**0.424 (0.01)**	**0.332 (0.01)**
Single parent	0.022 (0.00)	0.002 (0.00)	0.044 (0.00)	0.105 (0.01)
Member of a collective household	0.010 (0.00)	0.080 (0.07)	0.002 (0.00)	0.039 (0.01)
Other	0.019 (0.00)	0.001 (0.00)	0.013 (0.00)	0.012 (0.00)
Biomedical characteristics				
Type of chronic condition				
Only physical	0.891 (0.00)	0.863 (0.01)	0.664 (0.01)	0.610 (0.01)
Only mental	0.008 (0.00)	0.014 (0.00)	0.077 (0.01)	0.085 (0.01)
Combination of both	0.101 (0.00)	0.123 (0.01)	0.259 (0.01)	0.306 (0.01)
Socioeconomic characteristics				
Housing situation				
Owner-occupied	0.637 (0.01)	0.343 (0.01)	0.723 (0.01)	0.272 (0.01)
Rented	0.363 (0.01)	0.657 (0.01)	0.277 (0.01)	0.728 (0.01)
Source of income				
Paid work	0.018 (0.00)	0.007 (0.00)	**0.621 (0.01)**	0.047 (0.01)
Social welfare or unemployment benefits	0.002 (0.00)	0.002 (0.00)	0.195 (0.01)	**0.844 (0.01)**
Pension benefits	**0.981 (0.00)**	**0.990 (0.00)**	0.000 (0.00)	0.042 (0.01)
Without income	0.000 (0.00)	0.001 (0.00)	0.184 (0.01)	0.068 (0.01)
Number of people with an individual income in a household				
1	0.026 (0.00)	0.969 (0.01)	0.218 (0.01)	0.483 (0.01)
>1	0.974 (0.00)	0.031 (0.01)	0.782 (0.01)	0.517 (0.01)

Table 2.3 (continued)

Patient characteristics	Probability (SE)			
	Class 1 (n=4953)	Class 2 (n=3215)	Class 3 (n=2938)	Class 4 (n=1496)
Household dependence on social security payments, mean (SE)[a]	1.28 (0.09)	0.35 (0.06)	9.28 (0.33)	75.81 (0.64)
Care utilization				
Pharmaceutical costs				
≤€500	0.353 (0.01)	0.318 (0.01)	0.513 (0.01)	0.340 (0.01)
>€500 and ≤€1500	0.439 (0.01)	0.423 (0.01)	0.349 (0.01)	0.378 (0.01)
>€1500	0.208 (0.01)	0.259 (0.01)	0.138 (0.01)	0.282 (0.01)

[a] For continuous variables, mean (SE) is reported.

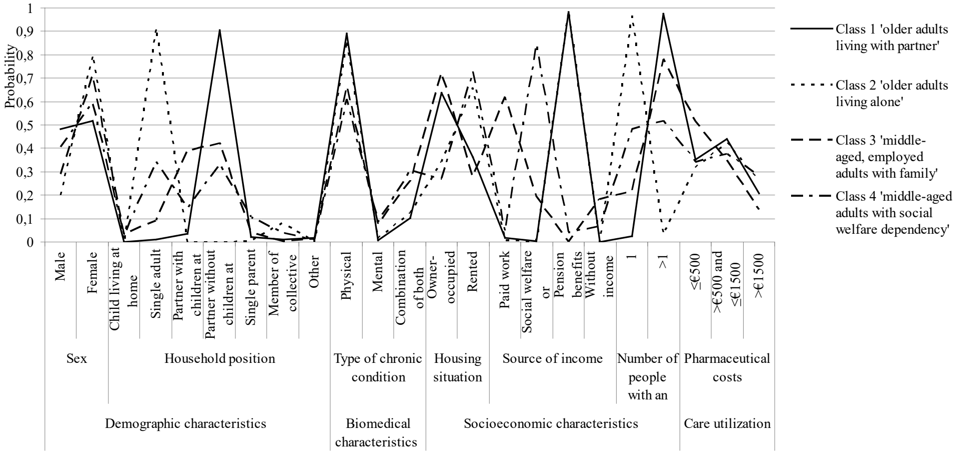

Figure 2.1 Probabilities of having the (categorical) patient characteristic, given class membership, for each class within the final 4-class model.

In terms of the top five chronic conditions per class at baseline (see Figure 2.2), diabetes mellitus was most common in each of the four classes, with prevalence ranging from 30.5% in class 3 to 43.4% in class 1. The second most prevalent condition differed between osteoarthritis in class 1 (21.7%) and 2 (23.8%), asthma in class 3 (25.3%), and mood disorders in class 4 (23.1%).

With regard to GP care utilization of the classes over the follow-up period (see Figure 2.3), class 2 showed the highest mean care utilization. Both classes with the older adults showed the largest mean (SD) increase in care utilization over time—from 9.8 (6.9) in the first to 11.7 (8.7) in the sixth half year and from 11.5 (8.3) in the first to 14.0 (10.5) in the sixth half year—while the classes with the middle-aged adults were more stable over time—from 10.1 (7.1) in the first to 10.7 (8.2) in the sixth half year and from 11.3 (8.0) in the first to 12.1 (9.5) in the sixth half year.

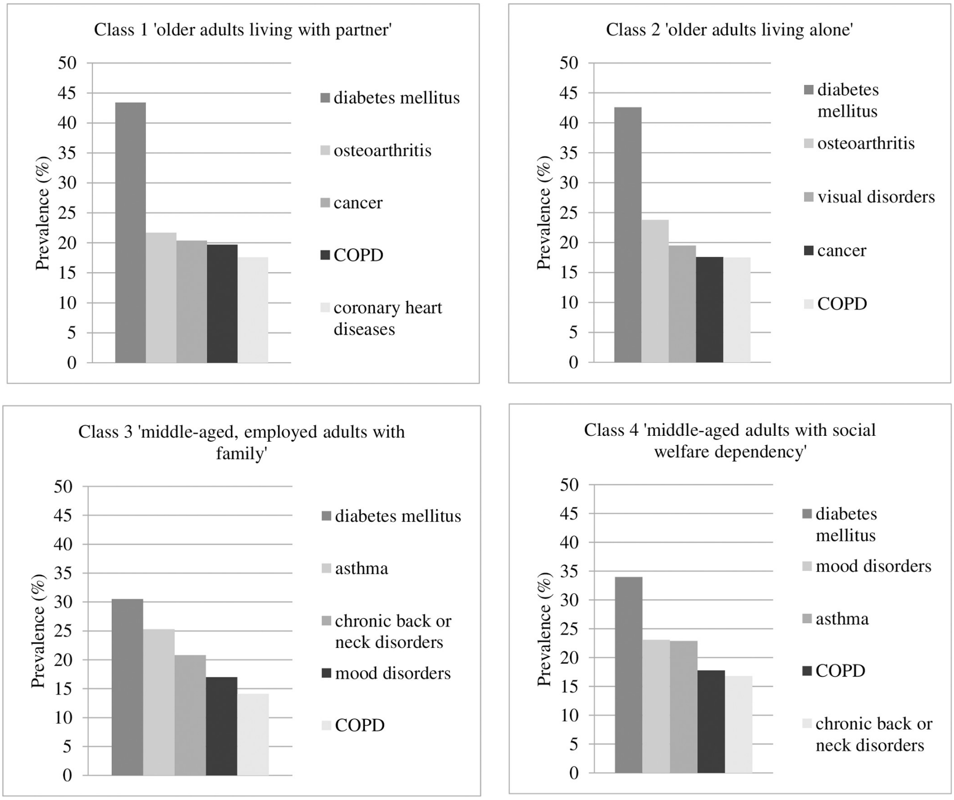

Figure 2.2 Top five of chronic conditions (%) per class within the final 4-class model.

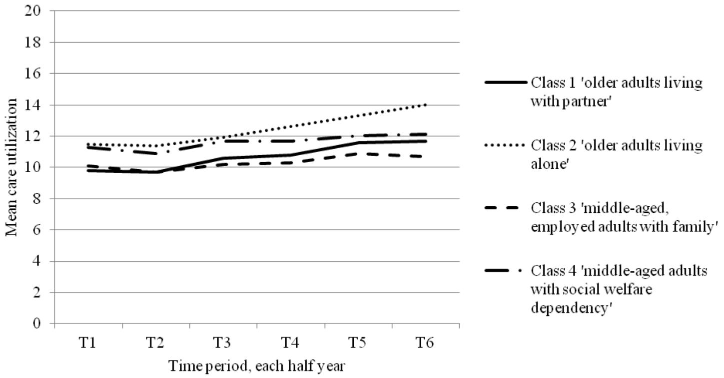

Figure 2.3 GP care utilization measured over the follow-up period for each class within the final 4-class model.

Discussion

The present study suggests that the HNHC population in primary care is a heterogeneous population, which can be divided into four subgroups with distinct patterns of particularly demographic and socioeconomic characteristics. Main differences between the subgroups were found in demographic and socioeconomic factors (i.e., age, household position, and source of income). In terms of chronic conditions, the subgroups with older adults most frequently suffered from physical and age-related conditions (e.g. osteoarthritis, cancer), while the middle-aged subgroups most frequently had conditions more typically found in relatively younger people (i.e., asthma and mood disorders). Furthermore, while the subgroups with older adults showed an increase in mean care utilization over time, the middle-aged subgroups showed a more stable pattern over time. In addition, class 2 ('older adults living alone') showed the highest mean care utilization over time. This finding corresponds with a study of Dreyer, et al.[36] who showed that living alone is associated with higher care utilization in older adults.

The current study indicates that the sex distribution within the HNHC population, as well as in three of the four identified subgroups, is unbalanced: more than 64% of the HNHC population is female. In the current person-oriented analysis, unlike in a variable-oriented analysis, there is no assessment of relations between variables including corrections for confounders. Rather, the current analysis has focused on identifying subgroups based on patterns of variables within individual patients. One possible explanation for the unbalanced population in terms of sex is that women typically get older and, as a result, are overrepresented among the older aged HNHC patients compared to men. In addition, scientific studies have found that women have significantly higher consultation rates compared to men, but particularly during working years[46,47].

Our findings show that the HNHC population is a demographically and socioeconomically diverse population and includes not only older adults but also many middle-aged people. To date, studies have predominantly focused on (biomedical) segmentation in populations of older adults: an example is the recent Embrace study,[48] which identified three risk profiles for older adults. In line with the demographic heterogeneity found in our study, a study by Wammes, et al.[12] found that many high-cost patients (in the Dutch curative health system) are not older than 65 years of age. Supporting our approach, the authors[12] emphasized the need for studying the general population with extensive data and targeting interventions toward high-cost patients of various ages. Furthermore, our findings suggest that middle-aged HNHC patients are generally characterized by more socioeconomic vulnerability (e.g., dependence on social welfare) and a higher prevalence of mental conditions (e.g., mood disorders) than are older HNHC patients.

These findings add to an increasing awareness about the importance of social and context-related determinants of health[25,49,50]. First, Shadmi[51] suggests broadening the understanding and measurement of multimorbidity by including a large variety of health and health-related aspects (e.g., social, cultural, and economic background of populations) that correlate with multimorbidity. In addition, corresponding to our finding that current segmentation often lacks inclusion of relevant demographic and socioeconomic characteristics, the study by Chin-Yee, et al.[52] and Khoury, et al.[53] also argued that adding environmental and social characteristics (a rather "population perspective") to the genetic profiling in precision medicine can be of added value to public health.

With the growing recognition of the effectiveness of segmentation for patient-centered interventions,[54] the segmentation conducted in the present study can guide clinical practice toward more integrated and person-centered care. By gathering insight into demographic characteristics other than age and gender (e.g., household position) as well as the socioeconomic context of patients (e.g., main source of income), clinical practice in primary care can be attuned to a more holistic view of patients. This view can suggest potentially relevant goals, interventions, and professionals (within primary care and in cooperation with other disciplines), which can be further discussed in a shared decision-making process with the patient. Such an approach can be inspired by the 'Bridges to Health' Model,[55] which aims to systematically connect priority concerns, major components of health care, and goals for health care within identified population segments[56]. Thus, while older adults living alone might benefit from increased social support, middle-aged adults with social welfare dependency might rather benefit from financial and mental support. As such, this segmentation approach can serve as a starting point for more biopsychosocial attention and can inform the discussion of tailored interventions with the patient[56]. However, the individual consultation is still key to assess personal needs and preferences with a patient during a consultation, and agree on an individual treatment course.

Further research, in particular qualitative inquiry, is necessary to identify the most important concerns and components of health care per HNHC subgroup. In addition, the current study has focused on HNHC patients in primary care, which is widely considered the most suitable medical home for chronically ill patients[57]. Although as a result, our findings are mainly useful for improvement of primary care management, there is some evidence that patients with a disproportionately high use of primary care resources also account for significantly high(er) costs in specialist care[58,59]. For policy making, the subgroups can also help to give insight into the distribution of the patient population over the identified subgroups within certain geographical areas and help to efficiently target resources. In more urban areas, for example, the middle-aged subgroups might be larger than in rural areas.

One of the most important strengths of the current study is the relatively large set of individual-level patient data, with a variety of patient characteristics. A second strength is the use of the model-based analysis technique LCA, which offers a large set of statistical indicators to decide on the best-fitting model and ways to cope with issues of local maxima and nonconvergence[38]. The study also has some limitations. First, individual level data of the non-participating practices were not available in this study. This hampered a direct comparison of participating practices (n=63; 48.5% of care group) with non-participating practices in order to assess representativeness of the sample. However, particular patient characteristics (i.e. sex, age, household position, and source of income) of the sample were compared to the patient characteristics of the general population in the northern region of the Netherlands that is covered by the primary care group. This comparison showed that the sample is largely similar in patient characteristics to the general population. For example, 50.8% of the sample is female; 50.5% of the general population is female, 20.1% of the sample receives pension benefits; 22.1% of the general population receives pension benefits. Second, EHRs typically include incomplete registrations and may have limited data quality. Nevertheless, the quality of registrations was checked and validated, and the (categorical) missing values were found to be MCAR. Third, the data set included patients who can be considered dependent, as they belonged to the same household. A sensitivity analysis with only completely independent observations showed the same division among classes, implying a negligible effect of the dependent observations on the identification of subgroups. Fourth, only patients with a full EHR registration over the research period were included. This has excluded specific types of patients, such as patients who died before the end of the follow-up period. It is possible that the excluded patients would have been identified as a separate 'near end of life' HNHC subgroup, as identified by some previous population segmentation studies as well[24,55,60]. Nevertheless, specific payments arrangements are already in place in Dutch primary care for this patient population who is near the end of life and needs (expensive) palliative care. Fifth, generalizability of the subgroups may be limited, as the data set was retrieved from a specific Dutch region with limited ethnic/cultural diversity and a relatively aged population, compared to the Dutch average. In future research, the generalizability of the subgroups needs to be determined.

Conclusions

Despite the heterogeneity of the HNHC population, distinct subgroups with relatively homogeneous patterns of particularly demographic and socioeconomic characteristics can be identified. This study adds to the increasing awareness of the demographic and socioeconomic heterogeneity of the HNHC population, in addition to biomedical diversity. To accommodate person-centered, integrated care delivery, the identified classes need to be connected to tailored care (i.e. concerns, components, goals). This connection can be inspired by the proposed strategies within The Bridges to Health Model[55].

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Appendix 2A Description of typical qualitative personas who characterize the four identified classes.

Qualitative persona of class 1 ‘older adults living with partner’

Mr. Taylor is 74 years old and living together with his wife, who receives pension benefits as well. For a couple of years now, he is suffering from multimorbidity (i.e. diabetes in combination with COPD).

Qualitative persona of class 2 ‘older adults living alone’

Mrs. Williams is 79 years old and living alone. Her husband has passed away five years ago. For some time now, Mrs. Williams has to deal with visual disorders and osteoarthritis. In addition, she has been suffering from diabetes for a long time.

Qualitative persona of class 3 ‘middle-aged, employed adults with family’

Mrs. Jones is 51 years old and living together with her husband and two sons of 19 and 22 years old. She works parttime as nursing assistant in a nursing home. Mrs. Jones has diabetes and chronic back and neck disorders.

Qualitative persona of class 4 ‘middle-aged adults with social welfare dependency’

Ms. Smith is 52 years old and living alone for some time now. Due to severe mood disorders, she is dependent on sickness benefits. Besides the mood disorders, she has been suffering from asthma since her youth.

Chapter 3

Person-centred and efficient care delivery for high-need, high-cost patients: Primary care professionals' experiences

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BMC Fam Pract 2020;21(1):106

Abstract

Background

High-need, high-cost (HNHC) patients, who typically have complex and long-term care demands, contribute considerably to the high work pressure of primary care professionals (PCPs). To improve patient as well as provider experiences, it is crucial to take into account the PCPs' perspective in designing health care strategies for HNHC patients. Therefore, this study aimed to create insight into PCPs' experienced barriers and possible solutions with regards to person-centred, efficient care delivery to HNHC patients.

Methods

We conducted a qualitative study using focus group interviews with PCPs at a Dutch primary care group. A semi-structured interview guide was developed for the interviews. Qualitative content analysis was employed deductively by means of a categorisation matrix. The matrix was based on the components retrieved from the SELFIE framework for integrated care for multi-morbidity.

Results

Forty-two PCPs participated in five focus group interviews. Discussed barriers and solutions were related to the core of the SELFIE framework (i.e. the individual and environment), and particularly four of the six health system components in the framework: service delivery, leadership & governance, workforce, and technologies & medical products. Many discussed barriers revolved around the complex biopsychosocial needs of HNHC patients: PCPs reported a lack of time (service delivery), insufficiently skilled PCPs (workforce), and inefficient patient information retrieval and sharing (technologies & medical products) as barriers to adequately meet the biopsychosocial needs of HNHC patients.

Conclusions

This qualitative study suggests that primary care is currently insufficiently equipped to accommodate the complex biopsychosocial needs of HNHC patients. Therefore, it is firstly important to strengthen primary care internally, taking into account the experienced lack of time, the insufficient number of equipped PCPs and lack of inter-professional information retrieval and sharing. Secondly, PCPs should be supported in cooperating and communicating more efficiently with health services outside primary care to adequately deliver person-centred, efficient care. As a prerequisite, it is crucial to direct policy efforts at the design of a strong system of social and community services. In terms of future research, it is important to assess the feasibility and effects of re-designing primary care based on the provided recommendations.

Background

In 2014, Bodenheimer, et al.[1] proposed expanding the Triple Aim to a Quadruple Aim. Specifically, the authors added the improvement of provider experience to the already existing aims of improving patient experience, improving population health, and reducing per capita costs[2]. The need for increased attention for provider experience was underlined by studies showing the growing prevalence of burnout among healthcare professionals, in particular among primary care professionals (PCPs)[1,3]. On the individual provider level, burnout is correlated with the prevalence of severe disorders, like depression and alcohol abuse[1,4]. Moreover, some studies showed that provider burnout is negatively associated with quality and safety of patient care, and may increase health care costs[4,5].

Previous studies suggest that many factors contribute to the rising work pressure in primary care. For instance, PCPs reported a changing work environment with large administrative tasks and non-face-to-face activities[1,6-8]. From a wider, system perspective, an important contributing factor is the growing population of patients with chronic conditions and multimorbidity. The increase in number of chronically ill treated in primary care is not only a result of socio-demographic transitions, but also a (policy) tendency to transfer care tasks from hospital and community to primary care settings[9,10]. As a result, primary care is faced with increased work pressure, alongside growing complexity of care demands which used to be dealt with in more specialised settings.

As an opportunity to improve provider experience, it is important to move towards more person-centred, efficient care delivery for chronically ill who have a disproportionately high care use. These patients are referred to as 'high-need, high-cost' (HNHC) patients[11-13]. Many studies have aimed to better understand the characteristics and needs of the HNHC patient population, in order to inform more high-quality care and lower costs [11-13]. Recent studies showed that the HNHC patient population cannot be captured only in a stereotype of clinical and biomedical complexity (e.g. multimorbidity, high prevalence of mental illness) and higher age[12,14]. Rather, the HNHC patient population was found to be heterogeneous in terms of biopsychosocial characteristics (e.g. type of chronic conditions, age, and source of income)[11,12,14,15].

While there is increasing insight into the characteristics and needs of the HNHC patient population, only a limited number of studies has addressed the experiences of PCPs with regards to care delivery to this population[16-19]. Taking into account the experiences of PCPs is crucial to create more person-centred, efficient care for the HNHC chronically ill patient population in primary care and, in so doing, to support efforts to move towards the Quadruple Aim[1]. Therefore, this study aimed to create insight into the experienced barriers and possible solutions with regards to person-centred, efficient care delivery to the HNHC patient population.

Methods

Setting

The present study was conducted at a primary care group in a northern, rural region of the Netherlands, covering 135 general practices and approximately 490,000 patients. In the Netherlands, chronically ill are mainly treated in a primary care setting. Many care tasks for chronically ill are currently transferred to practice nurses, with the general practitioner (GP) having a coordinating role. Practice nurses were first introduced in Dutch primary care in 2000, initially to provide care to patients with somatic chronic conditions (i.e. 'somatic practice nurse'), such as diabetes[20]. In 2008, a second type of practice nurse, the 'mental health practice nurse' was introduced to deal with the increasing demands for mental health care in general practice[20-23].

HNHC patient population

We defined the HNHC patient population in the participating primary care group as all chronically ill patients, who: (1) belonged to the top-10% of care utilisers; or (2) had multimorbidity in combination with an above-average care utilisation. In a previous study using this definition, we found that the HNHC patient population (using data from 63 practices and 12,602 HNHC patients) consists of four subgroups with distinct biopsychosocial profiles[15]. Although these profiles are multidimensional, they can be characterised as: (1) older adults living with partner; (2) older adults living alone; (3) middle-aged, employed adults with family; and (4) middle-aged adults with social welfare dependency[15].

The biopsychosocial heterogeneity of the HNHC patient population was illustrated by case descriptions in this study. These case descriptions were discussed at the beginning of each focus group. Four case descriptions were established, each describing one 'typical' patient of the four previously identified HNHC patient subgroups with distinct biopsychosocial characteristics. This means that the case descriptions included the following information of a 'typical' patient: patients' mean age, their most prevalent household position, source of income, and (top-5 prevalent) chronic conditions, and their health care use outside primary care (based on mean health care costs). To illustrate this, we developed the following case description for the subgroup of 'middle-aged adults with social welfare dependency': *Ms. Smith is 52 years old and living alone for some time now. Due to severe mood disorders, she is dependent on sickness benefits.*

Besides the mood disorders, she has been suffering from asthma since her youth. For a couple of years, she receives care from a specialised mental health professional, alongside the care she receives from the GP.

Focus group participants

In this qualitative study, focus group interviewing with PCPs was employed to collect a variety of experiences from interactive discussion[24-26]. In order to interview a relatively large number of PCPs, the method of convenient sampling was used. PCPs of the first two focus groups were gathered via a regional meeting for (somatic) practice nurses; PCPs of the following three focus groups were gathered via a primary care conference that was attended by various types of PCPs (i.e. GPs, practice nurses, doctor's assistants). Before the interviews, PCPs were given assurances about the confidentiality of their contribution and were asked for verbal informed consent to participate in the study and audiotape their responses.

Focus group interviews

Five focus group interviews were organised: two interviews lasted approximately 90 minutes, the remaining three lasted approximately 60 minutes. The interviews were organised at the location of the regional meeting and the conference (where PCPs were sampled). The focus group interviews were conducted by one author (RS or MK) and observed by another author (AE or NH) or the (somatic) practice nurse of the primary care group. The observers wrote down keywords from the interview on a flip-over, and complemented the researcher who conducted the interviews with follow-up questions. The interviews were audio-taped.

A semi-structured interview guide was developed for conducting the interviews. The guide was pre-tested with a (somatic) practice nurse to check the clarity and validity of the guide. The first theme included in the guide pertained to the experienced barriers with regards to person-centred, efficient care delivery to the HNHC patient population. To initiate the discussion on the experienced barriers, the PCPs were asked to fill in an assignment on the top-3 most important barriers. The second theme included in the guide pertained to the experienced possible solutions with regards to person-centred, efficient care delivery to the HNHC patient population.

Data analysis

Various theoretical models and frameworks for integrated care to patients with multimorbidity were introduced over the years[27,28]. In the current study, we selected the 'Sustainable intEgrated chronic care modeLs for multi-morbidity: delivery, FInancing, and performance (SELFIE)' framework to deductively analyse our focus group data, as it specifies important concepts for integrated care in a comprehensive way[27]. Furthermore, the application of the SELFIE framework can add to the systematic categorization and comparison of interview data. The SELFIE framework has categorised relevant concepts for integrated care according to six (adapted WHO health systems) components, each having three different levels (micro, meso, macro): service delivery, leadership & governance, workforce, financing, technologies & medical products, and information & research. In addition, a holistic understanding of the individual with multimorbidity and his/her environment is positioned centrally in the framework.

To analyse the data, qualitative content analysis was applied using a three-stage process: data preparation, organisation (i.e. analysis), and reporting[29]. In the preparation stage, the interviews were transcribed verbatim[29,30]. After repeatedly reading the interview transcripts in order to get acquainted with the data, a structured categorisation matrix was developed based on the SELFIE framework for coding purposes[27]. The matrix enabled categorization of the interview data according to 20 codes, derived from the SELFIE framework (see Table 3.1): one for the individual HNHC patient, one for his/her environment, and one for each level within the six components of the SELFIE framework. A code book with explanations and examples of the components from the SELFIE framework was developed to ensure a valid coding process. In the organisation stage, the data were stepwise organised according to the codes included in the matrix. This process supported the description of the data and identification of patterns within the data. Researchers RS and AE discussed the validity and consistency of the applied codes: disagreements were resolved by discussion. To facilitate the organisation stage, The Qualitative Data Analysis & Research Software ATLAS.ti (version 8.0) was used.

Table 3.1 Categorisation matrix, derived from the SELFIE framework [27]

<table>
<tr><th colspan="2" rowspan="2"></th><th colspan="3">Levels</th></tr>
<tr><th>micro</th><th>meso</th><th>macro</th></tr>
<tr><td rowspan="6">Six adapted WHO health system components</td><td>Service delivery</td><td></td><td></td><td></td></tr>
<tr><td>Leadership & governance</td><td></td><td></td><td></td></tr>
<tr><td>Workforce</td><td></td><td></td><td></td></tr>
<tr><td>Financing</td><td></td><td></td><td></td></tr>
<tr><td>Technologies & medical products</td><td></td><td></td><td></td></tr>
<tr><td>Information & research</td><td></td><td></td><td></td></tr>
<tr><td rowspan="2">Center of SELFIE framework</td><td>Holistic understanding of individual HNHC patient</td><td colspan="3"></td></tr>
<tr><td>Environment</td><td colspan="3"></td></tr>
</table>

Results

Forty-two PCPs participated in five focus group interviews (see Table 3.2 for background characteristics). The experienced barriers and possible solutions with regards to person-centred, efficient care delivery to the HNHC patient population are described below by the SELFIE framework, starting with the centre of the framework (individual and environment), followed by the six components for integrated care [27]. The barriers as well as the solutions are described from micro to macro level.

Table 3.2 Background characteristics of PCPs (n= 42) who participated in focus group interviews.

Characteristic	Total (n=42)	Focus group 1 (n=7)	Focus group 2 (n=7)	Focus group 3 (n=6)	Focus group 4 (n=8)	Focus group 5 (n=14)
	n (%)					
Sex						
Male	11 (26.2%)	0	0	1 (16.7%)	3 (37.5%)	7 (50%)
Female	30 (71.4%)	7 (100%)	7 (100%)	5 (83.3%)	5 (62.5%)	6 (42.9%)
Missing	1 (2.4%)	0	0	0	0	1 (7.1%)
Age, mean (SD)	46.7 (10.7)	41.9 (9.3)	54.7 (3.7)	46.2 (15.3)	45.0 (11.9)	46.9 (9.6)
Missing, n (%)	3 (7.1%)	0	1 (14.3%)	0	0	2 (14.3%)
Primary care profession						
Somatic practice nurse	19 (45.2%)	7 (100%)	7 (100%)	1 (16.7%)	2 (25%)	2 (14.3%)
GP	13 (31.0%)	0	0	3 (50%)	3 (37.5%)	7 (50%)
Other[a]	9 (21.4%)	0	0	2 (33.3%)	3 (37.5%)	4 (28.6%)
Missing	1 (2.4%)	0	0	0	0	1 (7.1%)
GP practice type						
General practice not part of multi-disciplinary health centre	26 (61.9%)	7 (100%)	5 (71.4%)	4 (66.7%)	4 (50%)	6 (42.9%)
General practice part of multi-disciplinary health centre	10 (23.8%)	0	2 (28.6%)	1 (16.7%)	3 (37.5%)	4 (28.6%)
Not applicable	4 (9.5%)	0	0	1 (16.7%)	0	3 (21.4%)
Missing	2 (4.8%)	0	0	0	1 (12.5%)	1 (7.1%)
Working experience in general practice (years), mean (SD)	14.8 (10.4)	15.9 (13.5)	12.3 (16.2)	9.1 (7.4)	10.1 (7.3)	21.2 (10.5)
Not applicable, n (%)	4 (9.5%)	1 (14.3%)	0	1 (16.7%)	0	2 (14.3%)
Missing, n (%)	3 (7.1%)	0	1 (14.3%)	0	1 (12.5%)	1 (7.1%)

[a] Other professions included doctor's assistant (n=4), coordinator elderly care at care group (n=1), programme manager pulmonary medicine (n=1), policy advisor (n=1), retired GP (n=1), manager of care group (n=1)

Individual HNHC patient

PCPs characterised the HNHC patient by a high burden of mental (e.g. dementia) and psychosocial problems (e.g. loneliness in older patients). In addition, it was reported that older HNHC patients who are living alone may have a tendency to avoid care. Due to these mental and psychosocial problems, PCPs reported that patients experience increased difficulty to efficiently manage their (physical) chronic conditions and improve their health:

> *"If you [as a patient] had a good weekend, then there is less urgency to visit the GP on Monday morning. […] I sometimes think: "What does this patient want?" It is just that this patient has nothing else to do. […] Of those 35% [of patient population] who visits the GP every single day, 80% has to deal with psychosocial problems."* (FG3)

Environment

PCPs reported a lack of sufficient informal care provision and a limited social network of some HNHC patients, also due to insufficient possibilities for PCPs to find volunteers. In particular in more urban (compared to rural) areas, (older-aged) HNHC patients may experience challenges in maintaining a supportive social network:

> *"I see a difference between the villages and the more urban population. I live in a village with strongly connected communities where people look after each other. I had a neighbour who took care of everything herself until she was in her nineties. […] Her kids live far away, but she could take care of herself because of us [the community]."* (FG3)

Furthermore, while a patient's partner can be supportive towards the patient, a partner can also have a more negative influence on the patient which can lead to increased care demands (e.g. a partner who is highly dominant). In addition, it was reported that some HNHC patients, in particular middle-aged employed patients, do not have enough time (due to a high burden of work and providing informal care) to visit the GP or do not have enough money to take the required medical examinations. Consequently, it can be challenging to have a clear overview over the patient's health situation. Also, PCPs mentioned that it is difficult to discuss poverty with patients.

Service delivery

It was mentioned that a lack of time is often experienced during consultations to approach patients in a holistic way and address psychosocial problems:

> *"If you take a look at what the consultations are about, then I sometimes wonder whether it is about the physical problems, or about people who want to share their story. There is always something alongside [the physical problem] that leads to the mental problem. […] As a result, it is difficult to set goals and it is also much more difficult to achieve those goals."* (FG1)

Furthermore, PCPs mentioned insufficient time is reserved for acute care demands (e.g. patients with deteriorated blood sugar control) which leads to increased workload. PCPs also mentioned that they spend increased time on prevention and pro-active care (e.g. screening for co-morbidities). In addition, care delivery is complicated by common treatment interaction issues (e.g. polypharmacy) in HNHC patients. PCPs reported that patients have, over the years, perceived primary care as increasingly accessible care which increases their use. Mental health care is nonetheless perceived less accessible; moreover, there is a certain extent of stigma around mental health care use in the

Netherlands. As a result, patients prefer to visit the GP or somatic practice nurse, even though their complex needs require more specialised care.

In terms of possible solutions, PCPs suggested to introduce expanded consultations to enable a more holistic approach:

> *"I have scheduled five [instead of six] consultations in one hour, which means that […] my consultations are substantially different. Which means that other things are addressed, which implies that I am able to solve more in just one consultation."* (FG5)

Also, PCPs discussed the importance of involving the informal caregiver in order to discuss the health situation of the patient (in particular for older HNHC patients who have an informal caregiver). At the same time, PCPs report challenges when an informal caregiver has a different opinion on the health status of the patient than the patient has. PCPs furthermore suggested to better integrate disease programmes and integrate care services into accessible multidisciplinary health centres as HNHC patients have diverse and complex needs:

> *"It would be good if, like it used to be, there would be one centre in one community with a GP, with a social worker […] where all disciplines are located. They [the care professionals] are familiar with the community and people can easily come by."* (FG4)

Leadership & governance

PCPs discussed policy efforts that stimulate task referral from settings outside primary care (like residential elderly care or the community setting) to primary care. This generally increases work pressure and complicates care delivery in primary care:

> *"These are the [older-aged] people who used to be institutionalised in a nursing home and who could participate with activities like drinking coffee and knitting, who are now just living alone at home.[...] These are the people who say: "Well, I will visit the GP to check if everything is okay."* (FG5)

Moreover, policy efforts focusing on the introduction of free market principles in health care were mentioned, which have led to an unstable market for home care organisations in the Netherlands, with many mergers and bankruptcies. Consequently, PCPs mentioned that it is challenging to keep an overview of and communicate adequately with home care organisations.

With regards to solutions, PCPs noted the importance of shared decision-making and individualised care planning in order to improve the health of patients. For instance, PCPs suggested to set small and achievable goals for patients and discuss the financial feasibility of examinations with the patient (particularly in case the patient has to deal with poverty).

Workforce

It was reported that communication between different professionals within and beyond the boundaries of primary care is sometimes inadequate. This can lead to inefficiencies in care delivery (e.g. inadequate information sharing). In addition, PCPs miss an overview of the different involved professionals in care delivery. Due to patients' complex needs and the variety of involved care professionals, PCPs moreover experience it as increasingly challenging to function as the 'named coordinator':

> *"There are people [HNHC patients] who see many different medical specialists and then […] it can be very complex, but you [as a PCP] are the coordinator who should maintain the overview."* (FG1)

Due to the increasingly complex and psychosocial demands of HNHC patients, PCPs reported that their traditional role gets expanded. Also, PCPs indicated it as challenging to offer sufficient support to the informal caregiver (of older HNHC patients) during consultations. PCPs furthermore reported that the volume and diversity of the primary care workforce does not always adequately accommodate the growing work pressure. For instance, an insufficient number of PCPs is available in order to be able to expand the consultation time per HNHC patient. In addition, some PCPs discussed that their professional education spend limited attention to psychosocial problems like loneliness.

Related to solutions, PCPs mentioned that cooperation with various disciplines (in multi-disciplinary meetings) is crucial for integrated, high-quality care to HNHC patients. Multi-disciplinary meetings are thought to unite different professional perspectives and enable efficient task division:

> *"I think our practice is very well organised with regards to multi-disciplinary meetings with different disciplines. You take a look at the patient's problems from different professional perspectives and then, yes, you can come up with a solution I think."* (FG2)

Furthermore, many PCPs suggested the introduction of new, expanded roles or a more efficient task division to deal with the increasing complex patient demands and associated workload:

> *"Sometimes I think that someone like this [patient receiving social welfare benefits] should just have a coach, who helps to get their life together. […] not only financially but also to help in making the right decisions, for example finding a job in society."* (FG1)

Financing

PCPs discussed that some important programmes (e.g. social event for older adults) and care services (e.g. physiotherapy) are not sufficiently financially covered and reimbursed generously enough. This implies that these types of services which are required for HNHC patients, due to their complex biopsychosocial problems, may not always be (financially) accessible.

Technologies & medical products

PCPs reported to experience a high burden of (growing) administrative tasks, especially when their general practice is connected to a pharmacy. This results in less available time for patients during consultations. Also, psychosocial patient information is largely lacking in electronic health records (EHRs), although this can facilitate a holistic approach:

> *"It would be very good to have a bit of background information of each patient, like where the patient lives, the household situation, who is the informal caregiver. But it is difficult where to register this information […] as you cannot remember all this information. […] This is a matter of ICT. That is the main barrier."* (FG2)

Some PCPs, on the other hand, commented that the registration of psychosocial patient information may increase the work load. Moreover, PCPs reported that EHRs do not facilitate optimal and most efficient registration or retrieval of relevant patient data. For instance, information for the same patient needs to be registered in different screens. There is also a lack of adequate shared information systems, which leads to inefficiencies and poor inter-professional communication:

> *"We would like those [ICT] systems to be connected to each other. […] The community nurse works with her own [ICT] system and the GPs work with the EHR. If we could connect those to each other. It is just actually three systems to be connected and then it covers it all."* (FG2)

Information & research

PCPs reported to be sometimes uncertain about the data they are allowed to register, for example related to the patient's work-related health issues. In terms of solutions, PCPs discussed the potential added value of stratifying their patient population into risk profiles. This stratification can be used to determine required care and spend more attention to specific patients with high needs.

Discussion

Summary

PCPs experience a comprehensive set of barriers with regards to the delivery of person-centred, efficient care to HNHC patients in primary care. Main barriers and solutions were related to the core of the SELFIE framework (i.e. the individual and his/her environment), as well as to (in particular) four of the six health system components of the framework: service delivery, leadership & governance, workforce, and technologies & medical products. Only a limited number of discussed barriers and solutions were directly related to the components of financing, and information & research.

Strengths and limitations

A strength of this study was that not only experienced barriers but also possible solutions were discussed during interviews. In addition, a relatively large number of PCPs with different professional backgrounds, i.e. GPs and somatic practice nurses, were interviewed. However, another important PCP with regards to care delivery to HNHC patients, the mental health practice nurse[20,23], was missing in the sample as a result of convenience sampling. After all, many HNHC patients have to deal with mental and psychosocial problems which underlines the important role of the mental health practice nurse in their care delivery[15].

Comparison with existing literature

In relation to the core of the SELFIE framework (i.e. individual patient and environment), the current study indicates that HNHC patients generally have to deal with complex biopsychosocial health problems. Often, HNHC patients' ability to deal with these complex problems is further challenged by their environment. For instance, older-aged HNHC patients may have a limited social network, which can lead to psychosocial issues like loneliness. On the other hand, employed HNHC patients may experience challenges in prioritising their health, as they have to balance, for example, work with informal caregiving to family members. The biopsychosocial complexity of HNHC patients as well as their various individual and environmental characteristics that are typically present in HNHC patients is also supported by previous studies[13,14,17,18]. Also, it was previously found that these characteristics can negatively affect a patient's ability to manage his/her health adequately, for instance by limiting the ability to understand and adequately follow treatment advice[19].

The barriers experienced by PCPs are related to different, but in particular four, health system components. This suggests a need for investment in a comprehensive set of interacting health system components to improve care for the HNHC patient population. In the majority of these components, i.e. service delivery, workforce, and technologies & medical products, experienced barriers relate to a micro or meso level. These can be summarised as a lack of time to address psychosocial problems, an insufficient number of PCPs skilled to address the complex, multidimensional needs of HNHC patients, and a lack of efficient inter-professional patient information retrieval and sharing. Only in one of the four most discussed components, i.e. leadership & governance, experienced barriers mainly relate to a macro level: policy efforts that (sometimes unintentionally) stimulate the transfer of complex care tasks to primary care. This may imply that PCPs predominantly experience barriers in the individual interaction with patients and on an organisational practice level. The SELFIE framework nonetheless underlines that integrated care requires alignment of macro level policies and regulations with the lower levels[27]. Only a limited number of barriers relate to the components of financing, and information & research. However, it can be argued that many of the discussed barriers are in fact related to or influenced by the underlying payment system. For instance, in order to stimulate more efficient cooperation and information sharing between disciplines, it is crucial to introduce payments systems that incentivise more collaboration. Also, reimbursement structures should allow the expansion of consultation time in case of complex needs[27]. Smith, et al.[17] have previously argued that although more time for patients with multimorbidity is experienced as a crucial solution, the broad set of additional solutions in particular supports the design of complex, comprehensive interventions.

It should be noted that the current study was conducted in a predominantly rural region in the Netherlands. However, it is expected that the reported barriers are also largely valid for practices located in other, (more) urban regions. After all, the Netherlands is a small, densely populated country, with limited regional differences between general practices, for instance related to PCPs' workload or care coordination[31-35]. The latter has significantly improved in both rural and urban areas due to the introduction of regional primary care groups, currently covering almost the entire country[32-34]. Care groups support practices in offering integrated chronic care under a bundled payment system[32-34]. In addition, several studies found no significant differences between rural and urban regions in terms of PCPs' workload, which is relatively high in all primary care regions[31,35].

Implications for practice and research

Firstly, PCPs should be enabled to spend more attention to the biopsychosocial complexities of HNHC patients, including the individual and environmental characteristics interacting with these complexities. This calls for re-organising primary care internally: taking into account the experienced lack of time, the insufficient number of equipped PCPs and lack of inter-professional information retrieval and sharing is crucial. Secondly, PCPs should be supported in cooperating and communicating more efficiently with health services outside primary care to adequately deliver person-centred, efficient care.

In order to strengthen primary care and stimulate adequate cooperation, a starting point may be to design expanded consultations for HNHC patients which specifically aim at increasing insight into biopsychosocial health issues of HNHC patients. Ideally, these consultations are led by PCPs who are specifically trained in the assessment and coordination of complex biopsychosocial needs. To efficiently assess the biopsychosocial complexities, it may be helpful to use a biopsychosocial assessment tool. An example of such a tool is the Patient Centered Assessment Method, which was designed for "assessing patient complexity in ways that are sensitive to the biopsychosocial dimensions of health"[36]. Informed by the assessment of biopsychosocial complexities, PCPs can determine the type and degree of inter-professional cooperation and communication that is required. A prerequisite for adequate cooperation is to have sufficient insight into involved disciplines and the network of available health services outside primary care. Furthermore, to enhance primary care and stimulate cooperation, several policy efforts need to be aligned. Amongst others, it is important to direct policy efforts at the design of a strong system of social and community services.

Conclusions

The present qualitative study suggests that the current system of care delivery within primary care is insufficiently equipped to accommodate the complex biopsychosocial needs of HNHC patients. To overcome those barriers and work towards the Quadruple Aim, comprehensive strategies are needed that not only strengthen primary care internally, but also support more adequate inter-professional cooperation and communication.

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Part II

Towards a first implementation of the TARGET program in Dutch primary care

Chapter 4

First things first: How to elicit the initial program theory for a realist evaluation of complex integrated care programs

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Milbank Q 2022;100(1):151-189

Abstract

Context

The complexity of integrated care and the need for transferable evaluation insights ask for a suitable evaluation paradigm. Realist evaluation (RE), underpinned by the philosophy of critical realism, is a theory-driven approach that addresses what works, how, for whom, and in what circumstances. The current study illustrates the process needed for RE's first step: eliciting the initial program theory (IPT). The TARGET program, a Dutch primary care initiative to facilitate more integrated care for chronically ill patients, i.e., care that is efficient, tailored, and holistic, was taken as a real-world case.

Methods

An RE approach informed the phased IPT elicitation: (1) identifying an abstract theory framework; (2) formulating the preliminary IPT, building on the abstract theory and informed by previous scientific studies that underpin TARGET; and (3) refining the preliminary IPT, informed by RE expert interviews (*n*=7). An RE heuristic tool, specifying the interplay between intervention-context-actors-mechanisms-outcomes (ICAMO) and retroductive reasoning, was applied to synthesize the underlying theory of individual TARGET components into TARGET's IPT.

Findings

Separate but related IPTs were identified for the two main types of actors involved in TARGET: primary care professionals (PCPs) and patients. For both actors, two sorts of mechanisms are assumed to be activated by TARGET, which—via instrumental outcomes—contribute to long-term quadruple aim targets. The first is confidence to enhance PCPs' person-centered conversational skills and to increase patients' active engagement in TARGET. The second is mutual trust, between PCPs and patients and between PCPs and their network partners. A supportive context is assumed crucial for activating these mechanisms—for example, sufficient resources to invest in integrated care.

Conclusions

Although the IPT elicitation process is time intensive and requires a mind shift, it facilitates a deeper insight into program functioning than accommodated by the prevailing experimental designs in integrated care. Furthermore, the design of a realist-informed evaluation process can be informed by the IPT.

Introduction

For more than a decade, scientific studies investigating the epidemiology of chronic disease have drawn notable conclusions: we face a worldwide "chronic disease epidemic" and "health care crisis"[1-3]. To illustrate this, a recent Global Burden of Disease study concluded that noncommunicable diseases, such as diabetes and respiratory illnesses, were responsible for 73% of deaths around the globe in 2017[2,4]. This epidemic puts tremendous pressure on the sustainability of health care systems. Hence, policymakers and health care providers need to seek strategies that organize and deliver care efficiently with high responsiveness to the needs of people living with chronic diseases[1,3,5].

A widely used strategy to accommodate the high burden of chronic diseases entails adopting an integrated care approach[6-10]. While various definitions of integrated care exist, their common thread is that integration—that is, combining parts to form a whole—is used as a vehicle to enhance care[6-10]. From a health systems' perspective, integrated care is generally characterized by services that are managed along a continuum, coordinated across levels of care, and adapted to patients' personal needs[6,9,10]. When appropriately implemented, integrated care can contribute to the quadruple aim: improving patient experiences, the work life of health care professionals, and population health, while reducing per capita costs[7,11]. Presumably, the growing population with multimorbidity will benefit most from integrated care, as they generally require care from multiple disciplines[12].

Despite receiving widespread support, the evidence base underpinning the effectiveness of integrated care programs remains limited and inconclusive[13,14]. One reason for the limited evidence base relates to inadequate evaluation design choices for these programs. A "pervasive belief in a hierarchy of evidence"[15] often drives researchers to prefer traditional experimental evaluation research designs[13-16]. However, there is increasing awareness of the shortcomings of experimental designs, in particular for complex programs[15-19]. Integrated care programs are considered complex because they require inputs from and interactions between multiple stakeholders, have several interacting program components, and are contingent on the interconnectedness with the health systems and policy environment to work successfully[6-8,13,20]. Experimental designs assume a simple linear model of causality, thus focused on what works in relation to the achieved outcomes. Although this approach can be valuable for "simple" interventions, they are of limited value for interventions of a complex nature such as integrated care programs[15,21]. An appropriate evaluation for complex interventions such as integrated care should not only focus on what works but also provide answers to why, for whom, and under what conditions. Answering these questions could contribute to the current evidence base on integrated care by opening the black box for implementers about how an integrated care program achieves its outcomes and which health systems and policy conditions are conducive[15,16,19].

Critical realism offers a suitable research paradigm for uncovering rich and transferable insights into the effects of integrated care programs, including their causal mechanisms and contextual influences[22,23]. Realist evaluation (RE), a theory-driven approach to program evaluation underpinned by the critical realist philosophy of science, supports the collection of context-linked insights to enhance program implementation[24-27]. The first phase of RE is to elicit the initial program theory (IPT), an underlying assumption of what works in the program, how, for whom, and in what circumstances[24,26]. Eliciting the IPT is a crucial but challenging step in RE and, although support for the use of RE for integrated care evaluation is growing, there is little practical guidance on how to elicit a robust IPT[26,28]. Therefore, we aim to provide insights into the required phased process for eliciting the IPT for an integrated care program in RE. We used the Dutch integrated care program TARGET[29] (Targeting Advanced Resources in General practice to create Efficient, Tailored and holistic care for chronically ill patients) as a real-world case to illustrate this process[30].

Real-world case: The TARGET program

TARGET (see Figure 4.1) was developed in close cooperation with Dutch primary care. The program was theoretically inspired and informed by various scientific studies[30-34]. TARGET is implemented and evaluated in Dutch general practice from 2020 until 2023. Due to the complex nature of the program, the evaluation of TARGET follows the principles of RE[17,18,35].

The TARGET program geographical setting

The TARGET program is implemented in Drenthe, which is a northern, predominantly rural province of the Netherlands. Similar to other Dutch rural regions, Drenthe is confronted with a rapidly aging population that leads to high demands for care[36]. At the same time, young general practitioners (GPs) prefer to settle in urban, more densely populated regions of the country[37]. Hence, this province expects an alarming primary care workforce shortage in the short term[38]. This shows the urgency for this region to invest in an efficient, integrated system of care in order to preserve the quality and accessibility of primary care. In response to this, the primary care group Huisartsenzorg Drenthe (HZD) commissioned authors RS, DH, MK, DR and AE of the current study to develop an integrated care program[39]. Primary care groups unite and consist of various care professionals, primarily GPs[40-42]. They were introduced in the Netherlands during the second half of 2000 and the majority of Dutch general practices are currently connected to a care group[41]. In short, care groups support general practices in delivering disease-specific, standardized chronic care programs for a number of conditions each under a bundled payment system (BPS). The latter means that "the price for the bundle of services (for instance, for diabetes) is freely negotiated by insurers and care groups"[43,44]. Hence, care groups represent affiliated professionals and promote their interests by functioning as the contracting party of bundled payment agreements every year. The aspects of chronic care as described in the standardized programs are delivered either by the care group itself or by other care providers (for instance, physical therapists of dietitians) who are subcontracted by the care group[43,44]. Further details on the role of care groups in the Dutch health system can be read elsewhere[43-45].

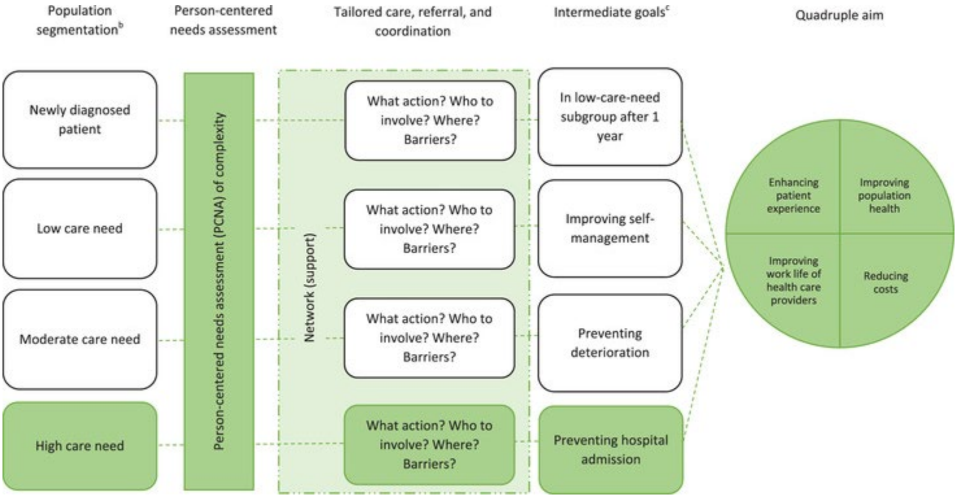

Figure 4.1 Framework of the TARGET Integrated Care Program[a]. [a] The TARGET integrated care program will initially be implemented for the high-care-need subgroup only, highlighted in green; [b] The population segmentation will include all chronically ill patients suffering from at least 1 of 13 common chronic conditions: anxiety dis- order, asthma, atrial fibrillation, overworking/burnout, cancer, chronic neck and back complaints, cardiovascular diseases, chronic obstructive pulmonary disease, dementia/Alzheimer's disease, diabetes mellitus, mi- graine, mood disorder, and peripheral arthrosis; [c] For each subgroup, various intermediate goals can be determined.

The content of chronic care programs is determined by health care standards, which define minimum requirements for high-quality care and specify criteria for improvements[45]. Currently, the primary care group HZD facilitates the delivery of chronic care programs under this BPS for patients suffering from type 2 diabetes, chronic obstructive pulmonary disease, cardiovascular risks, and heart failure, separately. In addition, there is a chronic care program exclusively targeting frail elderly[46].

Description of the TARGET Program

TARGET aims to create integrated care, i.e., care that is efficient, tailored, and holistic, for chronically ill patients suffering from at least 1 of 13 common chronic conditions in the HZD region (see Figure 4.1). The program includes three main program components: (1) population segmentation; (2) person-centered needs assessment (PCNA); and (3) network support. It is assumed that by integrating and streamlining these program components, the TARGET program will contribute to achieving the quadruple aim in the long term[11].

The population segmentation tool, TARGET's first program component, serves to allocate all eligible chronically ill patients to one of four mutually exclusive subgroups (see Figure 4.1). Patients who are chronically ill for less than 12 months are allocated to the newly diagnosed patient subgroup. For patients who are chronically ill for at least 12 months, their subgroup is — in agreement with one of our previous studies[30] — determined based on the number of weighted primary care consultations in the past year: 0-10, 11-20, and more than 20 weighted consultations per patient per year to be assigned to the low-, moderate-, and high-care-need subgroup, respectively[47,48]. The segmentation as conducted by the tool is visualized for the primary care practices in a digital environment.

The second program component of TARGET is a yearly PCNA for patients allocated to the high-care-need subgroup. TARGET initially focuses on these patients to keep the implementation of the program feasible by targeting patients who presumably benefit most from TARGET due to their complex biopsychosocial needs[33,34]. The aim of the PCNA is to enhance primary care professionals' (PCPs) insight into these needs. This insight is needed for PCPs to engage in shared dcision making with patients during the PCNA about the required tailored care, referral, and coordination. In this shared decisionmaking process, the following care-related aspects need to be addressed: nature of care/support to be provided, who to involve in this care/support, where to provide this care/support, and assessment of potential barriers to obtaining this care/support. To conduct the PCNA, an expanded consultation of 30 to 45 minutes between a PCP and a patient will be scheduled. The PCPs will be offered training to enhance their person-centered conversational skills. In addition, they can choose between two conversation tools. The first tool is the My Positive Health conversation tool, which is based on the concept of "positive health" as introduced by Huber and colleagues[49-51]. The second tool is the Patient Centered AssessmentMethod (PCAM) questionnaire and a visualization derived from the questionnaire. The latter also serves to record and evaluate the biopsychosocial complexities and possible actions[52].

The third component of TARGET relates to the provision of support to enhance the network of PCPs: enhancing the insight into, as well as communication and cooperation with, the network. After all, if the PCNA revealed that the patient's needs should be primarily dealt with elsewhere, referral will be facilitated only if a strong network has been composed. Relevant disciplines to be included in this network are, among others, mental health care, community nursing, and social care. The combination of these three program components is assumed to help PCPs to realize the determined tailored care, referral, and coordination, as an intermediate outcome for achieving quadruple aim targets.

Methodological approach

RE, introduced by Pawson and Tilley, is a theory-driven evaluation approach philosophically underpinned by critical realism[19,24,27,35]. One of the tenets of critical realism relates to the understanding that, in society and social activity, both social structure (i.e., the organized set of social institutions and patterns of institutionalized relationships) and agency (i.e., thoughts and actions taken by people) play a key role[53,54]. Structures as well as agents possess generative or causal powers, which are important to consider in understanding and explaining social behavior and change. More specifically, as described by Elder-Vass, "critical realist social theory recognizes that both human individuals and social structures (and indeed entities of other kinds) have causal powers that are distinct from each other, and that both (or all) interact to determine social events—even though human individuals are the parts of the social structures concerned"[55].

Mukumbang and van Wyk[54] argued that these powers only come about and lead to events when certain latent mechanisms are activated under the right conditions. For example, only if a team meeting generates a feeling of belongingness (the mechanism driving change) among team members, then better communication and cooperation are potentially achieved[54]. Because of the importance of generative mechanisms in explaining the occurrence of certain events, critical realist efforts are highly focused on their elicitation. However, traditional and direct empirical methods are often unsuited for understanding these latent mechanisms. Rather, "a combination of empirical investigations and theory construction" is needed[56]. In addition to this, Mukumbang and van Wyk[54] describe that, from a critical realist philosophy, the activation and effects brought about by mechanisms are contingent on contextual conditions[54]. See the Appendix 4A for a more elaborate discussion of the methodological differences between RE and prevailing approaches.

Corresponding to this central understanding of context-dependent mechanisms, RE traditionally uses the context-mechanismoutcome (CMO) configuration heuristic tool to support theory development[19,57-59]. This tool is used to illustrate how under certain conditions (C), naturally occurring mechanisms (M) or those provided by an intervention in the target population are activated to produce certain behaviors or outcomes (O). The RE literature shows small differences in the definitions of *context*, *mechanism*, and *outcome*. In the current study, we used the definitions as presented in a recent study by Mukumbang and colleagues[58] (Table 4.1), which correspond to the work of Pawson and Tilley[59]. In addition, the traditional CMO heuristic tool of Pawson and Tilley is expanded in the present study by adding “intervention” (I) and “actors” (A), as proposed by Mukumbang and colleagues and Marchal and colleagues[60,61]. This results in the ICAMO heuristic tool that will be used throughout this paper. After all, it can be argued that the degree to which outcomes (O) are achieved—by triggering mechanisms (M) under the right conditions (C)—is dependent on the degree to which the intervention (I) is successfully delivered and adopted by the various actors (A) who are involved in the implementation. The elements of the ICAMO tool, which are defined in Table 4.1, can be illustrated by the following simple example:

Regular team meetings (I) organized by a general practitioner (A) at an inspiring location (C) could give team members (A) a feeling of belongingness (M), potentially leading to better communication and cooperation within the team (O).

Table 4.1 Definitions of the Elements Included in the ICAMO Heuristic Tool.

Element of ICAMO Heuristic Tool		Definition
Intervention		A combination of program elements or strategies, in particular, those designed to produce behavior changes or improve health status among individuals or a group
Context		The salient conditions that are likely to enable or constrain the activation of program mechanisms
Actors		The individuals, groups, and institutions that play a role in the implementation and outcomes of an intervention
Mechanisms		Any underlying determinants of social behavior generated in certain contexts
Outcomes	Immediate	The immediate effect of program activities
	Intermediate	Behavioral changes that follow the immediate knowledge and awareness changes
	Long term	Changes in the medium and long term, such as a patient’s health status, and impact on community and health system

Data retrieved from Mukumbang et al.[58]

Methods

We used the ICAMO heuristic tool and retroductive theorizing to elicit the IPT of TARGET. An IPT process consisting of three phases was used, as depicted in Figure 4.2. This process was reflective in nature, implying that the different phases informed each other forward as well as backward.

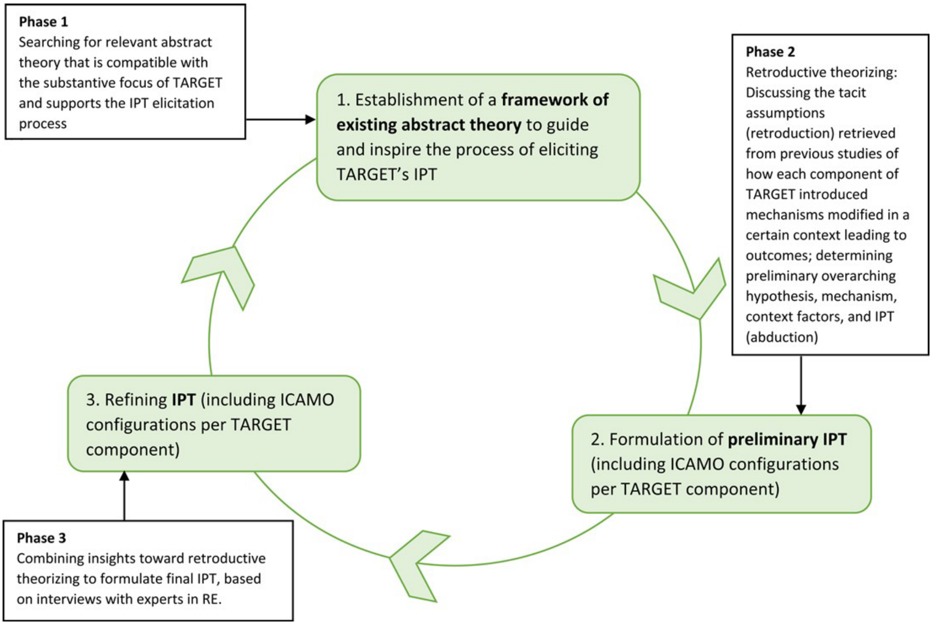

Figure 4.2 The Phased Strategy to Eliciting the IPT for the TARGET Integrated Care Program.

Phase 1: Framework of existing abstract theory

We chose the Comprehensive Theory of Integration proposed by Singer and colleagues to guide the IPT elicitation process.[7] The reasons for this choice were twofold. First, this theory is compatible with the substantive focus of the TARGET program—that is, the investment in integration of care services with the aim of achieving patient-centered integrated care. Singer defines integration as "the making of a unified whole from distinct and interdependent organizational components"[7]. In the field of integrated care, Singer's theory is considered a seminal contribution: it is built on a synthesis of previous theoretical and conceptual efforts in integrated care.

Second, the theory of Singer identifies some elements——constructed as a logic chain—that also have a place in the traditional RE heuristic tool and as such are critical to RE theory formulation: contextual factors, interventions (i.e., integration modalities), and intermediate and final outcomes. According to Singer and colleagues, contextual factors serve as "precursors to organizational (related to structures and systems) and social (related to norms and behavior) types of integration"[7]. By investing in different types of integration, it is assumed that both intermediate outcomes, such as integrated patient care, and final outcomes, such as efficiency, are potentially realized.

It should be noted, however, that Singer's theory also has limitations when assessed using a critical realist lens. This mainly pertains to the generative understanding of causality in RE that is not entirely represented in this theory. It largely overlooks the role of latent, generative mechanisms, such as mutual trust and provider confidence, in explaining the outcomes of integration efforts, and it tends to mainly focus on tangible intervention modalities. Therefore, other sources were needed to unravel the generative mechanisms that impact the hypothesized functioning of TARGET (see phases 2 and 3).

Phase 2: Preliminary IPT

In phase 2, we consulted different scientific studies in the field of integrated care, including our own previous studies[30-34]. These studies, displaying tacit theory, had collectively inspired and informed the composition of TARGET. From these studies, we retrieved insights into potential intervention users (key actors), possible key contextual conditions, and desired outcomes to supplement our developing IPT from Singer's theory.

A recent publication on effective care for high-need patients outlined the feasibility and clinical relevance of a simple stratification of high-need patients according to the type and intensity of expected care needs[31]. Routinely registeredmedical data were taken as a starting point of stratification. Subsequently, functional, social, and behavioral factors were also taken into account for each of the identified subgroups, as these factors are acknowledged as other key drivers of need. This comprehensive insight would subsequently provide guidance to determining tailored care models and care teams. In our first explorative cohort study, described next, we aimed to assess whether such a simple stratification tool, taking routinely registered data as a starting point, was equally feasible and clinically relevant for chronically ill people in the HZD region[30].

The cohort study showed that it is possible to create a segmentation tool that classifies a heterogeneous chronically ill population into three subgroups with varying care needs: low, moderate, and high. Although each subgroup is responsible for exactly one-third of the cumulative care utilization, the number of patients in each subgroup is significantly different[30]. Although the low-care-utilization subgroup includes 63.4% of chronically ill patients, with each consuming approximately five consultations per years, the high-care-utilization subgroup includes 12.3% of chronically ill patients, each consuming approximately 30 consultations per year. Furthermore, each subgroup is characterized by a different set of patient characteristics associated with the level of care utilization each subgroup consumes. Hence, patients in the high-care-utilization subgroup have, in sharp contrast to the low subgroup, individually significantly more chronic conditions and are more likely to be older, to be female, and to have a combination of physical and mental conditions[30].

The latent class analysis expanded on the previous explorative study by identifying, based on combinations of biopsychosocial patient characteristics, different relevant latent subgroups of high-need, high-cost.(HNHC) chronically ill people[33]. HNHC patients were defined as those who belonged to the top 10% of care utilizers and/or had multimorbidity accompanied with an above-average care utilization. This study revealed that the HNHC chronically ill patient population can be divided in four latent classes. The two largest classes, together including almost two-thirds of patients, represent older adults who mainly have physical and age-related conditions (e.g., diabetes, osteoarthritis, and cancer). The two remaining classes, together including more than one-third of patients, represent middle-aged adults who more often have to deal with social welfare dependency and mental conditions (e.g., mood disorders). As such, this study underlined the need to take into account the biopsychosocial diversity of the HNHC population in tailoring care to the complex needs of these patients.

Our third previous study that informed TARGET was a qualitative one: five focus group discussions were organized with 42 PCPs[34]. This study was inspired by the Bridges to Health model, which illustrated how priorities, components of care, and goals can be determined for previously identified subgroups of patients[32]. Corresponding to the approach taken in this Bridges to Health study, we developed case descriptions of typical patients of each of the HNHC classes identified in our previous study. Based on these case descriptions, we initiated a discussion with PCPs on the experienced barriers and possible solutions with regards to person-centered, efficient care delivery to each subgroup of HNHC patients. It was concluded that investment in the organization of primary care, as well as in the communication and cooperation (i.e., healthy collaborations) between primary care and other settings is needed for PCPs to effectively deal with the complex needs of HNHC patients. Thus, general practices need to be provided more consultation time, skilled PCPs, and information and communication technology solutions for efficient information retrieval and sharing. In addition to this, interdisciplinary communication and cooperation should be fostered, which could—among other outcomes—facilitate referral of primarily psychosocial patient needs to other settings.

The ICAMO configuration was used to construct the developing IPT. Authors RS, AE, and DH used several meetings to discuss the tacit assumptions of how each intervention component of TARGET shapes the mechanisms, when introduced in a certain context, and as such potentially leads to outcomes[33]. This was achieved through retroduction, which refers to "the activity of theorizing (and testing) for hidden causalmechanisms responsible for manifesting the empirical, observable world"[62] (see the Appendix 4A for more information)[22,62,63]. Retroduction in RE should be combined with a process of abduction, resulting in socalled retroductive theorizing. Abduction can be described as "inventive thinking required to imagine the existence of such mechanisms"[62] and is needed in order to actually study the mechanisms as identified by retroduction[22,62]. Hence, we applied abductive reasoning by taking a step back and formulating a preliminary overarching hypothesis as well as mechanism and context factors. The preliminary IPT (including configurations per TARGET component) as formulated by authors RS, AE, and DH was discussed with authors MK and DR to reach a consensus.

Phase 3: Refining the IPT

To formulate the final IPT of TARGET, the preliminary IPT (including configurations per TARGET component) that resulted from phase 2 was discussed with seven experts in RE over the course of five interviews: one focus group interview with three experts, and four individual interviews. A priori, we considered five interviews as sufficient to revise the preliminary IPT in a well-informed way. The experts were selected purposively to ensure that each expert had considerable and relevant expertise in RE, preferably related to the field of integrated care or a closely related field of study. Four respondents had two to five years of experience in RE; the other three respondents had seven to ten years of experience in RE. The interviews were conducted in pairs: RS guided the interviews, and AE or DH provided support by asking follow-up questions and taking notes during the interviews. Each interview lasted approximately one hour and was audio recorded. The secured video-conferencing platform Zoom was used to conduct the interviews.

Before the start of the interviews, we prepared respondents by sending them an email in which we explained the reason for the interview and provided a short description of TARGET, along with the preliminary IPT (including configurations per individual component) we formulated. In addition, information was provided on the ethical procedures of the interviews, and we asked participants to return a signed informed consent form before the interview. A structured interview guide was developed, including two topics: methodological validity and substantive judgmental rationality (evaluating the explanatory power of different theoretical explanations to select theories that most accurately represent how and why the program would work)[22,23]. Hence, we asked respondents to comment on the methodological validity of the preliminary IPT from the philosophical standpoint of RE, such as whether the identified mechanisms in the preliminary configurations could indeed be considered mechanisms[35,59,64]. Furthermore, respondents were asked to comment on the IPT, considering their theoretical knowledge of and/or experience with the implementation of integrated care interventions. By applying judgmental rationality one can unearth better or worse arguments on behalf of elicited theories[22,23].

After the last interview, authors RS, AE, and DH discussed whether theoretical saturation was reached and assessed whether additional interviews were needed. Theoretical saturation was determined by considering the degree to which interviews still provided reason to change the direction or consistency of the developing program theory[27,65]. Based on the criterion of theoretical saturation, we decided that no additional interviews were needed.

The ICAMO heuristic tool and the logic of retroduction guided the theory-refining process. The preliminary IPT was refined in a stepwise manner, based on the insights obtained from the interviews. First, author RS combined all insights of the interviews into a data matrix. In this matrix, themain comments, which were categorized as related to either "methodological validity" or "substantial relevance," were specified for each individual preliminary configuration. This helped to identify agreements as well as discrepancies among the comments from the different experts. From these comments, we derived overarching and specific recommendations and lessons to refine our IPT, and we composed an initial draft of the refined configurations, which was discussed with all authors. After formulating the final IPT and configurations per individual component, all configurations were transformed into if…, then…, because… statements[25,66,67]. More specifically, we defined "IF this intervention (I) modality is introduced for these actors (A), THEN this outcome (O) would be achieved, BECAUSE these mechanisms (M) are triggered under particular conditions (C)." These testable hypotheses, which are regarded as "the most basic format for programme theories",[25] aid in formulating underlying program theory in a simple, coherent, and functional way[25,66,67].

Results

Framework of abstract theory

Figure 4.3 shows the theoretical framework that was developed to inspire the RE process, underpinned by the theory of Singer and colleagues[7]. The arrows show the hypothetical relationships that are present according to Singer and colleagues,[7] which move from left to right, but also show directionality or feedback loops. It illustrates that the need to introduce different types of integration in the TARGET program is triggered by contextual factors, see first arrow on the left: among others, inadequate cooperation within primary care as well as between primary care and the network of relevant care and social disciplines. Introducing three program components, the TARGET program would contribute to all five types of integration: structural and functional integration (related to organizational features), normative and interpersonal integration (related to social features), and process integration (related to activities). Doing so is anticipated to contribute to integrated patient care on an intermediate level, and to reach the quadruple aim consequently (arrows 8 and 9).

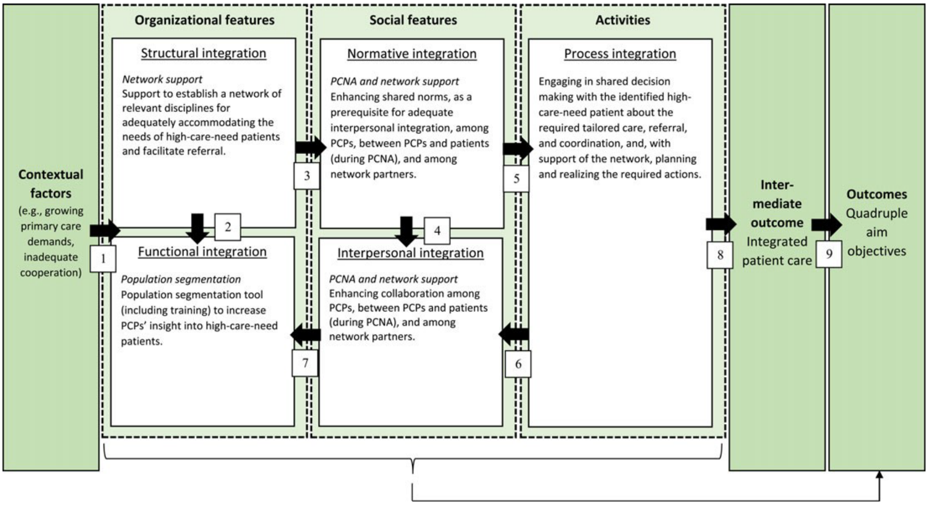

Figure 4.3 Framework of Existing Abstract Theory Underlying TARGET. PCNA, person-centered needs assessment; PCP, primary care professional. Adapted from the "conceptual model of integration types" as introduced by Singer et al.[7]

By offering network support and population segmentation, TARGET aims to invest in structural and functional integration. Hence, in a more direct way, the ties between professionals within and between organizations are strengthened. The segmentation tool would do this within general practice by offering digital information about patients' health care needs to the team of professionals. The network support is focused on creating partnerships between general practice and relevant network partners. This can help to work more functionally integrated (arrow 2). These tangible forms of integration intend to, subsequently, work toward integration on a social level (arrow 3). The PCNA and network support aim to enhance shared norms (i.e., normative integration) which strengthens collaboration (i.e., interpersonal integration) among PCPs, between PCPs and patients (during PCNA), and among network partners (arrow 4). The organizational and social forms of integration would serve as a foundation for integrating care in terms of the process (arrow 5), often referred to as clinical integration: engaging in shared decision making with the identified patients about the required “tailored care, referral, and coordination,” and, with support of the network, planning and realizing the required actions. Arrows 6 and 7 illustrate that the relationship between the different types of integration are bidirectional. Hence, stronger clinical integration would also strengthen shared norms and collaboration (related to social features). This may also enhance the network ties and valuable use of the population segmentation tool (related to organizational features).

Hypothesized functioning of TARGET component 1 from the PCP perspective

Figure 4.4 illustrates how component 1 (population segmentation) would function for the PCP. A population segmentation tool (I) instills confidence (M) in PCPs (A) to successfully identify chronically ill patients who most likely have complex biopsychosocial needs for a PCNA (O) in the context of a heterogeneous chronically ill patient population (C).

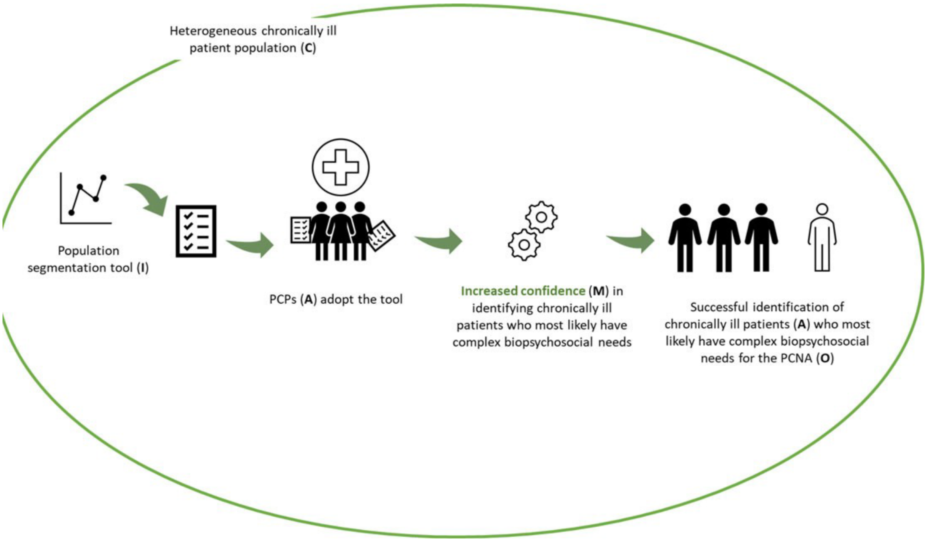

Figure 4.4 The ICAMO Configuration of the TARGET Population Segmentation Tool From the Perspective of the PCP. Abbreviations: I, intervention; C, context; A, actor; M, mechanism; O, outcome; PCNA, person-centered needs assessment; PCP, primary care professional.

Converting this theory into a testable hypothesis using the If…, then…, because… statement, we obtained the following:

> **IF** a population segmentation tool is provided to PCPs,
> **THEN** PCPs can successfully identify chronically ill patients who most likely have complex biopsychosocial needs for a PCNA,
> **BECAUSE** PCPs gained increased confidence in identifying chronically ill patients who most likely have complex biopsychosocial needs, in the context of a heterogeneous chronically ill patient population.

Hypothesized functioning of TARGET component 2 from the PCP perspective

Figure 4.5 illustrates how component 2 (PCNA) would function for the PCP. The PCNA conversation tool and training (I) instill confidence (M) in PCPs (A) to enhance their person-centered conversational skills (O). Enhanced conversational skills (C) incite mutual trust (M) between the PCP and the patient (A), enabling shared decision making about tailored care, referral, and coordination (O).

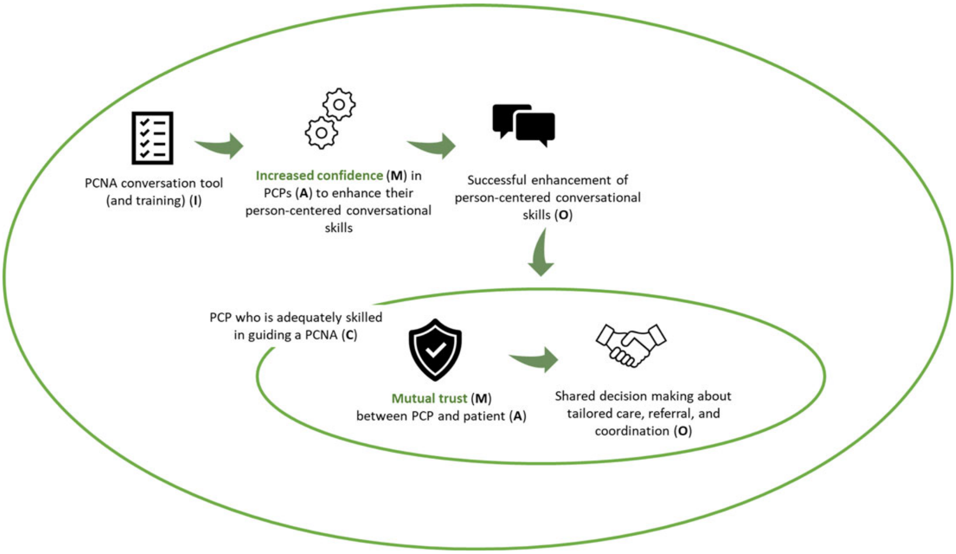

Figure 4.5 The ICAMO Configuration of the TARGET PCNA Tool, From the Perspective of the PCP. Abbreviations: I, intervention; C, context; A, actor; M, mechanism; O, outcome; PCNA, person-centered needs assessment; PCP, primary care professional.

Converting this theory into testable hypotheses using the If…, then…, because… statement, we obtained the following:

> **IF** PCPs are offered a PCNA conversation tool and training,
> **THEN** PCPs are likely to enhance their person-centered conversational skills,
> **BECAUSE** the tool and training instill confidence in PCPs to enhance these skills.
> **THEN**, in a context where PCPs are adequately skilled in guiding a PCNA, PCPs are enabled to engage in shared decision making about the required tailored care, referral, and coordination
> **BECAUSE** mutual trust is incited between the PCP and the patient.

Hypothesized functioning of TARGET component 2 from the patient perspective

Figure 4.6 illustrates how component 2 (PCNA) would function for the patient. Within a context of mutual trust (C), a structured PCNA (I) instills confidence (M) in high-care-need patients (A) to discuss not only biomedical but also psychosocial issues with their PCP (A) in a confidential and open way (O) and engage in shared decision making about the required tailored care, referral, and coordination (O). As a result, patients feel heard (O).

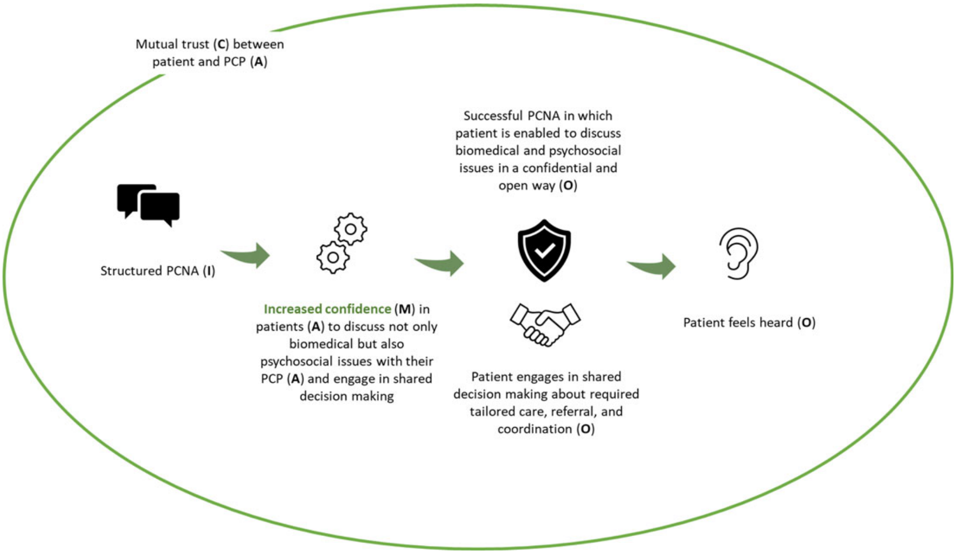

Figure 4.6 The ICAMO Configuration of the TARGET PCNA From the Perspective of the Patient. Abbreviations: I, intervention; C, context; A, actor; M, mechanism; O, outcome; PCNA, person-centered needs assessment; PCP, primary care professional.

Converting this theory into a testable hypothesis using the If..., then..., because... statement, we obtained the following:

> **IF** high-care-need patients are offered a structured PCNA within a context of mutual trust,
> **THEN** patients are offered the opportunity to discuss their biopsychosocial issues in a confidential and open way and engage in shared decision making about the required tailored care, referral, and coordination,
> **BECAUSE** confidence is instilled in patients to openly discuss their problems and engage in shared decision making. As a result, patients feel heard.

Hypothesized functioning of TARGET component 3 from the PCP perspective

Figure 4.7 illustrates how the program component—network support—introduced in component 3 would function for the PCP. The support offered by a "practice consultant" (A) to map PCPs' current network and develop a strategy for enhancing their network relations (I) would enhance mutual trust (M) between PCPs and network partners (A) with regards to communication and cooperation, in a context of sufficient resources within the network to invest in network enhancement (C). As a result, the PCPs' insight into, communication with, and cooperation within the network is improved (O).

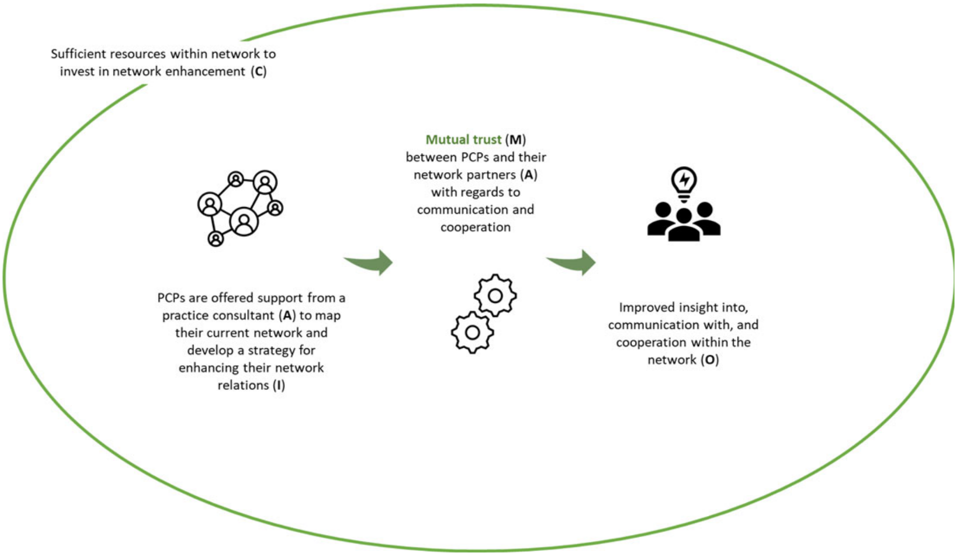

Figure 4.7 The ICAMO Configuration of the Network Support, From the Perspective of the PCP. Abbreviations: I, intervention; C, context; A, actor; M, mechanism; O, outcome; PCP, primary care professional.

Converting this theory into a testable hypothesis using the If…, then…, because… statement, we obtained the following:

> **IF** PCPs are offered support from a practice consultant to map their current network and jointly develop a strategy for enhancing their network relations,
> **THEN** their insight into, communication with, and cooperation within the network will be improved,
> **BECAUSE** mutual trust is—in a context where the network has sufficient financial resources to invest in network enhancement—incited between PCPs and their network partners with regards to communication and cooperation.

Hypothesized functioning of TARGET for PCPs

Figure 4.8 illustrates how the TARGET program would function (i.e., the overarching IPT) for the PCP. In the context of involved parties (e.g., patient population, practices, network partners) who have sufficient resources to invest in integrated patient care (C), the TARGET program offers PCPs (A), through the population segmentation and PCNA tools as well as support to enhance their network (I), opportunities and resources to identify efficiently patients with complex biopsychosocial needs (O), engage in person-centered and cooperative health care (O), and enhance the functioning of their network (O) as these tools incite confidence (M) in the PCPs and mutual trust (M). The TARGET program, therefore, empowers PCPs to offer integrated patient care (O) to high-care-need patients, thereby reducing PCPs’ work pressure and improving their work life (O). In the current study, integrated patient care is defined as “care that is efficient, tailored, and holistic.”

Converting this theory into a testable hypothesis using the If…, then…, because… statement, we obtained the following:

> **IF** PCPs are offered tools and support for population segmentation, PCNA, and network enhancement,
> **THEN** PCPs are provided opportunities and resources to efficiently identify patients with complex biopsychosocial needs, engage in person-centered and cooperative health care, and enhance the functioning of their network,
> **BECAUSE** these tools and support incite confidence in PCPs, and mutual trust (both between PCPs and patients, and PCPs and their network partners), in a context of sufficient financial resources among all involved parties to invest in realizing more integrated patient care. As a result, PCPs are empowered to offer integrated patient care to high-care-need patients, thereby potentially reducing PCPs’ work pressure and improving their work life.

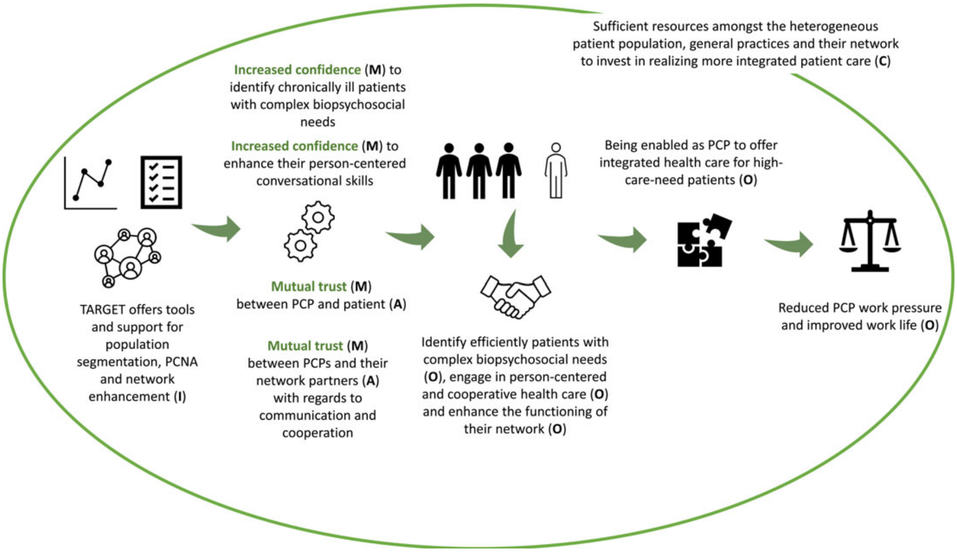

Figure 4.8 The ICAMO Configuration of TARGET's IPT from the Perspective of the PCP. Abbreviations: I, intervention; C, context; A, actor; M, mechanism; O, outcome; PCNA, person-centered needs assessment; PCP, primary care professional.

Hypothesized functioning of TARGET for patients

Figure 4.9 illustrates how the TARGET program would function (i.e., the overarching IPT) for the patient. In the context of mutual trust (C), the TARGET program offers patients with complex needs (A), through the PCNA (I), the feeling of being heard (O), as the PCNA incites confidence (M) in patients (A) to discuss not only their biomedical but also their psychosocial issues (O) and engage in shared decision making (O). In a context where patients feel heard and there is an efficiently organized practice and available network (C), confidence (M) is incited in patients that their required care will be delivered in an integrated, personcentered way, thus improving individual patient experience and, in the long term, patient population health (O).

Converting this theory into testable hypotheses using the If…, then…, because… statement, we obtained the following:

> **IF** high-care-need patients are engaged in a structured PCNA within a context of mutual trust,
> **THEN** patients will feel heard,
> **BECAUSE** the PCNA incites confidence in patients to discuss their biopsychosocial issues and engage in shared decision making.

THEN individual patient experience and, in the long term, patient population health is improved,
BECAUSE confidence is incited in patients that, in a context where patients feel heard and an efficiently organized general practice and network is available, their required care will be delivered in an integrated, person-centered way.

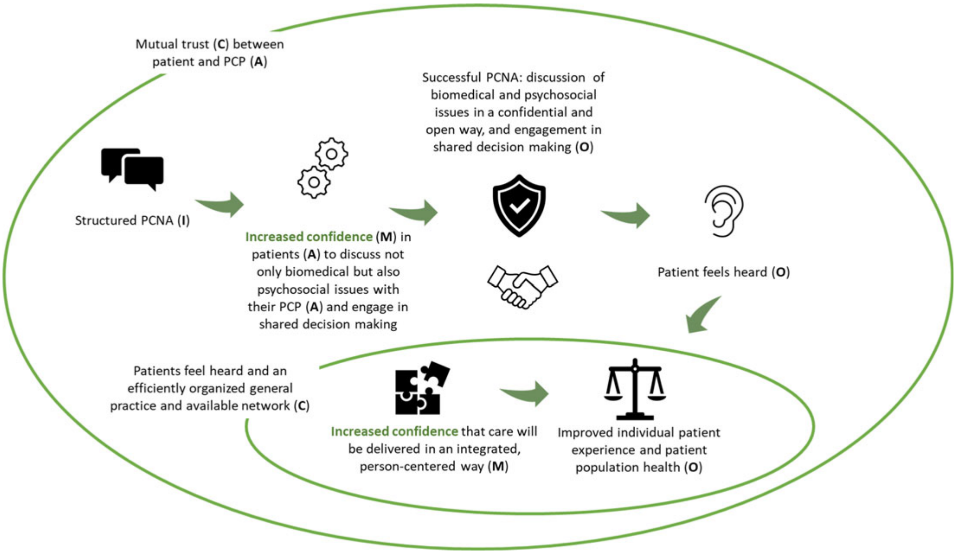

Figure 4.9 The ICAMO Configuration of TARGET's IPT From the Perspective of the Patient. Abbreviations: I, intervention; C, context; A, actor; M, mechanism; O, outcome; PCNA, person-centered needs assessment; PCP, primary care professional.

Discussion

In this paper, we illustrated how to derive an IPT for a complex integrated care program, as a first crucial step toward conducting an RE. The TARGET integrated care program, a Dutch primary care initiative to facilitate more efficient, tailored, and holistic care for chronically ill patients, was used as a real-world case to illustrate this process. By adopting the ICAMO heuristic tool and inspired by retroductive reasoning, ICAMO configurations of TARGET's three individual program components were established: population segmentation tool, person-centered needs assessment, and network support. Configurations of individual components were systematically synthesized into two separate but complementary IPTs, one for each main type of actor involved in TARGET: PCPs and patients. We identified two main mechanisms that are hypothesized to be activated by TARGET: confidence and mutual trust. These two are assumed to contribute—via instrumental outcomes—to the achievement of long-term quadruple aim targets. It is hypothesized that these mechanisms are only activated within a supportive context—for example, sufficient resources to invest in integrated care.

The IPT identified in this study shows how different types of integration, as identified by Singer and colleagues[7] and classified as organizational, social, and related to activities, would be enhanced by introducing the TARGET program in general practice. Although TARGET would focus on all five types of integration as deemed important by Singer, integrating in terms of social features (i.e., stimulating shared norms and cooperation) is most elaborately addressed by the program's components, as compared to the limited set of organizational integration efforts included in TARGET. Previous research suggests that organizational and social integration reinforce each other toward delivering integrated care and reaching improved outcomes, underlining the importance of investing equally in both forms of integration[7,68-70]. Hence, it is worth considering to expand the TARGET program in the future with additional organizational integration components, informed by the unfolding RE. For example, as elaborately described by Embuldeniya and colleagues,[68] introducing an integrated funding model as a new intervention may be a valuable addition. A bundled payment model already exists in the Netherlands for various disease management programs for common chronic conditions[43,45]. However, this model is criticized for facilitating integration between only a limited number of care professions and primarily in a single setting (i.e., primary care)[71,72]. As TARGET aims to facilitate collaboration and integration between a wide variety of disciplines and across health and social care settings, the current payment model would thus need revision and a broader scope to be a suitable new intervention modality.

Methodologically, this paper illustrates how the RE approach can help create insight into the often implicit theory underlying a program. In doing so, RE has the potential to reach a deeper insight into program functioning than allowed for by the prevailing evaluation approaches in the field of integrated care, which have relied on mostly controlled studies[13-15,21,73]. More specifically, experimental designs with a linear model of causality have a substantially different methodological standpoint about central RE concepts, such as mechanisms and contextual drivers of change[21]. For instance, experimental designs do not put generative mechanisms at the heart of behavior change and evaluation efforts. Rather, "experimental designs, especially RCTs [randomized controlled trials], consider human desires, motives and behavior as things that need to be controlled for"[21]. Likewise, context is not considered a central aspect of program functioning, which would determine whether or not mechanisms fire. Hence, in experimental designs, "the influence of context will be levelled out by, for example, including study sites whose contexts are broadly comparable"[21].

For the field of integrated care, new insights and lessons can be distilled from the presented, hypothesized IPT. First, the IPT suggests that there are certain mechanisms in TARGET that are activated under specific circumstances. These mechanisms in turn influence the different types of actors and lead to predefined outcomes. While TARGET's program components are considerably different from a substantive point of view, two types of overarching mechanisms are triggered: confidence and mutual trust. This corresponds with previous realist-inspired work in the field of integrated care addressing ***how*** initiatives work[68,73,74]. For instance, a realist synthesis by Tyler and colleagues identified "four consistent patterns of care that may be effective" in six unique social pediatric initiatives[74]. Similar to our findings, these include bridging trust and practitioner confidence, among others. Another realist review, by Kirst and colleagues, also identified "trusting multidisciplinary team relationships" as one of two overarching mechanisms in 28 integrated care programs[73]. At the same time, it should be acknowledged that evidence on crucial mechanisms in integrated care is scarce. This can be explained in part by the novelty of RE for the field of integrated care. Consequently, a generative understanding of causality, including the notion of mechanisms, is not yet integrated in much of the existing integrated care studies and theoretical frameworks[73]. For example, the theory on integration as introduced by Singer and colleagues does not explicitly acknowledge the potential role of generative mechanisms.[7] Nevertheless, particular concepts that may be closely related to mechanisms such as norms and collective attitude are discussed in Singer's theory[7]. Moreover, as found by Astbury and colleagues, typical RE concepts like mechanisms are still ambiguously conceptualized and used[75]. More specifically, the key features of mechanisms—that they are usually hidden, sensitive to variations in context, and may generate outcomes—are not always acknowledged[75]. As a result, RE studies have often conflated observable intervention modalities, modes of implementation, and activities with mechanisms[57,75]. This limits the usefulness of existing RE studies to inform future RE studies in the field of integrated care.

A second new insight for the field of integrated care, as retrieved from the presented IPT, relates to the hypothesized conditionality between context and outcomes, both within and between TARGET's program components. Singer's theory does acknowledge the relationship between context and outcomes in integrated care: the former would serve as the precursors to different types of integration and would, as such, indirectly trigger desired outcomes[7]. TARGET's IPT adds to this existing theory by suggesting that a new context is shaped by preceding intermediate outcomes. As such, the required circumstances are shaped in which the next mechanisms can be triggered, potentially leading to the desired final outcomes. For instance, an accommodating context would be shaped by the intermediate outcome, i.e., feeling heard, of the preceding PCNA for patients. This context would serve to trigger the next mechanism: confidence to receive integrated, person-centered care. By activating this mechanism, long-term outcomes, i.e., improved patient experience and population health would eventually be achieved. In realist literature, this is referred to as the ripple effect[76]. Underlying the ripple effect, there is the perception of an intervention as a "critical event in the history of a system, leading to the evolution of new structures of interaction and new shared meanings"[76,77].

Our in-depth, theorized insight into program functioning at the developmental stages can help to shape subsequent monitoring and evaluation efforts of the TARGET program when implemented. RE takes a more neutral position toward methodology than methodoriented approaches to evaluation[19,26]. Hence, a broad range of methods may be useful, but the chosen research methods must have the potential to substantiate the complex ICAMO in play[26]. This implies that traditional methods, tools, and analysis techniques may need to be adjusted to ensure that the RE philosophy is adequately accommodated[26]. An example of such an adjusted method is the realist, theory-driven interview, introduced by Pawson[78]. This technique requires that the interviewer first takes on a role to teach the respondent about the hypothesized program theory[78]. Subsequently, the respondent would "teach the evaluator about those components of a programme in a particularly informed way"[58,59,79]. As such, the developing program theory can be further refined. Qualitative methods are most commonly used in realistinspired studies in the health sector[79]. This seems defensible, given the latent nature of mechanisms.79 Still, to obtain insights into all elements of an RE heuristic tool, it is suggested to not only use a mixture of different methods and methodologies, but also to collect rich data: "Substantial amounts of primary or secondary data are needed—even when the sample is small—to move from constructions to explanation of causal mechanisms"[79].

A strength of the current study is that information was derived from multiple sources to elicit the IPT: existing theory on integration, previous studies into integrated care, and expert interviews. The different sources provided various abstract and/or tacit theoretical insights that contributed to a rich and reflective elicitation process. However, several limitations regarding the choice of data sources for IPT elicitation in this study are noteworthy as well.

Unlike other IPT elicitation studies, the current study was not informed by a realist synthesis of previous, comparable integrated care studies[67,80]. However, in different methodological steps, insights from existing integrated care literature were implicitly integrated. First, we used a widely known and applied theory on integration by Singer and colleagues, which itself is underpinned by a comprehensive synthesis of integrated care literature[7,81]. Second, existing integrated care literature, including our own studies informing TARGET, were consulted in phase 2 and helped in composing the preliminary IPT[30-34]. Third, the preliminary IPT was discussed with several experts who themselves have experience with specific programs in the field of integrated care and are informed of the functioning of comparable programs described in the literature. Given these steps, and considering the novelty of RE for the field of integrated care and prevailing misconceptions about RE concepts (in particular, mechanisms), we question to what degree a dedicated literature synthesis would have added further valid new insights to our IPT[57,75]. However, a broad literature synthesis could provide insight into promising new intervention components, resources, and related outcomes. Hence, although a realist review may not have led to significantly new insights for the IPT at this stage of the process, it may serve as a source of inspiration for the developing TARGET program and could be added in the subsequent stages of the RE process. A variety of other methods are needed in addition to this review, to ensure a reflective, robust evaluation process that addresses all different aspects of the evolving program theory. Examples are realist interviews with professionals and patients, observations of PCNAs, and analyses of PCAM results.

Another limitation pertains to the early phase, before implementation of TARGET, in which the IPT was formulated. As a result, the developing IPT could not be informed by preliminary evaluation insights—for instance, experiences of program users. Unraveling the IPT preimplementation, however, allows for subsequent evaluation efforts to explore the degree to which the hypothesized IPT is valid in practice. To this end, in-depth theory-driven realist interviews with program users, besides the range of other methods as described herein, will be a particularly important new source of information.

Conclusions

Rethinking the conceptualization of causality and evaluation of complex interventions within the critical realist paradigm has paved the way for RE. Methodologically, the RE approach is useful for unraveling why and how programs work, questions that are often left unaddressed when adopting a traditional, experimental design. Furthermore, the presented IPT in this paper has shed light on new theorized insights for the field of integrated care—that is, the overarching types of mechanisms (confidence and mutual trust) as well as the conditionality between context and outcomes. Above all, unraveling a program's IPT prior to implementation can inform robust evaluation processes and maximizes the opportunity to gather transferable insights. Hence, we conclude that putting "first things first,"—that is, eliciting the IPT for a theory-driven understanding of how and why complex programs work—is a methodological asset to the field of integrated care.

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Appendix 4A Methodological Comparison of RE With Traditional Evaluation Approaches

When compared to traditional, experimental approaches to evaluation, RE has a significantly different way of preparing, conducting, and optimizing the evaluation of an innovation[15,27]. This can be traced back to a distinct philosophical standpoint and understanding of causality. A linear, successionist understanding of causality is inherent to experiments[15,27]. This implies "that causality is established when the cause X is switched on (experiment) and effect Y follows"[27]. Within RE, the relation between what is offered and changed as part of a program and what (intendedly) comes out, is perceived as much more complex. Program effects are assumed to depend on whether the right intervention resources, within a supporting context, are able to *generate* mechanisms in the right actors. Hence, a generative notion of causality is what defines RE[15,27]. These fundamentally contrasting standpoints can be clarified and illustrated by the resulting difference in the mode of inference, as well as the use of visual representations to guide program planning and evaluation.

Induction and deduction are dominant modes of inference in scientific research[62]. Both modes are built on the assumption that empirical observations, from which evidence can be generated, play a key role in inference making. In induction, evidence derived from "studying one or many cases"[62] is used to come to general theories. In an opposite direction, deduction takes theory as a starting point and aims to test this theory by studying and generating evidence from specific cases[62]. In scientific realism, these modes are criticized in the light of so-called inference sufficiency. This means that both induction and deduction would be "insufficient for analyzing ontologically deep phenomena and risk creating scientific outputs that are ontologically flat"[62]. Realism assumes a deeper, latent, and difficult-to-observe layer of mechanisms playing a key role in how behavior is changed and programs work. Thus, it is key to adopt a mode of inference suited to move beyond that empirical, objective layer of reality. Therefore, the retroduction mode of inference is advocated in realism[22,62,63,82]. This is referred to as "the activity of theorizing and testing for hidden causal mechanisms responsible for manifesting the empirical, observable world"[62]. Retroduction is often alternated with and reinforced by another mode of inference called abduction. This last mode helps to creatively think about, imagine, and reconceptualize the mechanisms that were retroductively theorized[62].

Various ways of visualizing program components, their functioning, and their intended achievements, exist. Perhaps most well known and commonly used is the logic model[83-85]. A logic model is described as "a systematic and visual way to present and share your understanding of the relationships among the resources you have to operate your program, the activities you plan, and the changes or results you hope to achieve"[83].

To some extent, logic models show similarities with the visual representations as composed and presented in the current RE paper. Both ways of visualizing intend to clarify and simplify how the different components of a program should be positioned in relation to each other. Doing so can help to guide and plan the evaluation process. However, there are also important differences that reflect a different way of looking at an innovation, what defines its success, and how an evaluation process should be designed.

First, logic models present all kinds of program components (e.g., resources, activities, outputs) that are tangible and can be measured and monitored empirically and objectively. For instance, in a recently developed logic model for an integrated care program, different partnerships are identified as important inputs, without explicating the mechanisms and contextual influences determining the success of these inputs[85]. RE representations present a deeper, latent layer of generative mechanisms, which are positioned at the heart of program functioning, hence the visual representation.

Second, while evaluation efforts preceding and following development of a logic model may take into account the embeddedness of an intervention into an existing and dynamic context, contextual influences are not always explicitly visually included. In RE, however, context is perceived as an overarching layer that must never be overlooked, as it determines whether mechanisms fire or not.

And third, logic models are presented in a linear way. Inputs, activities, outputs, outcomes, and impact are positioned in a straight line, and models should be “read from left to right”[83]. The RE visualizations highlight the complex, nonlinear functioning of a program and the assumption that the outcomes of one program mechanism can lead to changed contexts in which new mechanisms may be triggered, referred to as the ripple effect[76].

Chapter 5

The Patient Centered Assessment Method (PCAM) for action-based biopsychosocial evaluation of patient needs: validation and perceived value of the Dutch translation

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Int J Environ Res Public Health 2021;18(22):11785

Abstract

The Patient Centered Assessment Method (PCAM) is an action-based tool that supports professionals to engage in a biopsychosocial assessment with patients and measure their needs. It is a promising tool for person-centred care. As the Netherlands lacks such a tool, a Dutch version was developed. Furthermore, we aimed to contribute to the relatively limited insights into the psychometric properties and value of the tool when used as part of a needs assessment in primary care. Confirmatory factor analysis was used to study construct validity and Cronbach's alpha was computed to assess reliability. Furthermore, we interviewed 15 primary care professionals who used the PCAM. It was confirmed that each PCAM domain measures a separate construct, informed by the biopsychosocial model. The tool showed adequate reliability (Cronbach's alpha = 0.83). Despite face validity concerns, the tool was mainly valued for measurement of patient needs and to facilitate action planning. Criticism on the PCAM pertained to a limited focus on the patient perspective, which is one of the crucial aspects of person-centred care. These rich, mixed-method insights can help to improve the value of the PCAM, as one of the few multifunctional tools to support professionals in holistic assessments.

Introduction

The Patient Centered Assessment Method (PCAM) was developed by Maxwell and colleagues in 2013 to support holistic assessment of biopsychosocial patient needs in primary care[1,2]. The PCAM includes 12 items clustered into four domains, i.e. health and well-being; social environment; health literacy and communication; and service coordination. Each item is scored using a four-point traffic light-style system indicating the growing need for (professional) action, ranging from 'routine care', 'active monitoring' and 'plan action' to 'act now[1]. Hence while the PCAM is primarily a conversation tool to take a comprehensive, person-centred approach to patients, it also supports measurement and monitoring of patient need[1]. To make a shared decision about the required 'actions' (e.g. referral, behaviour change intervention) for a patient, also called action planning, the tool ends with four questions. These relate to what action is needed, who needs to be involved, what barriers exist, and what action will be taken.

Although the PCAM was originally designed for primary care, insights into the feasibility and perceived value of applying the tool in this setting are relatively scarce. A substantial part of the existing studies of the instrument have been conducted in the context of transitional or hospital care[3-6]. However, available primary care studies conclude that PCAM is a feasible and valuable tool that supports holistic assessment and allows for referral to a spectrum of services[1,2,7]. Insights into the psychometric properties of the tool are also relatively sparse and ambiguous. While existing studies conclude that the PCAM has good internal consistency, insights into the theoretical constructs (also described as 'factors') measured by the tool are conflicting[1,5]. Maxwell, et al.[1] studied a former version of PCAM and concluded that the domains 'health and well-being', 'social environment' and 'health literacy and communication' each constitute a separate theoretical construct, followed by one question related to required actions. In contrast, Yoshida, et al.[5] distinguished two constructs underlying the current 12-items PCAM tool. These were 'patient-oriented complexity', related to internal health determinants (e.g. health literacy) and 'medicine-oriented complexity' related to the external health determinants (e.g. service coordination).

Professionals need support to engage in holistic conversations with patients, but a valid, reliable and feasible tool that is sensitive to the biopsychosocial needs of patients is still missing in the Netherlands[8,9]. Therefore, we aimed to (1) translate and contextualize the PCAM for use in Dutch primary care. Furthermore, as there is a knowledge gap concerning the psychometric properties and value of the PCAM in primary care, we formulated two additional research aims relevant for an international context: (2) to increase insight into the psychometric properties, i.e. the (construct) validity and reliability of the tool, by testing and comparing both previously identified factor structures to determine the best-fitting structure[1,5]; and (3) to assess the perceived value, feasibility and face validity of the PCAM when used to support a person-centered needs assessment as part of the TARGET integrated care program.

PCAM: theoretical foundation

The theoretical foundation of the PCAM builds on the INTERMED and Minnesota Complexity Assessment Method (MCAM), from which the tool originated[1,10-13]. As the MCAM was an American tool, it needed adaptations and new validation analyses in order to be applicable to a UK setting[1,2]. This led to the PCAM, which is an adapted version of the MCAM. The name of the tool was changed in order to move from a focus on 'complexity' to an emphasis on 'patient centeredness'[2]. Biopsychosocial complexity, described as "the interaction of biological (medical), psychological and social problems with a person's health" is a central theoretical concept within the PCAM[1]. In particular, Engel's biopsychosocial model of illness supports the operationalisation of the biological and psychological dimensions (i.e. the domain of 'health and well-being') as well as the social dimension (in the domain of 'social environment') of health and complexity[14]. As such, using the PCAM may help to deliver person-centred care, by taking the biopsychosocial needs, values and preferences of individuals as starting point for collectively determining required referrals or other follow-up actions[15,16]. Although the evidence is (still) limited, person-centred care potentially improves quality of care and may lower work pressure in primary care when referrals following a PCAM assessment, for example to social care, are successful[17-19].

TARGET program for integrated, person-centred care

We translated and psychometrically tested PCAM in the context of a recently developed Dutch integrated, person-centered care program called TARGET[20]. TARGET is the acronym for 'Targeting Advanced Resources in General practice to create Efficient, Tailored and holistic care for chronically ill patients'. This program was piloted from September 2020 to March 2021 in seven general practices located in the north of the Netherlands, where TARGET was developed. Data gathered during the pilot were used for psychometric assessment of the Dutch version of the PCAM. According to the Medical Research Committee Academic Hospital Maastricht/University Maastricht, the Netherlands, this pilot study was not prone to ethical review as the Dutch Medical Research (Human Subjects) Act (WMO) does not apply (#10117; July 21, 2020).

The development of TARGET was initiated by primary care group 'HZD', located in a northern, predominantly rural area of the Netherlands. In brief, care groups support affiliated practices in organising and delivering high-quality care to chronically ill patients. See Appendix 5A for more information about the role of care groups in the Netherlands and the Dutch primary care system in general. The TARGET program aims to facilitate care that is person-centered and delivered in an integrated way, thereby working towards better results in terms of the Quadruple Aim[21]. Although TARGET is intended for all chronically ill, the program was – for feasibility reasons – initially piloted among the subgroup with high care needs, as part of a larger-scale, ongoing realist evaluation. More information about how we selected high care need patients and the working mechanisms of TARGET can be found elsewhere[20,22]

PCAM was introduced in the TARGET program to facilitate a so-called person-centered needs assessment (hereafter referred to as 'needs assessment'). This is a comprehensive conversation with a patient in general practice that takes about 30 to 45 minutes and is led by a trained care professional. Depending on the practice, this can be a general practitioner (GP) or practice nurse. The purpose is to discuss a patient's biopsychosocial needs and subsequently use the PCAM's action planning section to engage in shared decision-making about required follow-up actions. The PCAM served, for all seven practices, as a tool to measure the biopsychosocial needs as identified during the needs assessment, and make a shared decision about and register an action plan. A separate website was built to facilitate digital completion and retrieval of the PCAM. When professionals clicked on one of the answering options of the digital PCAM, the corresponding traffic light-color appeared. This website also provided a list of high care need patients which served to help professionals to select eligible patients for the needs assessment. For every high care need patient, a page with additional (visual) information about his/her care use during the previous year was available. Examples of provided information are the types of health problems for which a patient visited the primary care practice.

The 'My Positive Health' tool served as primary conversation tool to support professionals and patients to engage in the needs assessment. This tool is derived from the 'positive health' concept as introduced by Huber and colleagues[23,24]. The main reason for choosing this instrument as primary conversation tool, was that most practices were familiar with the concept and some practices already had positive experiences with using the tool. Professionals received a needs assessment training in which they learned interview techniques inspired by 'positive health' and how to use the related tool during the needs assessment. The PCAM could be used by practices as complementary conversation tool.

Materials and methods

Translation and contextualization

For the translation of the PCAM, guidelines as specified by the WHO were used[25]. Hence, our main goal was to reach cross-cultural and conceptual equivalence of the tool, rather than linguistic/literal equivalence. In agreement with WHO guidelines, a three-stage process was followed: (1) forward translation; (2) expert panel back-translation; and (3) pre-testing and cognitive interviewing[25].

In the first stage, author DH – whose mother tongue is Dutch, but is fluent in English – independently conducted a first forward translation of the PCAM into Dutch[25]. Authors RS and AE subsequently reviewed the translation and checked if any inadequate expressions were used or discrepancies existed between the translation and original PCAM. A bilingual expert panel was composed, consisting of the three authors (RS, DH, AE) involved in the forward translation, to reach consensus on a final forward translation of the PCAM. In stage 2, back-translation of the tool was conducted by an independent professional translator whose mother tongue is English and who was unfamiliar with the PCAM. Back-translation results were discussed and any identified discrepancies were resolved between the independent translator and authors RS, DH and AE[25].

Finally, the translated tool was pre-tested with the target population (stage 3), i.e. Dutch primary care professionals involved in needs assessment as part of the TARGET pilot study. All professionals of the seven general practices were invited for an in-depth interview, organised per general practice, about the comprehensibility and contextual relevance of the translated PCAM. We developed a case description of a typical Dutch chronically ill patient with high care needs who is primarily monitored by the GP. The case description contained information about the patient's biopsychosocial complexity, such as the number and type of conditions, latest blood values, housing circumstances, social network, and health literacy[26]. The Dutch case description was inspired by one of the patient cases offered by the University of Minnesota as training materials for PCAM users[26]. Before the interviews, respondents were asked to fill in the PCAM tool based on the provided case description. Either author DH conducted the interviews individually, or authors RS and DH collectively. Each interview started with general questions about how professionals experienced completing the PCAM (i.e. based on the case description) and what their impression of the tool was. After that, each individual PCAM item and corresponding answering categories were discussed, by asking professionals (1) to describe in their own words what the item addresses; (2) what answering category they chose; (3) how they chose their answer; and (4) if there were any unclear or contextually irrelevant words or phrases. The interviews were performed either digitally, using the videoconferencing software 'Zoom', or via telephone. After finishing the interviews, authors RS, DH, and AE discussed the comments raised by the target population and composed a final version of the translated PCAM.

Psychometric properties

Population

Chronically ill with high care needs were included in the TARGET pilot study, hence considered eligible for the needs assessment, if they were at least 18 years old and had sufficient mastery of the Dutch language. Patients who received palliative care and/or were institutionalized during the pilot study were excluded from the program. For psychometric testing, we used the PCAM results (i.e. 12 items, scored on a 4-point scale) of all patients who received a needs assessment during the pilot. From the electronic health record, we retrieved the following descriptive patient information: age, sex, weighted care utilization during the year preceding the needs assessment, number of chronic conditions, type of chronic conditions (only physical, only mental, combination of both), and prevalence of 28 common chronic conditions. All variables were measured at the time of the needs assessment. As we need the robust weighted least squares (WLS) estimator for a confirmatory factor analysis (CFA) of a tool with ordinal response categories like the PCAM, we considered, a priori, a minimum sample size of 200 patients for whom the PCAM was completed as sufficient[27-29].

Analysis

Psychometric testing started with assessing the general properties, also called data quality, of the PCAM tool, as an indication of how well the translation and contextualization was performed. Hence, we computed frequency distributions of the answers to each PCAM item, to assess if the complete range of answering categories was used[30]. We assessed the number of missing values and calculated the median and mode score for each PCAM item.

In terms of validity, the PCAM's construct validity was assessed by performing a CFA. Factor analysis assumes that "measurable and observable variables can be reduced to fewer latent variables"[31]. Both of the previous factor structures as identified by Maxwell, et al.[1] and Yoshida, et al.[5] were tested in a CFA. See Figure 5.1 for a more detailed specification of the two tested structures and related PCAM items. Maxwell, et al.[1] originally did not perceive the latter domain, then mentioned 'action' and consisting of one item, as a separate and fourth construct. However, as this domain was further developed, called 'service coordination' and expanded with one item in the current version of the PCAM, we hypothesize that the latter domain constitutes an additional, fourth theoretical construct[2]. Hence, we tested a four-factor structure, consistent with the three-factor structure as identified by Maxwell, et al.[1], but expanded with a separate factor for the latter domain.

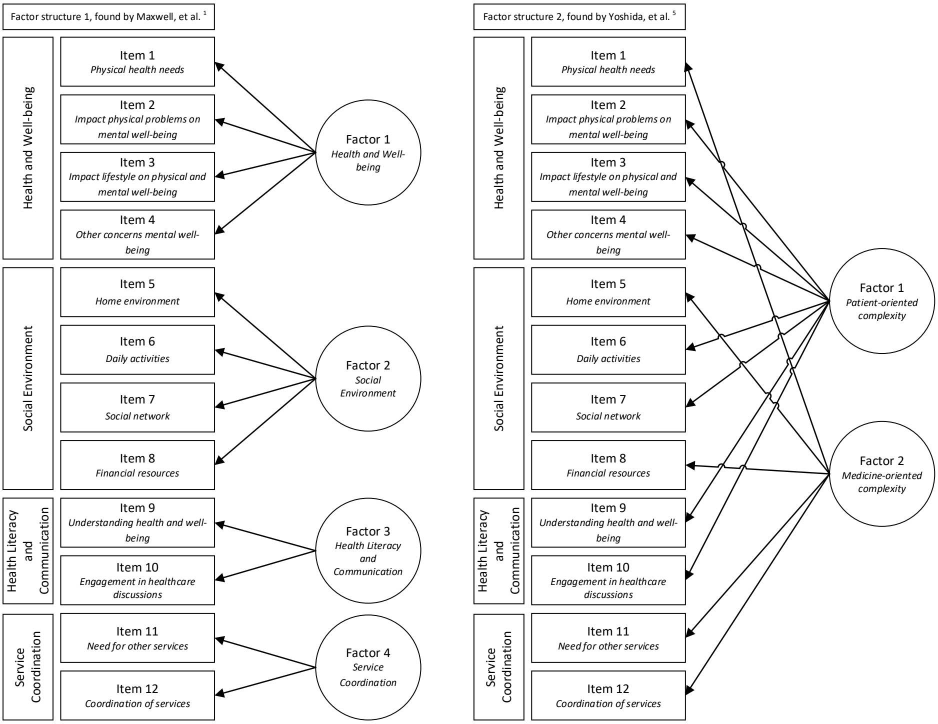

Figure 5.1 Overview of the two different factor structures as identified for the PCAM.

Due to the low ratio of items per factor of each structure, we handled missing data by listwise deletion. The CFA was conducted using the robust WLS estimator[28]. For each of the two factor structures, the following parameters were calculated and compared to assess what structure best fits the PCAM data. Factor loadings and standard errors of each PCAM item in relation to the assigned factor were derived from the CFA output. Loadings of at least 0.3 and 0.5 are generally considered acceptable and strong, respectively[5,32,33]. To assess model fit, it is recommended to use a variety of fit indicators that cover different aspects of model-data fit[27,34]. As a measure of global fit we used the Standardized Root Mean Square Residual (SRMR) with a cut-off score of 0.08 or lower. To assess relative fit, i.e. fit of the tested models as compared to the unstructured model, the Tucker Lewis fit Index (TLI) was used. For the latter index, we considered a score of 0.90 or higher as an indication of acceptable model fit[27,34]. In addition to this, the Root Mean Square Error of Approximation (RMSEA) was calculated – using a cut-off score of 0.06 or lower[27].

In terms of reliability, we examined the internal consistency (i.e. degree to which items are intercorrelated) of the complete tool, and of items within each factor, for both factor structures[35]. A Cronbach's alpha value of ≥0.70 and ≥0.80 are signs of acceptable and adequate internal consistency, respectively[35,36]. In the interpretation of the alpha's value, we took into consideration that the alpha's value of factors with a small (less than three) number of items, may be reduced[35,36]. To assess the general properties, IBM SPSS Statistics (version 25) was used. For the psychometric tests, the statistical environment RStudio (version 1.4.1106) was used.

Perceived value, feasibility and face validity

As part of the TARGET pilot, individual interviews with primary care professionals were organised at the end of the study period. Aim of the interviews was to get insight into the feasibility and acceptability of TARGET, including the perceived value, feasibility and face validity of the PCAM in the context of the needs assessment. We aimed to interview 14 professionals in individual interviews, two of each of the seven practices participating in the TARGET pilot. A semi-structured interview guide was developed. The first interview was conducted by authors RS and DH collectively; subsequent interviews were conducted by either author RS or DH. The interviews were audio-taped and transcribed verbatim.

We used thematic analysis with an inductive approach for the qualitative data analysis[37]. A phased process was followed. In brief, authors RS and DH prepared the analyses by (re-)reading all transcripts, after which initial codes were applied. The first transcript was coded by the two researchers independently and the codes were compared and discussed for purposes of reflexivity. The remaining interviews were divided. Author RS drafted a first version of the subthemes and overarching themes that could be identified from the initial coding, which were discussed with DH. This helped to identify patterns of codes and relationships between the codes, which supported to understand, interpret and report the main insights flowing from the data.

Results

Dutch version of PCAM

During the forward translation, first adaptations were made to contextualize the PCAM. For instance, the term 'client' was replaced by 'patient', to adapt the PCAM for use in a primary care setting. Furthermore, as there was discussion about the interpretation of several words in the original version (e.g. ‘usual activities’ and ‘caregiving’), their meaning was verified with one of the developers of the PCAM to ensure correct translation. The back-translation showed small translation discrepancies that were resolved by discussion between authors RS, AE and DH.

Twelve primary care professionals – i.e. six somatic practice nurses, two mental health practice nurses, one GP, one physician assistant, one nurse specialist and one doctor’s assistant – pre-tested the translated PCAM. Most professionals reported that they considered the PCAM as a short but comprehensive tool to get a broad overview of the patient’s biopsychosocial situation. Challenges to complete the tool were also reported. For example, many professionals mentioned not being used to answering questions about a patient from their perspective as a professional. Hence, as they needed to complete the items based on their interpretation of a patient’s situation, professionals expected some degree of subjectivity, also between different professionals.

Discussion of each translated item and corresponding answering categories revealed that the Dutch translation was generally considered clear. Some words or phrases were perceived as complex and suggestions to rephrase were discussed. As an example, the literal Dutch translation of ‘inconsistency’ in the answering category “Safe, stable, but with some *inconsistency*” was changed into a simpler, but conceptually equivalent term. As the use of examples to clarify the content of each PCAM item was considered helpful, professionals often proposed to add new examples or adjust existing examples to optimize relevance for a Dutch context. Amongst others, we added participation in (community) associations as an example of patients’ social network, as suggested by one professional. The final Dutch version of the PCAM can be found in Appendix 5B.

Study participants

For 232 patients who received a needs assessment as part of the TARGET program, the PCAM was completed. The background characteristics of included patients are shown in Table 5.1. On average, patients were 72.5 years old and the majority was female (70.9%). More than eighty percent of patients had at least two chronic conditions. While most (70.7%) patients had only physical condition(s), 27.6% of patients had a combination of physical and mental conditions and 1.8% had merely mental condition(s). During the year before the needs assessment, patients had a mean weighted care utilization of 46.9 contacts. Diabetes (55.1%), asthma (22.2%) and cancer (21.8%) were the top-3 most prevalent chronic conditions.

Table 5.1 Background characteristics of study participants (n=232).

	N (SD/percentage)
Age in years [a], mean (SD)	72.5 (±14.1)
Age in years [a], number (percentage)	
< 65 years	55 (23.7%)
≥ 65 and < 80 years	85 (36.6%)
≥ 80 years	92 (39.7%)
Sex, number (percentage)	
Male	64 (29.1%)
Female	156 (70.9%)
Weighted care utilization, mean (SD)[b]	46.9 (±20.4)
Number of chronic conditions[c], number (percentage)	
One	41 (18.2%)
Two	78 (34.7%)
Three of more	106 (47.1%)
Type of chronic condition(s)[c], number (percentage)	
Only physical	159 (70.7%)
Only mental	4 (1.8%)
Combination of physical and mental	62 (27.6%)
Chronic conditions[c], number (percentage)	
Diabetes mellitus	124 (55.1%)
Asthma	50 (22.2%)
Cancer	49 (21.8%)
Chronic obstructive pulmonary disease (COPD)	45 (20.0%)
Coronary heart diseases	37 (16.4%)
Chronic back or neck disorder	35 (15.6%)
Heart failure	33 (14.7%)
Mood disorders	32 (14.2%)
Heart arrhythmia	31 (13.8%)
Osteoarthritis	31 (13.8%)
Visual disorders	23 (10.2%)
Stroke (including TIA)	21 (9.3%)
Anxiety disorders	19 (8.4%)
Burnout	12 (5.3%)
Osteoporosis	10 (4.4%)
Rheumatoid arthritis	8 (3.6%)
Dementia including Alzheimer's	7 (3.1%)
Hearing disorders	7 (3.1%)
Endocardial conditions, valvular conditions	5 (2.2%)
Chronic alcohol abuse	4 (1.8%)
Mental retardation	3 (1.3%)
Migraine	3 (1.3%)
Epilepsy	1 (0.4%)
Parkinson's disease	1 (0.4%)
Personality disorders	1 (0.4%)
Schizophrenia	1 (0.4%)

Note: The characteristics age and weighted care utilization had no missing values; the remaining characteristics had either 7 (3%) missing values (i.e. number, type and prevalence of chronic conditions) or 12 (5%) missing values (i.e. sex). [a]Measured at the time of the needs assessment. [b]Based on the care use during the year before the needs assessment and weighted for the intensity of types of consultations used; applied weights are described elsewhere [20,21]. [c]Based on the care use for chronic conditions during one and a half year preceding the needs assessment. The conditions congenital cardiovascular anomaly and HIV/AIDS were not included in the table as their prevalence was zero.

PCAM general properties

PCAM item response was high: 228 of the 232 PCAMs were completed without any missing values. In four PCAMs, there was one missing value (in items 7, 11 or 12). See Figure 5.2 for the frequency distribution and general properties of the 232 PCAM items scored using a four-point traffic light-style system indicating the growing need for action, ranging from 'routine care' (green) to 'act now' (red). For ten out of the 12 items, the most frequently used (i.e. mode) answer (in bold and delineated) was 'routine care', i.e. indicating the lowest need for action. The percentage of responses in 'routine care' ranged from 26% in item 2, related to the impact of physical problems on mental well-being, to 79% in item 8, related to financial resources. Two items (2 and 4), both concerning mental well-being, had a mode answer of 'active monitoring'. 'Routine care' was also the median answer (indicated by the dotted line) for seven out of the 12 items, implying that this answer was scored for at least 50% of the patients in those items. The remaining five items, related to physical health needs, impact physical problems on mental well-being, (other concerns) mental well-being, social network and need for other services, had a median of 'active monitoring'.

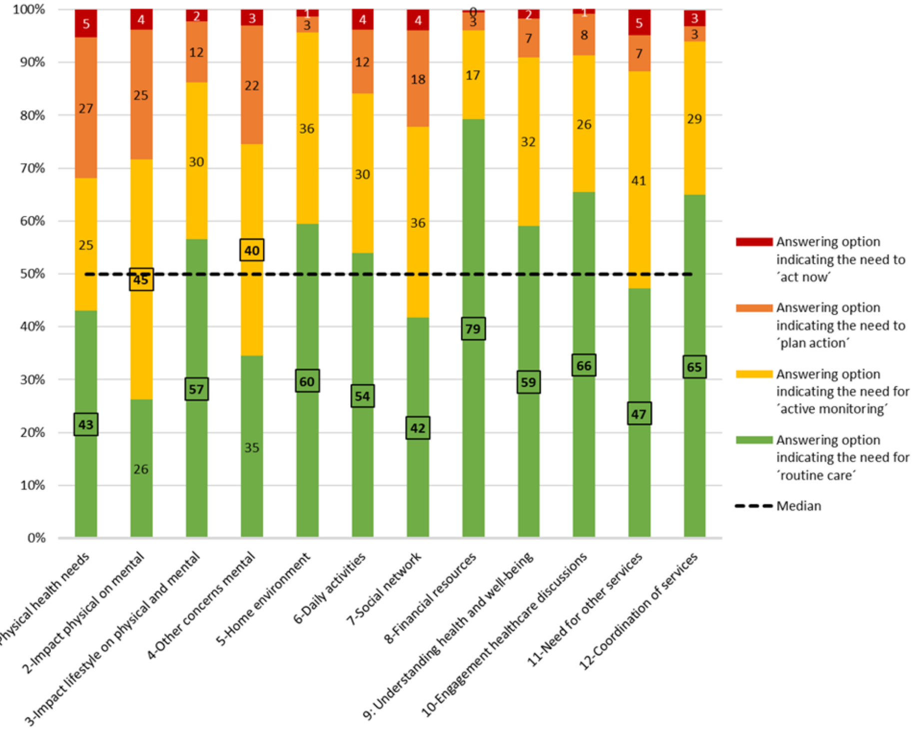

Figure 5.2 PCAM general properties.

‘Routine care’ (green) and ‘active monitoring’ (yellow) are the most frequent responses overall. On a patient level, 40% (n=92) of patients scored only ‘routine care’ (green) or ‘active monitoring’ (yellow) in all PCAM items. Hence, the majority (60%; n=140) of patients was indicated to need ‘plan action’ (orange) or ‘act now’ (red) on at least one of the 12 PCAM items. Of those 140 patients, 84% (n=117) was indicated to need ‘plan action’ or ‘act now’ in at least one item of the domain of ‘health and well-being’. The remaining 16% (n=23) did not score the orange or red option in the first domain, while they did need ‘plan action’ or ‘act now’ in at least one item of the remaining three domains.

Psychometric properties

The CFA was conducted with the 228 complete PCAMs. In Table 5.2, the factor loadings of the two assessed structures are provided. All loadings are above the minimally acceptable threshold of 0.3. The majority of loadings are above 0.5, indicating that most loadings can be classified as strong. Exceptions (in bold) are – for factor structure 1 – the loading of item 1 (physical health needs) on factor 1 (health and well-being), and the loading of item 8 (financial resources) on factor 2 (social environment). For factor structure 2, item 1 (physical health needs) and item 8 (financial resources) also showed acceptable but not strong loadings on factor 2: medicine-oriented complexity.

Table 5.3 shows the goodness-of-fit indices and Cronbach’s alpha values that were calculated for the two structures. For structure 1, all indices (i.e. SRMR, TLI and RMSEA) met the thresholds of acceptable fit. For structure 2, none of the indices met the thresholds of acceptable fit. The Cronbach’s alpha of the complete PCAM tool (0.83) met the threshold of 0.8, indicating adequate internal consistency. For factor structure 1[1], the Cronbach’s alpha values of factor 3 and 4 met the threshold of acceptable internal consistency (i.e. 0.70), while the values for factor 1 and 2 were just below the threshold, with values of 0.69 and 0.66. If item 1, concerning physical health needs, would be dropped from factor 1, the Cronbach’s alpha value of factor 1 would increase from 0.69 to 0.72. If item 8, concerning financial resources, would be dropped from factor 2, the Cronbach’s alpha value of factor 2 would increase from 0.66 to 0.70. With regards to the second tested factor structure[5], only the first factor showed adequate internal consistency (0.8), while the Cronbach’s alpha value of the second factor (0.59) was below the threshold. Again, if item 1 would be dropped, the Cronbach’s alpha value of factor 2 would be 0.64 and if item 8 would be dropped, the current Cronbach’s alpha value (0.59) would be maintained. No other items would lead to improved Cronbach’s alpha values if dropped.

Table 5.2 Factor loadings of items within the two assessed factor structures.

Factor structure 1, by Maxwell, et al. [1]		Factor structure 2, by Yoshida, et al. [5]	
Factors	Factor loadings	Factors	Factor loadings
Factor 1: health and well-being	**Item 1: 0.432**	Factor 1: patient-oriented complexity	Item 2: 0.654
	Item 2: 0.692		Item 3: 0.596
	Item 3: 0.630		Item 4: 0.832
	Item 4: 0.897		Item 6: 0.684
			Item 7: 0.713
			Item 9: 0.701
			Item 10: 0.701
Factor 2: social environment	Item 5: 0.681	Factor 2: medicine-oriented complexity	**Item 1: 0.426**
	Item 6: 0.748		Item 5: 0.664
	Item 7: 0.783		**Item 8: 0.382**
	Item 8: 0.409		Item 11: 0.773
			Item 12: 0.842
Factor 3: health literacy and communication	Item 9: 0.860		
	Item 10: 0.853		
Factor 4: service coordination	Item 11: 0.827		
	Item 12: 0.917		

The factor loadings in bold are below the threshold of 0.5 indicating they are acceptable but not strong.

Table 5.3 Fit indices and Cronbach's alpha values for the two assessed factor structures.

	Factor structure 1, found by Maxwell, et al.[1]	Factor structure 2, found by Yoshida, et al.[5]
SRMR[a]	0.061*	0.098
TLI[b]	0.968*	0.885
RMSEA[c]	0.057*	0.109
Cronbach's alpha	Factor 1: 0.69	Factor 1: 0.8*
	Factor 2: 0.66	Factor 2: 0.59
	Factor 3: 0.75*	
	Factor 4: 0.75*	

[a]SRMR is the Standardized Root Mean Square Residual, acceptable fit ≤0.08. [b]TLI is the Tucker Lewis fit Index, acceptable fit ≥0.90. [c]RMSEA is the Root Mean Square Error of Approximation, acceptable fit ≤0.06. *Fit indices and Cronbach's alpha values that meet the thresholds indicating acceptable fit and internal consistency, respectively.

Perceived value, feasibility and face validity

As intended, we interviewed two professionals of each of the seven practices, except for one practice of which we interviewed three professionals. Hence, 15 professionals were interviewed in total. All interviews were performed individually, except for one interview with two professionals. Amongst the participants, there were six GPs, five somatic practice nurses, two mental health practice nurses, one physician assistant and one doctor's assistant. Twelve of the 15 participants were female. Their mean age was 50 years (SD=12.5). The youngest was 22 and the oldest 63 years old. On average, they had 14 years of work experience in primary care (SD= 9.6). Below, the value of the PCAM is described by the different functions the tool had in the current study (i.e. to facilitate measurement, action planning and serve as a complementary conversation tool).

PCAM as measurement tool

Professionals reported that they mainly perceived the PCAM as a measurement tool. It enabled measurement of the outcomes of the needs assessments and helped some professionals to determine how complete their ‘picture’ of a patient is. Nevertheless, professionals saw the measurement function of the PCAM as predominantly valuable for scientific research and as less important for daily practice:

> *“We have got more measurement tools, for instance for people with COPD. It could have some value [to use the PCAM as measurement tool], but on the other hand I think: we have got so many measurement tools. With the conversation [the needs assessment] you mainly focus on: Who is in front of you? What can you do for someone?” (Primary care professional 2)*

Furthermore, some professionals reported a disagreement between the PCAM (as measurement tool) and the needs assessment: while a professional interpretation of a patient’s situation is needed to fill in the PCAM, the needs assessment should be focused on the patient perspective:

> *“Such a conversation [the needs assessment] is about things that are very important for the patient. […] So it happens that topics are not addressed which I, as a caregiver, wanted to address but the patients did not want to. And when you then fill in the PCAM, you sometimes miss information. So it is a matter of translating the thoughts of the patient to how the professional interprets it.” (Primary care professional 3)*

Most needs assessments were conducted by practices nurses, who subsequently completed the PCAM together with a GP. The GP helped to fill in the PCAM – based on prior experiences with the patient instead of the needs assessment – because practice nurses were sometimes unsure whether they interpreted the situation of the patient correctly and in line with the interpretation of the GP. Some professionals reported that their interpretations often matched, while others indicated that objective completion of the PCAM was difficult, as assessments of the complexity of a patient’s needs can differ between professionals. Completing the PCAM together was valued by professionals. It offered the chance to share new information of the patient that was discussed during the needs assessment, and to collectively think about the required actions for a patient. Practice nurses also saw it as a way to create shared responsibility with the GP to act upon the action plans.

PCAM as action planning tool

Many professionals considered the action planning section of the PCAM as clear and helpful to determine and register follow-up actions. It stimulated critical thinking about the needed follow-up actions after the needs assessment:

> *"It is helpful to have a sort of evaluation moment at the end of such a conversation [the needs assessment]. […] I like to wrap it up like: What types of challenges does the patient encounter? And what is already going well? The PCAM is suited for this, in my opinion." (Primary care professional 9)*

Others argued that the existing electronic health record as well as the 'My Positive Health' primary conversation tool already facilitates action planning sufficiently so the PCAM is redundant for this purpose. In addition, professionals indicated that the action planning section was not always completed, as the situation of the patient did not call for (new) follow-up actions or because professionals were unsure about how to fill in this section. It was therefore suggested to practice the completion of the action planning section with colleagues before starting to use it.

PCAM as conversation tool

A small number of professionals used the PCAM as a second, complementary conversation tool next to 'My Positive Health'. They argued that it helped them to adequately prepare and conduct the needs assessment. Some PCAM questions (e.g. about alcohol use and debts) were not included in 'My Positive Health', but were seen as important and complementary questions to address during the needs assessment. Hence, the PCAM helped to get a "complete picture" of a patient. However, some professionals mentioned to perceive those questions as emotionally charged and therefore challenging to ask.

Most professionals did not use the PCAM as complementary conversation tool and considered 'My Positive Health' as sufficient for this purpose. Some professionals mentioned specific shortcomings of the PCAM as a conversation tool. First, the PCAM does not have a patient version, which limits the opportunity for patients to prepare the needs assessment. Furthermore, professionals indicated that the PCAM is mainly focused on determining actions, rather than on the needs assessment itself. For instance, the PCAM does not facilitate to summarize what was discussed about the situation of a patient. Only the registration of actions is supported.

Feasibility

In terms of feasibility, most professionals perceived the PCAM as a clear and easy to use tool. It only took them a few minutes to fill in the items, which was most frequently done right after the needs assessment. However, some professionals did experience the PCAM as time-consuming and therefore did not always manage to fill in the PCAM items shortly after the needs assessment. To make it less time-consuming and improve efficiency, professionals indicated the need to integrate the PCAM into the electronic health record instead of having to access the tool via a separate website. This would also help to get a comprehensive overview of the needs assessment and related actions, as all information is stored in one location.

Face validity

Professionals indicated that the PCAM contains legitimate questions for a holistic, biopsychosocial conversation with a patient. However, professionals also mentioned validity concerns of the tool. Firstly, the differences between the answering options were seen as large. Hence, professionals were sometimes unable to find the correct answer for the specific situation of the patient. To overcome this, they suggested to create an open field to add some more detailed information about the patient. Also, some questions and answering options were considered complex, asking for two assessments at once. For instance, the answering option ‘financially insecure, very few resources, immediate challenges’ contains an assessment of the patient’s financial situation (‘financially insecure, very few resources’) and an assessment of the urgency to respond to the situation (‘immediate challenges’). This also shows the assumption underlying many PCAM items that a more complex situation asks for a higher level of intervention, which is sometimes incorrect:

> *“A red score on ‘financial problems’ does not have to indicate that there is a problem. We’ve got one patient who scores definitely ‘red’ in terms of the financial situation, but she still manages it with some help. So it is not really a problem, but I still have to score it as a problem. […] It should be a green score, but that is not possible because green says there are no financial problems.” (Primary care professional 8)*

The needs assessments were only done with patients with high care needs, but professionals reported that they rarely indicated urgent needs for intervention with the PCAM. Professionals still valued a holistic conversation with these patients.

Discussion

This study aimed to create a contextualized Dutch version of the PCAM, increase insight into the psychometric properties of the tool, and test the perceived value, feasibility and face validity of the PCAM as a measurement, action planning and (complementary) conversation tool. The results show ambiguity, particularly across the quantitative and qualitative analyses. On the one hand, the internal consistency of the complete tool was of an adequate level (Cronbach's alpha is 0.83). In terms of construct validity, the CFA confirmed that the four-factor structure of Maxwell, et al.[1] fitted the PCAM data well, in contrast to the two-factor structure of Yoshida, et al.[5]. On the other hand, the qualitative results revealed that the PCAM needs some validity improvements. But professionals also indicated that the PCAM has value for measurement, as a first function. In terms of the other functions of the PCAM, the tool was mainly valued for action planning and only by a minority of professionals used as complementary conversation tool.

Despite concerns about the face validity of the tool, the quantitative results confirm that the PCAM is adequate for its first function in the current study, i.e. to support measurement of needs assessment outcomes. Similar to previous studies, the internal consistency was of an adequate level[1,5]. All 12 PCAM items contribute to valid and reliable measurement of the related construct, except for item 1 and item 8 in both tested factor structures. For item 1, this may be explained by the content of the item: item 1 is purely focused on physical health needs while item 2 to 4 (amongst others) focus on mental well-being. With regards to item 8 about financial resources, the percentage of patients who were indicated to only need routine care was substantially higher (i.e. 79%) than in the other three items of the domain 'social environment' (i.e. between 42 and 60%). There are several possible explanations for this. First, as this study was conducted in a predominantly rural area of the Netherlands, with less deprivation than in other, more urban regions of the country, the prevalence of financial issues may actually be lower[38]. However, previous research shows that the target population of this study, i.e. high care need patients, more often has financial problems than found in this study[39-42]. Therefore, a second possible explanation is that financial problems were not always identified and acted upon. In line with this study, research shows that barriers (e.g. taboo) exist to discuss financial issues in primary care[43-45]. In a recent study on the Japanese version of the PCAM, item 8 was also identified as problematic for the validity of the tool[46]. But it was still considered an important topic to address in primary care, in line with the findings of the current study[46].

A point of criticism on the PCAM as measurement tool, expressed by the interviewed professionals, is that a professional interpretation of the patient's situation is required to fill in the PCAM, while the needs assessment should be focused on the patient perspective. On the one hand, this is quite remarkable as professional interpretation is inherent to each medical profession and does not necessarily mean the patient perspective is overlooked. Furthermore, the PCAM requires a focus on the patient experiences during the assessment in order to adequately fill in the 12 items. On the other hand, this point of criticism uncovers a difference in theoretical models underpinning the PCAM and the needs assessment. The adequate fit of the four-factor model of Maxwell, et al.[1], in which the biological-psychological domains (combined into 'health and well-being') and social domain ('social environment') were identified as two of the four separate constructs, shows that the biopsychosocial model has informed the PCAM. While the biopsychosocial model does consider multiple aspects of the person, it does not have an explicit focus on the individual personhood of patients, i.e. how patients perceive their situation[47]. However, this is a crucial element of the more comprehensive and contemporary concepts of person-centred holistic care, described as the aims of the needs assessment[15,47,48]. To make the PCAM more compatible with the needs assessment, creating a patient (next to a professional) measurement tool may be helpful. It should however be noted that directly measuring the subjective experiences of patients in a valid and reliable way is challenging, as demonstrated by the efforts to transform the patient-directed conversation tool 'My Positive Health' into a comprehensive measurement instrument[49].

The second function of the PCAM, i.e. to support action planning, was appreciated by many professionals in the current study. This corresponds with previous studies, describing that the action component of the PCAM was in particular helpful to guide patients towards the right intervention, referral or other follow-up action[1,2,7]. Doing so has the potential to lower the work pressure in primary care and ensure patients receive the care or support best fitting their needs[1,2,7]. As shown in this study, it may be helpful to complete the action plan with a team of professionals after it was discussed with the patient. Especially patients with complex biopsychosocial issues – for whom the 'regular' care paths are often insufficient – may benefit from the collective expertise of various professionals[50-52]. Yet, the number of identified actions with the label 'plan action' or 'act now' in one of the PCAM items was lower (i.e. for 60% of patients) than expected in a population with high care needs[50-52]. In addition to this, professionals had mainly identified those actions in 'health and well-being', a domain that is traditionally addressed by primary care. For a minority of patients (i.e. 16%), the actions were indicated to only relate to the other three, more social domains. An explanation may be that professionals have more knowledge, skills and trust to discuss items and plan actions closely related to the domain of primary care than to the more social domains[44,45]. Furthermore, to succeed in social actions or referrals to other settings and professionals, strong network relations are crucial, but may not be present or developed sufficiently during the course of the pilot study[44,45,53].

The use and appreciation of the PCAM in its third function, i.e. as a conversation tool, was limited. Professionals reported several reasons for this, for example the fact that the PCAM lacks a patient version which prepares patients for the needs assessment. This finding conflicts with previous PCAM studies, in which the tool was valued as a framework to guide the conversation and considered a helpful instrument to improve the quality and openness of communication[1,2,7].However, it should also be noted that the PCAM was not fully tested as conversation tool in this study. This is due to the fact that some professionals already had positive experiences with the primary conversation tool ‘My Positive Health’ before the start of the pilot. This may have served as a barrier to using a second and new tool. The needs assessment training, which was largely influenced by ‘positive health’, possibly also ‘steered’ towards using ‘My Positive Health’.

Practical implications, future research and policy

The face validity concerns as expressed in this study as well as the finding that the current concept of ‘person-centred care’ is not fully supported by the PCAM, call for a revision of the tool as both a measurement and conversation tool. In addition, a patient version of the tool is needed, as was also suggested by the developers of the PCAM[1,54]. This can help to have more explicit attention for the ‘individual personhood’ of a patient. To make the tools relevant and appealing, an expert group with patients should be composed. Patients with different characteristics, for instance in terms of age, socioeconomic status and health literacy, should be included in this expert group to ensure the tool is relevant for the diverse population of patients who (often) consult primary care.For the revision of the professional version, a professional expert group is helpful. In this process, it is important to ensure that the good properties of the tool are maintained: the adequate psychometric qualities and the action planning component. In terms of policy, the findings of the current study point to the importance of a well-functioning network surrounding the primary care practice. When there are strong connections with, for instance, the social domain, professionals may have more confidence to act upon issues of a social kind when these are identified.

Strengths and limitations

A strength of the current study is the mixed-methods design. This helped to compare the quantitative insights into the PCAM’s measurement qualities with the experienced validity and value. As such, a rich understanding of the value of the PCAM in its different functions was obtained. A limitation is that some psychometric properties of the tool, i.e. the stability ,inter-rater reliability and the criterion validity, were not studied. Main reason for this was that the pilot study was aimed at investigating the feasibility and acceptability of the TARGET program. It was therefore considered out of the scope of the study to, for instance, ask professionals to complete a second measurement instrument next to the PCAM (to study criterion validity). Previous studies have investigated criterion validity, but the results are mixed[1,5,46]. As far as we are aware, the other two psychometric properties have not yet been studied. However, it is arguable whether a high inter-rater reliability is attainable. Professionals reported that some degree of subjectivity is inherent to professional interpretation of a patient’s situation.

Conclusions

The PCAM is an adequate biopsychosocial measurement tool. Furthermore, it helps professionals to – when professionals have strong connections with their network and referral options – plan actions based on a needs assessment with (high care need) patients in primary care. However, to support a holistic, person-centred needs assessment, the tool needs a patient version and revision – while keeping the strong elements – to fully meet the features of person-centred care as the concept is described today.

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Appendix 5A Additional information about the Dutch primary care system

In the Dutch healthcare system, the general practitioner (GP) has a strong gatekeeping function: in order to access care in more specialized settings, a referral from the GP is needed[55,56]. GPs traditionally play a major role in delivering and coordinating care for chronically ill[55,56]. From the beginning of this century, two types of 'practice nurses' were introduced in Dutch primary care to support GPs by taking over a significant part of the standardized, routine care for the chronically ill[57]: the 'somatic practice nurse' ,introduced in 2000, and a practice nurse with expertise in mental health, introduced in 2008[57].

Care for chronically ill is largely guided by disease-management programs in primary care settings. These programs – currently nationwide available for common conditions such as diabetes type 2 and COPD – are based on disease-specific, standardized guidelines for individual conditions[58]. The delivery of care from disease-management programs is facilitated by so-called 'care groups', under a bundled payment system[59]. These GP-owned "principal contracting entities" were introduced in the Dutch healthcare system from the second half of 2000[58,59]. Care groups negotiate and make agreements with health insurers about bundled payments: a fixed fee for patients with a specific chronic condition for all primary care practices belonging to a particular care group[55,59].

Appendix 5B Final Dutch version of the PCAM

Patient Centered Assessment Method (PCAM)

ID patient_________

Datum: _ _/_ _ /20_ _

Zorgverlener:

Vs2.0 februari 2015
Nederlandse vertaling april 2020

Instructie: gebruik dit formulier als richtlijn, stel de vragen in uw eigen woorden tijdens een consult om u te helpen elke vraag te beantwoorden. Omcirkel in elk gedeelte één optie, om de mate van complexiteit bij deze patiënt weer te geven. In te vullen tijdens of na een consult.

Gezondheid en Welbevinden			
1. Als u nadenkt over de **fysieke gezondheid** van uw patiënt, zijn er dan enige symptomen of problemen (risico indicatoren) waar u over twijfelt, die verder onderzoek behoeven?			
Geen twijfels <u>of</u> problemen worden al onderzocht	Milde vage fysieke symptomen <u>of</u> problemen; <u>maar</u> die hebben géén impact op het dagelijks leven <u>of</u> leiden niet tot ongerustheid bij de patiënt	Matige tot ernstige symptomen <u>of</u> problemen die impact hebben op het dagelijks leven	Ernstige symptomen <u>of</u> problemen die een significante impact veroorzaken op het dagelijks leven
2. Hebben de **fysieke gezondheidsproblemen** van de patiënt impact op zijn/haar **mentaal welbevinden**?			
Geen redenen tot ongerustheid	Milde impact op het mentaal welbevinden, bijvoorbeeld “verminderd genieten”	Matige tot ernstige impact op het mentaal welbevinden en verhinderen het genieten van dagelijkse activiteiten	Ernstige impact op het mentaal welbevinden en verhinderen het uitvoeren van dagelijkse activiteiten
3. Zijn er problemen met het **leefstijlgedrag** (alcohol, drugs, dieet, lichaamsbeweging) van uw patiënt, die impact hebben op het **fysiek** of **mentaal welbevinden**?			
Geen redenen tot ongerustheid	Enige milde ongerustheid over potentieel negatieve impact op het welbevinden	Matige tot ernstige impact op het welbevinden van de patiënt, verhinderen het genieten van dagelijkse activiteiten	Ernstige impact op het welbevinden van de patiënt en mogelijke invloed op de omgeving
4. Heeft u enige **andere redenen tot zorgen** over het **mentaal welbevinden** van uw patiënt? Hoe zou u de ernst en impact daarvan op uw patiënt beoordelen?			
Geen redenen tot ongerustheid	Milde problemen- beperken het functioneren niet	Matige tot ernstige problemen die het functioneren beperken	Ernstige problemen die de meeste dagelijkse functies aantasten

Sociale Omgeving			
1. Hoe zou u hun **thuisomgeving** beoordelen in termen van **veiligheid en stabiliteit** (waaronder relatieproblemen, onzekere thuissituatie, burenoverlast)?			
Constant veilig, ondersteunend, stabiel, geen problemen geïdentificeerd	Over het algemeen veilig, stabiel, maar met enige uitzonderingen	Veiligheid/stabiliteit twijfelachtig	Onveilig en onstabiel
2. Hoe hebben **dagelijkse activiteiten impact op** het welbevinden van de patiënt? (waaronder huidige of verwachte werkloosheid, werk, (mantel) zorgtaken, mogelijkheid tot vervoer of anderszins)			
Geen problemen geïdentificeerd of positieve voordelen waargenomen	Enige algemene ontevredenheid, maar geen ongerustheid	Draagt bij aan een sombere stemming of stress op sommige momenten	Ernstige impact op slecht mentaal welbevinden
3. Hoe zou u hun **sociale netwerk** beoordelen (familie, werk, vrienden en verenigingsleven)?			
Goede participatie in sociale netwerken	Voldoende participatie in sociale netwerken	Beperkte participatie, met enige mate van sociale isolatie	Weinig participatie, eenzaam en sociaal geïsoleerd
4. Hoe zou u hun **financiële middelen** beoordelen (waaronder mogelijkheid om in de basisbehoeften te voorzien en alle benodigde medische zorg te betalen)?			
Financieel zeker, voldoende middelen, geen problemen geïdentificeerd	Financieel zeker, enkele uitdagingen om rond te komen	Financieel onzeker, enkele uitdagingen om rond te komen	Financieel onzeker, heel weinig middelen, acute uitdagingen om rond te komen
Gezondheidsvaardigheden en Communicatie			
1. Hoe goed **begrijpt** de patiënt nu zijn/haar gezondheid en welbevinden (symptomen, signalen of risicofactoren) en wat hij of /zij moet doen om regie te voeren over zijn/haar gezondheid?			
Redelijk tot goed begrip en voert al regie over zijn/haar gezondheid of is bereid om betere regie te voeren	Redelijk tot goed begrip, maar voelt zich op dit moment niet in staat om met adviezen bezig te zijn	Weinig begrip, wat impact heeft op hun vermogen om betere regie te voeren	Slecht begrip met significante impact op het vermogen regie te voeren over gezondheid
2. Hoe goed denkt u dat uw patiënt **mee kan doen** in zorggesprekken? (beperkingen zijn bijvoorbeeld taal, doofheid, afasie, alcohol- of drugsproblematiek, leerproblemen, concentratie)			
Duidelijke en open communicatie, geen beperkingen geïdentificeerd	Voldoende communicatie, met of zonder minieme beperkingen	Enkele moeilijkheden in communicatie, met of zonder redelijke beperkingen	Serieuze moeilijkheden in communicatie, met ernstige beperkingen
Zorgcoördinatie			
1. Moeten andere disciplines betrokken worden om deze patiënt te helpen?			
Andere zorg/disciplines niet nodig op dit moment	Andere zorg/disciplines betrokken en voldoende	Andere zorg/disciplines betrokken, maar niet toereikend	Andere zorg/disciplines niet betrokken, wel nodig
2. Zijn de disciplines, die op dit moment bij de patiënt betrokken zijn, goed op elkaar afgestemd? (houdt rekening met andere disciplines die u nu aanbeveelt)			
Alle benodigde zorg/disciplines betrokken en goed op elkaar afgestemd	Benodigde zorg/disciplines betrokken en voldoende op elkaar afgestemd	Benodigde zorg/disciplines betrokken met enkele belemmeringen voor het afstemmen van zorg	Benodigde zorg/disciplines ontbreken en/of werken niet goed samen
🟩 Reguliere zorg	🟨 Actief monitoren	🟧 Plan Actie	🟥 Handel Nu

Welke actie is nodig?	Wie moet betrokken worden?	Belemmeringen voor actie?	Welke actie wordt ondernomen?
Notities:			

Vragen? Neem dan contact op met Rowan Smeets of Dorijn Hertroijs, onderzoekers TARGET programma:

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Chapter 6

Supporting professionals to implement integrated, person-centred care for people with chronic conditions: The TARGET pilot study

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Submitted

Chapter 7

General discussion

Rowan G.M. Smeets

Introduction

With this dissertation, we aimed to advance the field of integrated care for people with chronic conditions. While few people would disagree that integrated care is the way forward, given the growing group of people with complex conditions and needs, it remains unclear how to actually 'practice' integrated care, in terms of valuable design, implementation and evaluation. Therefore, as first objective, we studied how integrated, person-centred care for people with chronic conditions should be designed, taking into account the needs of this patient population as well as the organizational innovations needed to accommodate those needs. **Part I** 'Assessing the needs for and organizational building blocks of the TARGET integrated care program' of this dissertation, containing Chapters 2 and 3, was performed to reach this first objective. **Part II** 'Towards a first implementation of the TARGET program in Dutch primary care', containing Chapters 4 to 6, was performed to reach the second objective. The second objective was to translate the insights gained into the TARGET integrated care program, after which we theoretically and methodologically prepared the implementation of this program and gathered first implementation insights. TARGET is short for 'Targeting Advanced Resources in General practice to create Efficient, Tailored and holistic care for chronically ill patients'. This general discussion highlights the main findings of this research, as well as the theoretical and methodological considerations surrounding it. We end this chapter with discussing what this dissertation implies for future practice, policy and research in the area of integrated care.

General findings

How should integrated care be designed?

In part I of this dissertation, first steps were taken to unravel what the population with chronic conditions looks like and needs, and what organizational integrated care strategies might be required. By means of an advanced quantitative analysis, latent class analysis (LCA), we made sense of what defines people with chronic conditions who most often visit general practice, the high-need, high-cost (HNHC) population (Chapter 2). It was found that those patients do not have a single profile of characteristics and needs, but can be divided into four distinct subgroups. While two subgroups (together around 2/3rd of the population) include people who are retired and suffer from mainly somatic conditions, the remaining two subgroups (together around 1/3rd of the population) include people who are middle-aged and rather have socio-economic and mental issues. Furthermore, the patient groups were mainly distinct in their demographic and socioeconomic factors, rather than their biological characteristics, like chronic conditions. The four patient profiles were, in a qualitative study (Chapter 3) discussed with primary care professionals to find out what hampers a person-centred, efficient care delivery and what could be done to remove those barriers. Professionals described HNHC patients as people who often have to deal with complex biopsychosocial problems. Barriers to integrated care as well as innovations were mainly discussed on the lower levels of the healthcare system, where the interaction between patients and providers as well as amongst providers takes place, rather than on a macro, policy-level. It became clear that innovations are needed in several parts of the healthcare system, ranging from service delivery to leadership and governance, workforce, and technologies and medical products. More specifically, HNHC patients need more consultation time to adequately address their complex problems and need professionals who are well-trained to take a broad perspective to their problems and cooperate with other care professionals if needed.

Towards a first implementation of TARGET

Based on the research insights from the first part of this dissertation and in close cooperation with primary care group 'Dokter Drenthe' (formerly known as 'Huisartsenzorg Drenthe') and related steering groups, we developed the TARGET program (see Figure 7.1). Before we did a first pilot implementation of the program, we took two preparing steps: (1) we built a theory of how TARGET is expected to work, to increase our understanding of TARGET, prepare the evaluation and guide the final realist evaluation (RE) of the program; (2) we translated and tested the 'Patient Centered Assessment Method' (PCAM) to be used as biopsychosocial measurement tool within the TARGET program during the pilot.

The two program theories we built for TARGET – for professionals and patients, respectively – revealed that the success of the program would be dependent on the activation of 'soft' mechanisms like confidence and mutual trust (Chapter 4). For instance, confidence to enhance conversation skills and mutual trust between professionals and patients. Those mechanisms cannot be disconnected from context, like sufficient resources to invest in integrated care, which is needed to activate the mechanisms. Also, the program theory of TARGET clarified the expected phased achievement of results, with short term results like identification of patients with complex needs preceding longer term goals like care provided in an integrated way and reduced work pressure.

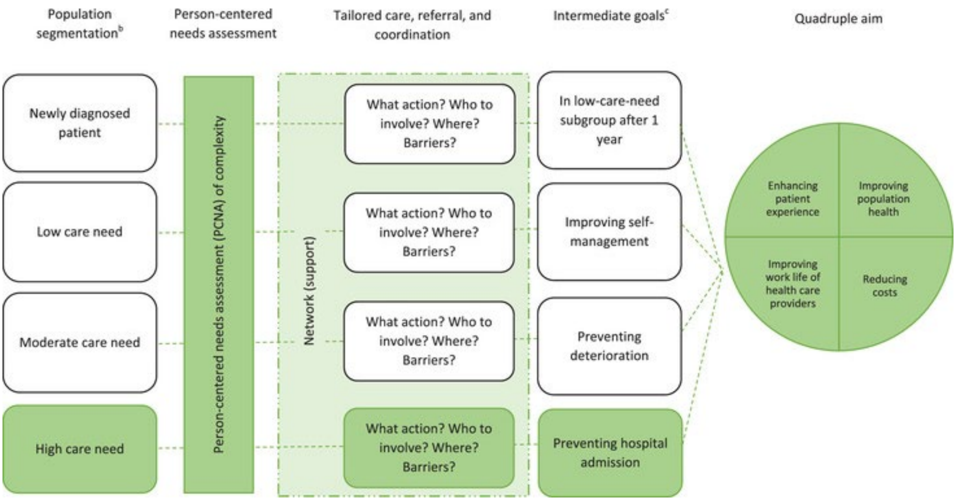

Figure 7.1 Framework of the TARGET integrated care program[a]
[a]The TARGET integrated care program will initially be implemented for the high care need subgroup only, highlighted in green; [b]The population segmentation will include all chronically ill patients suffering from at least one of 13 common chronic conditions: anxiety disorder, asthma, atrial fibrillation, overworking/burn-out, cancer, chronic neck- and back complaints, cardiovascular diseases, COPD, dementia/Alzheimer's disease, diabetes mellitus, migraine, mood disorder, and peripheral arthrosis; [c]For each subgroup, various intermediate goals can be determined.

As a second preparatory step towards the TARGET pilot, the PCAM was translated to Dutch (Chapter 5). The tool was offered to practices involved in the pilot to support the so-called PCNA, the person-centred needs assessment, which is an expanded biopsychosocial consultation. The PCAM served to measure biopsychosocial issues identified during the PCNA and to accommodate discussion and registration of follow-up actions. The measurement qualities of the PCAM were confirmed by an adequate Cronbach's alpha of 0.83 and a four-factor structure supporting the distinction between four biopsychosocial domains included in the PCAM. In addition, the tool helped to plan and register follow-up actions. But professionals also criticized the PCAM because the tool was focused on professionals and how they perceive the situation of a patient, while the current notion of person-centred care asks for a focus on the experiences of patients.

The TARGET program was implemented in seven general practices that were most motivated and eligible to test the feasibility and acceptability of the program (Chapter 6). The tools and trainings were feasible to use in practice and professionals learned new skills, for instance to engage in a PCNA. The PCNAs were valued by both professionals and patients, amongst others because of the explicit attention for positive aspects of health. The pilot study also revealed preconditions that are important for successful functioning of the complete program in the future: full practice commitment to the implementation and strong network relations, particularly with disciplines outside the general practice.

Theoretical considerations

Integrated care terminology

Various terms are being used in scientific research, as in this dissertation, to describe the way health care (systems) should be changed to overcome fragmentation and a disease-specific focus towards patients. The two key terms of this dissertation are 'integrated care' and 'person-centred care'. Simply described, integrated care means that care is well coordinated across different settings and providers[1]. Person-centred care refers to attention for 'the person behind the patient' and acknowledgement of patients as co-creators of health and care[2-5]. Depending on the study setting and types of stakeholders involved, one of the two key terms was sometimes given a more central position in the different studies. For example, in interviews with care professionals, the term 'person-centred care' was considered more appealing as it relates – also in other scientific studies – more to a micro level of patient-physician interaction[6,7]. While in the theoretical development of TARGET, 'integrated care' was the key term, which is usually perceived from a 'macro' point of view, 'on structures and organizational mechanisms that support coordinated care'[6,8-10]. Furthermore, 'integrated care' and 'person-centered care' are 'umbrella' terms having many related terms. Also in this dissertation, closely associated terms were used, like 'tailored' and 'efficient' in relation to integrated care, and 'holistic' and 'biopsychosocial' in relation to person-centred care. Some researchers would argue that this has clear drawbacks, as described by a study of Berntsen, et al.[8] about Person-Centered and Integrated Care (PC-IC): "The literature on PC-IC is awash with overlapping and conflicting concepts and terminology, making it challenging to develop united frameworks that may structure patients' experiences of care quality". The different language used throughout the field makes standardized evaluations and thus valid comparisons between studies challenging[8,9,11,12]. But this reflects the idea that researchers should always strive for standardization in evaluation, while the dynamic and 'fluid' nature of these terms is above all helpful. It expands the scope to which the terms are applicable and allows for making them compatible with how the particular setting or stakeholders perceive them. The main point is to be aware of the connotations attached to the key terms and how they relate to each other. Making this explicit and embracing the variety in operationalization of concepts instead of eliminating it while searching for standardization, is central to the philosophy of RE. An RE-approach can help to, in an early stage of the research, make the different concepts as well as underlying mechanisms and contextual factors explicit, and perceive outcomes in the light of the employed concepts[13,14]. In this dissertation, this value of RE was illustrated[15]. For instance, it was clarified how the two key concepts relate to each other: 'person-centred' care is considered to precede and inform integrated care, as getting holistic insights into the needs of patients (via the PCNA) can inform and create awareness of the need for (new) network relations, for instance. On the other hand do functional integrated care instruments, like a visual tool with information about patients' health care consumption (subgroup), create the right circumstances to take an informed person-centred approach during the PCNA.

Classification of people with chronic conditions

The classification of people (with chronic conditions) into subgroups with a distinct profile, also called 'population segmentation' is internationally seen as a promising strategy within the field of integrated care[1,16-20]. The idea behind it, is to make good use of resources and proactively organise strategies and tailor them to different identified subgroups which are relatively homogeneous in their needs[1,16,17]. Internationally, many different segmentation models for health care were developed over the years. Kaiser Permanente, the conceptual model presented by the National Academy of Medicine (NAM) and the 'Bridges to Health' approach, are well-known examples of influential and actionable segmentation models[21-24]. Despite (methodological) challenges, such as the small size of high-need subgroups, to make valid conclusions about the effects of segmentation, there are clear signs that segmentation can indeed inform care management[1,25]. This, in turn, leads to improved outcomes, such as decreased admission rates, more use of evidence-based preventive services and increased patients' self-confidence to manage their conditions[1,25].

In this dissertation, two different segmentation approaches were presented: a relatively simple threefold division in Chapter 1 and a more sophisticated segmentation based on biopsychosocial data in Chapter 2[26,27]. The three influential international segmentation models are partly similar to these two segmentation approaches[21-24]. A first similarity can be found in the use of existing (biomedical) electronic data. However, the second segmentation approach presented in this dissertation is unique because of the biopsychosocial comprehensiveness of the dataset. As stated by one of the interviewed professionals in this dissertation: "Of those 35% [of patient population] who visits the GP every single day, 80% has to deal with psychosocial problems" [7]. Hence overlooking social issues and patient information would leave professionals and organisations with a blurred understanding of what patients actually need, which limits the effectiveness of tailored population interventions in the end[23,28,29].

A second similarity pertains to the level of precision and number of subgroups that were created: a simple segmentation approach was preferred in this dissertation[21-24]. One of the main benefits of creating a limited number of subgroups relates to 'substantiality', which means that each subgroup is of considerable size[17,30]. This warrants the introduction of (new) strategies and interventions potentially supporting the subgroups[17,30]. The creation of subgroups of substantial size, with some degree of inevitable heterogeneity between included patients, seems to be at odds with realizing person-centred care where the individual needs and desires of people are acknowledged. However, it should be noted that a simple segmentation approach should mainly inform organizational-level interventions and strategies that can be used as a foundation for determining person-centred care plans in individual doctor-patient encounters. For some purposes, for instance to adjust for case mix in a capitation payment system, it may be helpful to design a more precise segmentation model with a high number of subgroups. For example the 3M Clinical Risk Groups classification methodology[31]. It uses a range of data, like inpatient diagnosis codes and pharmaceutical data, to allocate people to one of more than 200 groups.[31]

Similar integrated care initiatives

Reviews of the international literature show that the TARGET components, the population segmentation tool and in particular the PCNA and network support, are commonly implemented components of integrated care initiatives worldwide[32-36]. Also on a national level, partly comparable integrated care initiatives – in Dutch called 'Ketenzorg Ontketend' and 'CO-PILOT' – arose over the past few years[37-39]. Plans and experiences were shared on a regular basis amongst these initiatives during stakeholder meetings and (inter)national conferences. Commonalities between TARGET and the initiatives mentioned above include: (1) the aims, in the sense of striving for more person-centred care and overcoming fragmentation; (2) some of the basic program components, such as a holistic needs assessment; (3) the close cooperation between practice and science, as well as involvement of other stakeholders such as health insurers to build the right preconditions for integrated care. What makes TARGET unique is the aim to *transform* the current way of care delivery, while other initiatives are more focussing on *reforming* what is currently done. In 'Ketenzorg Ontketend' for instance, "the starting point is to reform the current Dutch disease management programs for people with diabetes, cardiovascular diseases and COPD, into one program for chronic conditions" [38,39]. This is a more conservative, incremental innovation than TARGET, which is aimed at transforming the current fragmented disease programs and supporting professionals to adopt a completely new way of integrated thinking and doing. More radical innovations like TARGET entail greater risks and ask for even larger investments in new skills than incremental innovations do. Nonetheless, the current alarming rise in the prevalence of chronic conditions accompanied by increasing workforce shortages need nothing less than a radical change and undivided attention for a new organisation of primary care[40,41].

Methodological considerations

Collaboration between science and practice

A close collaboration between science and practice was established from the beginning of the research described in this dissertation. This is not only demonstrated by the active participation of professionals and patients in the different scientific studies (Chapters 3, 5 and 6), but also by the different steering groups which were regularly informed about the study and consulted to translate research findings into a practical program. This science-practice collaboration has supported the development of the TARGET program and has shaped its implementation process. For example, the meetings with the ‘internal’ steering group – consisting of care professionals in the region of primary care group ‘Dokter Drenthe’– created (more) awareness of the large diversity between the practices and professionals. While some practices were quite multidisciplinary and had some experience with holistic assessments, others were more monodisciplinary and mainly worked in a standardized way. Practices also stressed the importance of some degree of autonomy within the program, for instance to continue using conversation instruments (for instance ‘My Positive Health’) they had positive experiences with. Therefore, it was decided to only offer professionals a basic set of components, tools and trainings within the pilot study, without fully prescribing how they should be implemented or blocking the use of additional or alternative tools. Hence practices could, amongst others, decide themselves how to select patients for a PCNA and what care professional(s) would perform the PCNAs.

People with chronic conditions were actively involved in this dissertation from the start: they were part of the ‘external’ steering group bringing together patient organisations and other stakeholders to co-create the program and patients were interviewed as part of the TARGET pilot study in Chapter 6. However, the active participation and consultation of patients did not equal that of professionals, who were interviewed in Chapters 3, 5 and 6 and took part in an ‘internal’ steering group that united only professionals. A principal focus on professionals was a conscious decision, as Dokter Drenthe perceives the high work pressure amongst professionals, which is also acknowledged internationally[42,43], as one of the most urgent reasons for re-organizing care. Not surprisingly, the Triple Aim was in 2014 expanded with a fourth aim to ‘improve the work life of health care providers’, as “care of the patient requires care of the provider”[44]. Hence our primary intention was to equip professionals with the right skills and tools to work in a more person-centred and integrated way, as made explicit in

TARGET's program theory (Chapter 4). Doing so – as we outline in Chapter 4 – can help to activate patients more, especially in the PCNA, where the holistic situation of a patient is discussed and patients should be equal partners to professionals. This dissertation at the same time underlines the importance of (more) active involvement of patients in further research and implementation efforts. As suggested by Chapters 3 and 6, there may be important barriers to integrated care (such as resistance to be referred) which exist on a patient level and need further exploration. That said, it should be noted that involving patients in research is challenging, as also identified in Chapter 6, where some patient interviews lacked depth. This struggle is also acknowledged by literature into inclusive research, which "epitomizes the transformation away from research *on* people, to research *with* them"[45]. Hence creative strategies, such as different ways of interviewing (in a discursive rather than a formal way) to make people feel comfortable, are needed to support people in active contribution to research[46]. All in all, active patient participation seems worthwhile, although it should always be considered it the light of why and how it is needed – especially because it is time intensive and requires creative strategies – and should never become a goal in itself.

Mixed-methods approach

In part I of this dissertation, we employed mixed-methods: the HNHC population was first unravelled into subgroups in a quantitative way (Chapter 2) and our understanding of these subgroups was subsequently deepened in a qualitative way (Chapter 3). Considering that the effectiveness of segmentation is determined by – amongst others – identifiability and actionability, pure reliance on quantitative data is insufficient. By interviewing professionals and gathering their ideas and experiences, it can be checked whether they recognize the identified segments (i.e. identifiability) and whether these segments provide enough guidance for decisions on what organisational strategies are needed (i.e. actionability)[17,30]. Furthermore, in-depth interviews are helpful to determine what and how these organisational strategies should specifically be designed to accommodate the needs of these segments, as was done in Chapter 3. Also internationally, it is acknowledged that asking primary care professionals for suggestions to refine data-driven segmentation approaches (for instance by adding new relevant variables) "can increase the usefulness of results, as well as frontline providers' willingness to use them"[25]. In practice, most existing tools are purely expert-driven, probably caused by the limited timely availability of electronic health record (EHR) data.[17,47] But using expert-input only may bring along limitations and bias as well. For instance, a recent review into population segmentation[17] found that expert-driven tools are commonly based on purely medical indicators. Data-driven tools, on the other hand, more often use social or socio-demographic data next to medical data, although this heavily depends on how adequately social patient data is registered[48,49]. Hence experts and data inevitably need each other in building segmentation tools: to identify subgroups based on a comprehensive set of relevant variables, and to make sense of them and link subgroups to actionable interventions.

Realist evaluation

In Part II of this dissertation, we gradually worked ‘towards a first implementation of the TARGET program in Dutch primary care’. For this part we chose to use the innovative evaluation approach called realist evaluation (RE) as a theoretical lens for designing, implementing and (small-scale) piloting the TARGET program[14,50]. This choice was influenced by the awareness, gained from Part I, that the setting of primary care is highly diverse, dynamic and above all complex. Primary care is continuously confronted with new policies and innovations, and Chapters 2 and 3 show that both professionals and patients differ considerably in what they want and need. Also, especially for care to people with chronic conditions, primary care needs cooperation with other disciplines and domains. This asks for RE, an evaluation approach that supports tailoring of the TARGET program. Furthermore, RE perceives the diversity in program implementation and context as helpful – instead of troublesome like in experimental designs – to answer interesting research questions, such as ‘how’ and ‘why’ programs work (or not)[14,50]. Doing so helps to retrieve transferable insights into program functioning, without losing the connection with outcomes. This means that the context (C) in which an intervention is implemented and may trigger certain mechanisms (determinants of behaviour) (M), is always perceived in the light of achieved outcomes (O)[14,50]. To assess the CMO-configurations, RE amongst others introduces new ways of interviewing, so-called realist interviewing. In those interviews, a hypothetical program theory consisting of CMO-configurations is explained by a researcher after which a respondent can explain and refine the program theory based on his/her experiences with the program in practice[51].

RE is increasingly being used because of a ‘changing conversation about causality’[52]. An experimental design used to be considered “the superior method for assessing causality”[13]. However, those designs generate results which are difficult to generalize to other settings or populations as – in the field of chronic care – the study population is often limited to people with a single condition and the context is controlled. What actually defines ‘superiority’ is the match between the methodological choices on the one hand and the study aims, the type of intervention and context, and the needs and wishes of the involved actors on the other[13]. Hence, an experimental design should be preferred only when: (1) the primary aim of a study is to – with the largest strength of evidence – find out program effects; and (2) the program in question and its context are simple and can be controlled. Not only a number of researchers still thinks of experimental designs as ‘the gold standard’ when evaluating effects of a program. The same may apply to other stakeholders, such as care professionals, health care insurance companies and funders of research. As such, it is crucial to make all actors involved in a study part of the 'changing conversation about causality' to avoid misunderstandings about the potential of RE and above all manage expectations. For instance, it is important to explain how RE offers a better alternative to experimental designs in certain cases and to have an open and honest discussion about what can be expected in terms of research findings and how different stakeholders can benefit from those findings.

Recommendations

Practice

For 15 years, since the introduction of the first disease management programs in Dutch primary care, professionals have been encouraged to place people into programs based on their chronic illness and offer largely medical and standardized care. Not surprisingly, current 'disease management' behaviour is deeply rooted in both professionals and their patients. Changing this behaviour and installing new routines in a successful way takes time en energy, as assumed in TARGET's program theory and supported by the pilot study. A first recommendation for primary care practice is therefore to give professionals time and space to install new integrated care behavioural routines. Behavioural theories can provide inspiration for how to change behaviour in an intrinsic way. Working from the self-determination theory (SDT)[53], it is crucial to find a good balance between enhancement of professionals' *autonomy* on the one hand, and stimulating *competence* (i.e. skills) and *relatedness* (i.e. social relations that can offer support and inspiration) on the other, to make sure that professionals feel enabled and confident to make autonomous choices.

A second recommendation for practice is to equally invest in changing the attitude and behaviour of patients. The TARGET pilot study showed that providers perceive patients to sometimes show resistance to a referral to another discipline. In addition, a discrete choice experiment with people with type-2 diabetes showed that people have clear preferences for the current way of care provision, i.e. being provided three or four consultations every year, regardless of whether this frequency is actually needed[54]. Similar to professionals, patients may be highly used to a 'disease management' approach and organization of care. Breaking these routines and installing new behaviour also requires a change in autonomy, competence en relatedness for patients[53]. As a starting point, it is important to make patients aware of the movement towards integrated care, what this means for their role in the care process, and how this can benefit them.

Thirdly, this dissertation gives reason to critically think about the different functions within general practice, the skill-mix, and the division of tasks between functions. Already in 2012, the Netherlands Institute for Health Services Research (Nivel in *Dutch*) concluded that while practice nurses are well-equipped to offer protocol-based care to people with chronic conditions, future competences (for instance to perform preventive tasks) “will ask for professionals who are educated in a more generalist way”[55]. Looking at the need to approach people with chronic conditions in a comprehensive way and to have good insight into the network of professionals surrounding the patient, it is questionable whether specialized practice nurses are future-proof. Throughout the country, general practices therefore currently experiment with generalist practice nurses[56]. It is important to give general practices freedom to experiment with different types of functions and to create the ideal skill-mix befitting their patient population and vision on care. To achieve this, practices first of all need insight into their skill-mix and how this matches with the care consumption and needs of their patient population. To this end, the TARGET digital segmentation tool should be expanded with information about the organization of practices, amongst others their skill-mix. This can be a starting point for improving the organization of care and achieving an adequate balance between supply and demand, not only within a general practice but also on the level of the primary care group.

Policy

To move towards an integrated, person-centred way of working in daily primary care practice (and its network), policy needs to create supporting circumstances and offer the right incentives. It is in the first place recommended that the payment system underlying chronic care management in primary care supports a person-centred approach, gives freedom to do ‘what is needed’ for a patient, and incentivizes intersectoral cooperation and referral. Those principles are not met by the current payment system underlying chronic care, which is aligned with disease management programs implying that fragmented fees per patient – for the management of a specific chronic condition – are provided and that cooperation is almost exclusively limited to primary care. For the future of the TARGET program, healthcare insurance company Zilveren Kruis has, in close cooperation with Dokter Drenthe, already taken first steps towards a more value-based payment system: since 2022, financial resources are bundled for practices that aim to work in an integrated care based on TARGET. Those practices receive a fixed fee per patient with a chronic condition per year to organize integrated, person-centred care befitting the needs of their population. This means that practices receive more autonomy and freedom, also in terms of registration of patient and health indicators. This underlines the importance to involve health care insurers from the early stages of research, which increases their willingness to make innovative contracting agreements that incentivize the new way of working. Overall, good examples of innovative payment systems seem scarce in the Netherlands and primary care regions need inspiration and guidance on how to make the payment system more value-based. The Dutch taskforce BUNDLE, which is recently established and includes researchers as well as national healthcare authorities, aims to assess different innovative payment models and develop an evidence-based guide to help practice to “initiate, adjust and/or continue payment reforms”[57].

A second recommendation for policy is to reconsider and, where possible, limit registration duties for primary care, in order to save more time for patient care. As found in Chapter 3 of this study as well as in a range of other scientific studies, primary care professionals report a high administrative burden, heavily impacting their work pressure[7,44,58]. At the same time, patient records are mainly filled with medical information, while social patient information – crucial to take a holistic approach to patients – is missing[48,49]. Different national organisations that represent primary care, i.e. InEen (in *Dutch*), the National GP Association (LHV in *Dutch*) and the Dutch GP Association (NHG in *Dutch*), call for more differentiation between practices in quality policies, which includes registration. A practice’s vision on care should be leading in how quality policy is established and trust – instead of control and accountability – should be a guiding principle[59]. This is in accordance with the viewpoint of Dokter Drenthe as to registration. Under the new agreement with Zilveren Kruis, practices are encouraged to only register a minimum set of standardized indicators for quality monitoring and improvement. Hence, they are largely free to decide what information is relevant and useful to register. Not only in primary care, but also on a system level, changes can be made to make registration more efficient. For instance, to avoid duplicate registration, information systems of different domains should be connected to each other and enable exchange of data[58].

In line with the need to be connected with other professionals by means of information systems, a third recommendation for policy is to invest in a stronger social domain surrounding primary care and enhance the network relations of primary care with this and other domains. After all, a substantial amount of a GP’s time is spent on social rather than medical determinants of health[60]. The fact that some regions introduce financial practice nurses while financial issues are not part of primary care’s main scope shows how much the social domain is failing to effectively help and guide people[61]. In a recently launched awareness campaign of the Dutch Care institute (Zorginstituut Nederland in *Dutch*) about the future of healthcare, one of the most frequently mentioned suggestions is to have more attention for the social root causes of health issues[62]. If those are not sufficiently addressed, these social vulnerabilities lead to high care demands[62]. If one wants to decrease work pressure in primary care, it is thus inevitable to enhance the capacity and functioning of the social domain in the future. This should be accompanied with efforts to stimulate primary care professionals to get to know professionals from social domain (and other domains) better, develop trust in each other, and incentivize cooperation between domains by creating a shared payment system[63,64]. In addition, in a recent column in a large Dutch newspaper (i.e. de Volkskrant in *Dutch*), a GP called for more strict 'gatekeeping' behaviour of GPs, also towards other professionals "who deposit their own tasks on the GP's plate"[65].

Research

Based on this dissertation, different recommendations can be given for how research is designed in the field of integrated care and what research questions should be addressed. In 2014, the European Commission initiated a large evaluation on integrated care[66]. The involved researchers had to conclude that the evidence on the economic impact of integrated care is weak and inconsistent. In their reflection on these disappointing results, they suggest that integrated care should not be seen as "an intervention that, by implication, ought to be cost-effective and support financial sustainability"[66]. Rather, it is "a complex strategy to innovate and implement long-lasting change in the way services in the health and social-care sectors are being delivered"[66]. This implies that evaluation approaches should embrace the complexity of integrated care and focus on 'how' innovations work, rather than 'if' they work. This is in line with the findings of this dissertation, and a first and foremost recommendation is therefore to move beyond the traditional 'hierarchy of evidence pyramid' and broadly consider relevant design options for evaluating integrated care, befitting the complex nature of such innovations[13]. RE is a promising and innovative approach to evaluate programs with an underlying complex theory and model of causality. RE above all offers concrete tools, such as CMO-configurations, to acquire an in-depth understanding of 'how, why and under what circumstances', programs work[14,50]. However, working with these tools and getting to know the philosophical foundation of RE takes time and training. Scientific education and training should thus also be focused on developing 'non-traditional' research knowledge and skills.

A second recommendation for research is to get insight into the long-term effects of TARGET, considered in the light of mechanisms and context playing a role. With financial support from health insurer Zilveren Kruis, a larger-scale implementation and realist evaluation of TARGET is currently performed over the course of one year. However, as supported by this study, long-term Quadruple Aim outcomes such as a decrease in work pressure and (related to that) a decrease in healthcare costs will take time. Therefore, measuring outcomes over several years is essential. This requires sufficient (financial) resources and patience. All stakeholders, including funders, should be made aware that patience is required and for what reasons. The long timeframe of an RE also underlines the importance to share results and findings throughout the study process, to ensure that stakeholders stay connected to the study and to give them opportunity to learn from intermediate research insights.

As a final recommendation for research: more insight is needed into the factors that hamper and facilitate strong network ties, cooperation and referrals. After all, strong network ties were identified in this dissertation as essential in relation to the success of TARGET, but efficient strategies to improve these ties seem to be lacking. Furthermore, this dissertation suggests that it is key to study these factor on a variety of levels, including the patient and professional level (and the interaction between those actors, the micro level), but also the macro level (e.g. policy and payment mechanisms) of the healthcare system. Intersectoral cooperation and referral (meso level) seems mainly studied in relation to the healthcare system and professionals, while patients are sometimes overlooked. Nonetheless, as found in this dissertation, the involvement of new disciplines is to a considerable extent hampered by barriers on the patient level, such as resistance of patients to be referred. Hence, in a follow-up study about network ties, but also generally speaking, it is important to more actively involve patients and acquire insight into their experiences and suggested solutions.

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Addenda

Summary

Life expectancy of people is growing worldwide and so does the prevalence of chronic conditions. Not rarely, people have more than one condition at once. This makes adequate management of their health and well-being complex, especially because a considerable number of people encounters challenges in other areas of life as well, such as a poor social network or poverty. Given these comprehensive needs of patients, it is not surprising that the – to date – still largely fragmented and medically-oriented healthcare systems lead to inefficiencies and frustration, for patients as well as professionals. In policy and practice, 'integrated, person-centred care' is considered a promising, new model of care that takes the needs of people (not conditions) as starting point to offer streamlined care and realize 'the right care in the right place'. But figuring out 'how' to design integrated, person-centred care, as well as how to implement and evaluate it in a meaningful way, remains a challenge. This dissertation addresses this challenge with the overarching aim to advance the field of integrated, person-centred care. To do so, two overarching objectives were formulated:

1. To increase insight into how an integrated, person-centred program for people with chronic conditions should be designed, taking into account the needs of this patient population as well as the organizational innovations needed to accommodate those needs.
2. To translate those insights into the TARGET integrated care program, prepare the implementation of this program and gather first implementation insights.

The scientific studies included in this dissertation came about in the context of a participative research commissioned and funded by Dokter Drenthe (formerly known as 'Huisartsenzorg Drenthe'), a primary care group that unites and promotes the interests of general practitioners (GPs) in the north of the Netherlands. The Dutch health insurance company Zilveren Kruis (Stichting Achmea Gezondheidszorg) was a second funder of this scientific work.

Chapter 1, the general introduction, describes the context in which this scientific work was performed. It is outlined how the traditional disease management approach has been beneficial to the healthcare system, but at the same time leads to suboptimal care for patients and a growing burden on healthcare professionals. The movement to integrated care is then discussed, including the use of population segmentation (i.e. allocating people to subgroups based on a similar profile of characteristics), which is an important starting point for integrated care. Before the research aims are discussed, this first chapter provides a description of the Dutch context, particularly the northern, predominantly rural region covered by primary care group 'Dokter Drenthe', in which this dissertation came about.

Chapter 2 is a large quantitative study about people with chronic conditions who use primary care most often, the so-called high-need, high-cost (HNHC) population. As this population has a large share of the total consumption of care, it is an interesting population to focus on if one wants to decrease work pressure. Chronically ill patients were included in the HNHC population if they belonged to the top 10% of care utilizers and/or suffered from multimorbidity and had an above-average care utilization. To understand what clinically relevant subgroups of HNHC patients could be unravelled, we used a sophisticated person-centred analysis technique called latent class analysis (LCA). Using a large dataset of 12,602 patients containing demographic, biomedical, socioeconomic and care utilization data, we were able to identify four distinct HNHC subgroups: 'older adults living with partner' (subgroup 1; 39.3% of patients), 'older adults living alone' (subgroup 2; 25.5% of patients), 'middle-aged, employed adults with family' (subgroup 3; 23.3% of patients), and 'middle-aged adults with social welfare dependency' (subgroup 4; 11.9% of patients). Although the subgroups have distinct characteristics in terms of demographic and socioeconomic characteristics, they are more similar in their most common chronic conditions, i.e. the most common condition is diabetes in all subgroups. This study suggests that the HNHC population in primary care is a heterogeneous population, which includes not only older adults but also groups of younger people, who more often have socioeconomic issues and mental health issues and thus need distinct types of care and support.

In order to validate the HNHC subgroups and discuss how the organization of care needs to be changed to accommodate their needs, a qualitative study was performed (**Chapter 3**). In five focus groups, 42 primary care professionals were interviewed about barriers and solutions with regards to person-centred, efficient care delivery to HNHC patients. Analysing the qualitative results from the perspective of the SELFIE framework for integrated care for multi-morbidity, we found out that the HNHC population, as expected, often has to deal with complex, biopsychosocial problems which are insufficiently addressed by the current system of care. Professionals mainly discussed barriers and solutions that were related to the doctor-patient interaction (micro-level) or practice organization (meso-level). In short, professionals mentioned a lack of time to take a comprehensive approach to patients, an insufficient number of skilled professionals to address the multidimensional needs of patients, and inefficient inter-professional patient information retrieval and sharing. However, on a macro level, professionals reported policies (unintentionally) leading to transferral of tasks from other, social or more specialized settings to primary care.

Based on the insights gained from Chapters 2 and 3, and in close cooperation with primary care group Dokter Drenthe and related steering groups, the TARGET program was developed. TARGET is the acronym for 'Targeting Advanced Resources in General practice to create Efficient, Tailored and holistic care for chronically ill patients'. To prepare TARGET’s first implementation and evaluation, two studies were performed. In the study reported in **Chapter 4**, we prepared the evaluation of TARGET methodologically by taking the first steps towards a realist evaluation (RE) of the program. This means that the initial program theory (IPT) of TARGET, specifying ‘how, why and under what circumstances’ the program is supposed to work, was elicited in a phased process. By describing the process of theory elicitation in detail, this paper also served to illustrate how RE could be applied and what benefits it has for the field of integrated care. A preliminary version of the IPT was developed by using existing theories on integrated care and insights from previous integrated care studies, including Chapters 2 and 3. During interviews with experts in RE, the IPT was finalized. A separate IPT for both professionals and patients was unravelled. Both IPTs are linked to each other and include ‘confidence’ as well as ‘mutual trust’ as key ‘soft’ mechanisms of change (often described as determinants of social behaviour), which only ‘fire’ when a supporting context is created, such as sufficient resources for integrated care (e.g. time). This study illustrated how RE has the potential to help researchers finding out ‘how and why’ integrated care works (or not), as opposed to the focus of traditional evaluation approaches on ‘if’ programs work. As such, RE delivers transferable insights, which are highly needed in order to advance successful implementation of integrated care.

To support the person-centred needs assessment (PCNA), one of the key program components of TARGET, we translated and contextualized a promising biopsychosocial tool, the Patient Centered Needs Assessment (PCAM), to Dutch in **Chapter 5**. To create a contextualized translation, the World Health Organization (WHO) guidelines about the process of translation and adaptation of instruments were followed. Furthermore, there were knowledge gaps regarding the psychometric properties and value of the tool for integrated care. Therefore, we assessed the (face) validity, reliability, value and feasibility of the PCAM as implemented during the TARGET pilot study. It was found that the tool has mainly value for scientific measurement of patient needs and to support determining required follow-up actions for patients after a needs assessment. Hence, the PCAM has good reliability (Cronbach’s alpha is 0.83). The four-factor structure that was tested, with a factor for each of the four biopsychosocial domains, showed adequate fit. As the PCAM was not fully tested as conversation tool during the pilot of TARGET, conclusions about the tool in this function should be drawn carefully. Still, the criticism on the PCAM in this function uncovers the difference between the biopsychosocial model of illness underlying the tool, which is more comprehensive than the medical model but still is more conservative than the broad concept of person-centred care. As professionals argued that the main focus should be on how patients experience their health and what they prioritize, development of a patient version of the tool is recommended.

The preparatory steps taken in the chapters described above, among others, enabled a small-scale pilot test of the TARGET program in practice, described in **Chapter 6**. Main aims were to get insight into the program's feasibility and acceptability, and to learn first lessons about the preconditions for successful larger-scale implementation of TARGET in the future. Seven frontrunner general practices experimented with the first two program components of TARGET, including accompanying tools and trainings: the digital population segmentation tool to identify the subgroup of patients (with chronic conditions) with the highest care needs, and the PCNA which is a comprehensive assessment about the biopsychosocial needs of patients and required follow-up actions. The pilot lasted six months and started in August 2020. Different methods were used: a review of the digital segmentation tool, observations of trainings and 15 PCNAs, and interviews with professionals (n= 15) and patients who received a PCNA (n= 12). Findings suggest that the content of the program is feasible and acceptable for both professionals and patients: the offered tools and trainings enable professionals to use the segmentation tool and engage in the PCNA. The PCNAs were highly valued by both professionals and patients, as these assessments provide new insights into patients' health and well-being. However, the process of implementation needs more attention: team commitment to TARGET is key and to enhance cooperation and referral, professionals need stronger network ties and patients need more encouragement to be referred to for instance mental health or social services.

To conclude, in **Chapter 7**, a reflection was given on the main findings of this dissertation from a theoretical and methodological perspective. This resulted in recommendations for practice, policy and research. Firstly, both 'integrated care' and 'person-centred care' are umbrella terms with slightly different meanings. It is argued that this 'dynamic' nature of terminology is helpful (instead of troublesome from a traditional research approach) to make terms relevant for different stakeholders. Secondly, the population segmentation approaches presented in this dissertation are partly similar to well-known international approaches, but unique because of the social comprehensiveness of underlying data. Thirdly, while TARGET bears similarity to other Dutch integrated care initiatives, it is more innovative in its focus on transforming rather than reforming the current approach to chronic care. Regarding the methodological considerations, the broad science-practice collaboration underlying TARGET, with a predominant and deliberate focus on healthcare professionals, was firstly discussed. The findings of this dissertation at the same time underline the need to get more insight into patient experiences and barriers in relation to integrated care. Secondly, in Part I of this dissertation, a mixed-methods approach was employed in order to develop a segmentation approach based on a comprehensive dataset and subsequently make the segments actionable. Despite these benefits, also acknowledged internationally, segmentation approaches are rarely designed based on mixed methods. Last methodological consideration is related to RE. This dissertation, especially Part II, highlights the need to think more critically about methodological choices, which should not be determined by the traditional ‘hierarchy of evidence pyramid’ but rather by the study aims, setting and stakeholders.

Addenda

Samenvatting

De levensverwachting van mensen neemt wereldwijd toe en dat geldt ook voor de prevalentie van chronische aandoeningen. Niet zelden hebben mensen meer dan één aandoening tegelijk (i.e. multimorbiditeit). Dit maakt het adequaat managen van hun gezondheid en welzijn complex, vooral omdat een aanzienlijk aantal mensen ook op andere levensterreinen met uitdagingen te maken krijgt, zoals een slecht sociaal netwerk of armoede. Gezien deze complexe behoeften van patiënten is het niet verwonderlijk dat de – tot op heden – nog steeds grotendeels gefragmenteerde en medisch georiënteerde zorgsystemen leiden tot inefficiënties en frustratie, voor zowel patiënten als professionals. In beleid en praktijk wordt 'integrale, persoonsgerichte zorg' gezien als een veelbelovend, nieuw zorgmodel dat de behoefte van mensen (niet hun aandoeningen) als uitgangspunt neemt om gestroomlijnde zorg te bieden en 'de juiste zorg op de juiste plek' te realiseren. Maar het blijft een uitdaging om erachter te komen 'hoe' integrale, persoonsgerichte zorg het best ontwikkeld wordt, en hoe dit op een zinvolle manier kan worden geïmplementeerd en geëvalueerd. Dit proefschrift pakt deze uitdaging aan met het overkoepelende doel om het veld van integrale, persoonsgerichte zorg vooruit te helpen. Hiervoor zijn twee overkoepelende doelstellingen geformuleerd:

1. Inzicht vergroten in hoe een integraal, persoonsgericht programma voor mensen met chronische aandoeningen het best ontwikkeld wordt, rekening houdend met de behoeften van deze patiëntpopulatie en met de organisatorische innovaties die nodig zijn om aan die behoeften tegemoet te komen.
2. Deze inzichten vertalen naar het TARGET integrale zorgprogramma, de implementatie van dit programma voorbereiden en eerste implementatie-inzichten verzamelen.

De wetenschappelijke studies die in dit proefschrift zijn opgenomen, zijn tot stand gekomen in het kader van een participatief onderzoek in opdracht van en gefinancierd door Dokter Drenthe (voorheen bekend als 'Huisartsenzorg Drenthe'), een zorggroep die huisartsen in het noorden van het land verenigt en hun belangen behartigt. De Nederlandse zorgverzekeraar Zilveren Kruis (Stichting Achmea Gezondheidszorg) was een tweede financier van dit wetenschappelijke werk.

Hoofdstuk 1, de algemene inleiding, beschrijft de context waarin dit wetenschappelijk werk werd verricht. Er wordt geschetst hoe de traditionele benadering van ziektemanagement gunstig is geweest voor het zorgsysteem, maar tegelijkertijd niet leidt tot optimale zorg voor patiënten en een groeiende druk op professionals. Vervolgens wordt de beweging naar integrale zorg besproken, inclusief het gebruik van populatiesegmentatie (d.w.z. het toewijzen van mensen aan subgroepen op basis van een vergelijkbaar profiel van kenmerken), wat een belangrijk uitgangspunt is voor integrale zorg. Voordat de onderzoeksdoelen aan bod komen, wordt in dit eerste hoofdstuk een beschrijving gegeven van de Nederlandse context, in het bijzonder het noordelijke, overwegend landelijke gebied van zorggroep ‘Dokter Drenthe’, waarin dit proefschrift tot stand kwam.

Hoofdstuk 2 is een groot kwantitatief onderzoek over mensen met chronische aandoeningen die het meest gebruik maken van de huisartsenzorg, de zogenaamde ‘high-need, high-cost’ (HNHC) populatie, in het Nederlands ook wel frequente bezoekers genaamd. Aangezien deze populatie een groot aandeel heeft in de totale zorgconsumptie, is het een interessante populatie om op te focussen als je werkdruk wilt verlagen. Chronisch zieke patiënten werden geïncludeerd in de HNHC-populatie als ze tot de top 10% van zorgvragers behoorden en/of multimorbiditeit hadden in combinatie met een bovengemiddeld zorggebruik. Om te begrijpen welke klinisch relevante subgroepen van HNHC-patiënten kunnen worden ontrafeld, gebruikten we een geavanceerde persoonsgerichte analysetechniek, ‘latent class analysis’ (LCA) genaamd. Met behulp van een grote dataset van 12.602 patiënten met demografische-, biomedische-, sociaaleconomische- en zorggebruiksgegevens, konden we vier verschillende HNHC-subgroepen identificeren: 'oudere mensen die samenwonen met een partner' (subgroep 1; 39,3% van de patiënten), 'alleenstaande oudere mensen' (subgroep 2; 25,5% van de patiënten), 'werkende mensen van middelbare leeftijd met gezin' (subgroep 3; 23,3% van de patiënten) en ‘mensen van middelbare leeftijd met uitkeringsafhankelijkheid' (subgroep 4; 11,9% van de patiënten). Hoewel de subgroepen verschillende demografische en sociaaleconomische kenmerken hebben, lijken ze meer op elkaar in hun meest voorkomende chronische aandoeningen, d.w.z. de meest voorkomende aandoening is diabetes in alle subgroepen. Deze studie suggereert dat de HNHC-populatie in de huisartsenzorg een heterogene populatie is, die niet alleen oudere mensen omvat, maar ook groepen jongere mensen, die vaker sociaaleconomische problemen en psychische problemen hebben en dus verschillende soorten zorg en ondersteuning nodig hebben.

Om de HNHC-subgroepen te valideren en te bespreken hoe de organisatie van de zorg moet worden aangepast aan hun behoeften, is een kwalitatief onderzoek uitgevoerd (**Hoofdstuk 3**). In vijf focusgroepen werden 42 eerstelijnszorgprofessionals geïnterviewd over belemmeringen en oplossingen met betrekking tot persoonsgerichte, efficiënte zorgverlening aan HNHC-patiënten. Door de kwalitatieve resultaten te analyseren vanuit het perspectief van het SELFIE-raamwerk voor geïntegreerde zorg voor multimorbiditeit, kwamen we erachter dat de HNHC-populatie, zoals verwacht, vaak te maken heeft met complexe, biopsychosociale problemen die onvoldoende worden aangepakt door het huidige zorgsysteem. Professionals bespraken vooral belemmeringen en oplossingen die gerelateerd waren aan de arts-patiënt interactie (micro-niveau) of de praktijkorganisatie (meso-niveau). In het kort, professionals noemden een gebrek aan tijd om patiënten op een holistische manier te benaderen, een ontoereikend aantal bekwame professionals om de complexe behoeften van patiënten aan te pakken, en inefficiënties in het opvragen en delen van patiëntinformatie tussen professionals. Op macroniveau rapporteerden professionals beleid dat (onbedoeld) leidt tot overdracht van taken van andere, sociale of meer gespecialiseerde settingen naar de eerstelijnszorg.

Op basis van de inzichten uit hoofdstukken 2 en 3 werd het TARGET-programma in nauwe samenwerking met zorggroep Dokter Drenthe en de opgezette stuurgroepen ontwikkeld. TARGET is de afkorting van 'Targeting Advanced Resources in General practice to create Efficient, Tailored and holistic care for chronically ill patients'. Om de eerste implementatie en evaluatie van TARGET voor te bereiden, zijn twee onderzoeken gedaan. In de studie gerapporteerd in **Hoofdstuk 4** hebben we de evaluatie van TARGET methodologisch voorbereid door de eerste stappen te zetten naar een realistische evaluatie (RE) van het programma. Dit betekent dat de initiële programmatheorie (IPT) van TARGET, waarin wordt gespecificeerd 'hoe, waarom en onder welke omstandigheden' het programma zou moeten werken, gefaseerd tot stand is gekomen. Door het proces van theorievorming in detail te beschrijven, diende dit document ook als illustratie hoe RE zou kunnen worden toegepast en welke voordelen het heeft voor het veld van integrale zorg. Een voorlopige versie van de IPT werd ontwikkeld door gebruik te maken van bestaande theorieën over integrale zorg en inzichten uit eerdere studies naar integrale zorg, waaronder hoofdstuk 2 en 3. Tijdens interviews met experts in RE is de IPT definitief gemaakt. Een aparte IPT voor zowel professionals als patiënten werd ontrafeld. Beide IPTs zijn met elkaar verbonden en omvatten zowel '(zelf)vertrouwen' als 'wederzijds vertrouwen' als belangrijke 'zachte' mechanismen van verandering (vaak beschreven als determinanten van sociaal gedrag), die alleen 'ontvlammen' wanneer een ondersteunende context wordt gecreëerd, zoals voldoende middelen voor integrale zorg (bijvoorbeeld tijd). Deze studie illustreerde hoe RE het potentieel heeft om onderzoekers te helpen ontdekken 'hoe en waarom' integrale zorg werkt (of niet), in tegenstelling tot de focus van traditionele evaluatiebenaderingen op 'of' programma's werken. Als zodanig levert RE overdraagbare inzichten, die hard nodig zijn om een succesvolle implementatie van integrale zorg te bevorderen.

Ter ondersteuning van het persoonsgerichte gesprek, een van de belangrijkste programmacomponenten van TARGET, hebben we in **Hoofdstuk 5** een veelbelovend biopsychosociaal instrument, de Patient Centered Needs Assessment (PCAM), vertaald en gecontextualiseerd naar het Nederlands. Om een gecontextualiseerde vertaling te maken, werden de richtlijnen van de Wereldgezondheidsorganisatie gevolgd over het proces van vertaling en aanpassing van instrumenten. Verder ontbrak er kennis over de psychometrische eigenschappen en waarde van het instrument voor integrale zorg. Daarom hebben we de (indruks)validiteit, betrouwbaarheid, waarde en haalbaarheid van de PCAM zoals geïmplementeerd tijdens de TARGET-pilotstudie beoordeeld. Het bleek dat het instrument vooral waardevol is voor het wetenschappelijk meten van de behoeften van patiënten en voor het bepalen van de benodigde vervolgacties voor patiënten na een persoonsgericht gesprek. De PCAM heeft dus een goede betrouwbaarheid (Cronbach's alpha is 0,83). De vierfactorstructuur die werd getest, met een factor voor elk van de vier biopsychosociale domeinen, bleek passend te zijn. Aangezien de PCAM tijdens de pilot van TARGET niet volledig is getest als gespreksinstrument, moeten we voorzichtig zijn met het trekken van conclusies over het instrument in deze functie. Toch onthult de kritiek op de PCAM in deze functie het verschil tussen het biopsychosociale ziektemodel dat aan het instrument ten grondslag ligt, dat uitgebreider is dan het medische model, maar nog steeds conservatiever is dan het brede concept van persoonsgerichte zorg. Omdat professionals betoogden dat de belangrijkste focus zou moeten liggen op hoe patiënten hun gezondheid ervaren en wat zij prioriteit geven, wordt de ontwikkeling van een patiëntenversie van het instrument bovendien aanbevolen.

Mede door de voorbereidende stappen in de hierboven beschreven hoofdstukken is een kleinschalige pilottest van het TARGET-programma in de praktijk mogelijk gemaakt, zoals beschreven in **Hoofdstuk 6**. Hoofddoelen waren inzicht te krijgen in de haalbaarheid en acceptatie van het programma en eerste lessen te trekken over de randvoorwaarden voor een succesvolle grootschaligere implementatie van TARGET in de toekomst. Zeven vooroplopende huisartsenpraktijken hebben geëxperimenteerd met de eerste twee programmacomponenten van TARGET, inclusief bijbehorende instrumenten en trainingen: het digitale populatiesegmentatie-instrument om de subgroep van patiënten (met chronische aandoeningen) met de hoogste zorgbehoeften te identificeren, en het persoonsgerichte gesprek dat een uitgebreid gesprek is over de biopsychosociale behoeften van patiënten en de benodigde vervolgacties. De pilot duurde zes maanden en ging van start in augustus 2020. Er zijn verschillende methoden gebruikt: een review van het digitale segmentatie-instrument, observaties van trainingen en 15 persoonsgerichte gesprekken, en interviews met professionals (n=15) en patiënten die een persoonsgericht gesprek hadden gehad (n=12). De resultaten laten zien dat de inhoud van het programma haalbaar en acceptabel is voor zowel professionals als patiënten: de aangeboden instrumenten en trainingen stellen professionals in staat om de segmentatietool te gebruiken en een persoonsgericht gesprek te voeren. De persoonsgerichte gesprekken werden zeer gewaardeerd door zowel professionals als patiënten, omdat deze gesprekken nieuwe inzichten opleveren in de gezondheid en het welzijn van patiënten. Het implementatieproces heeft echter meer aandacht nodig: teambetrokkenheid bij TARGET is essentieel en om samenwerking en verwijzing te verbeteren, professionals hebben sterkere netwerkrelaties nodig en patiënten moeten meer aangemoedigd worden om doorverwezen te worden naar bijvoorbeeld de geestelijke gezondheidszorg of het sociaal domein.

Om af te sluiten, werd in **Hoofdstuk 7** een reflectie gegeven op de belangrijkste bevindingen van dit proefschrift vanuit een theoretisch en methodologisch perspectief.

Dit resulteerde in aanbevelingen voor praktijk, beleid en onderzoek. Ten eerste zijn zowel ‘integrale zorg’ als ‘persoonsgerichte zorg’ overkoepelende termen met enigszins verschillende betekenissen. De 'dynamische' aard van terminologie is (in plaats van lastig vanuit een traditionele onderzoeksaanpak) nuttig om termen relevant te maken voor verschillende betrokkenen. Ten tweede zijn de benaderingen voor populatiesegmentatie die in dit proefschrift worden gepresenteerd, deels vergelijkbaar met bekende internationale benaderingen, maar uniek vanwege de brede sociale kenmerken waarop de segmentatie gebaseerd is. Ten derde, hoewel TARGET lijkt op andere Nederlandse integrale zorginitiatieven, is het meer innovatief in zijn focus op het transformeren in plaats van het hervormen van de huidige benadering van chronische zorg. Wat de methodologische overwegingen betreft, werd eerst de brede samenwerking tussen wetenschap en praktijk die ten grondslag ligt aan TARGET, met voornamelijk en bewust een focus op professionals in de gezondheidszorg, besproken. De bevindingen van dit proefschrift onderstrepen tegelijkertijd de noodzaak om meer inzicht te krijgen in patiëntervaringen en -belemmeringen in relatie tot integrale zorg. Ten tweede werd in deel I van dit proefschrift een mixed-methods aanpak gebruikt om een segmentatiebenadering te ontwikkelen op basis van een uitgebreide dataset en vervolgens de segmenten bruikbaar te maken. Ondanks deze voordelen, die ook internationaal worden erkend, worden segmentatiebenaderingen zelden ontworpen op basis van mixed-methods. De laatste methodologische overweging heeft betrekking op RE. Dit proefschrift, met name deel II, benadrukt de noodzaak om kritischer na te denken over methodologische keuzes, die niet bepaald zouden moeten worden door de traditionele 'hiërarchie van bewijspiramide', maar eerder door de onderzoeksdoelen, setting en betrokkenen.

Addenda

Impact

The studies included in this dissertation were performed within the Living Lab for Sustainable Care (AWDZ)[1] at Maastricht University, in which a close collaboration is developed between policy, practice, research and education. Main reason for introducing this living lab in 2013 is to make sure that research is not done from an ivory tower, but is responsive to the needs of patients, professionals and the society as a whole and can create a societal impact by informing, inspiring and actually changing policy, practice and education. Additionally, conducting research within this living lab improves the scientific impact of our work as the lab unites researchers with expertise covering the wide field of health services research and with experience in a range of methodologies. This provides opportunities to share, discuss, and reflect on each other's scientific work. In this chapter, it is outlined how this dissertation specifically has an impact on society as well as science.

Societal impact

The societal impact of this dissertation is visible at different levels of the healthcare system, first of all on a meso level (care groups and affiliated practices; health insurers) and micro level (patients and doctor-patient interaction) and via these levels also on a macro level (national branch organizations and policymakers). The scientific work in this dissertation responds to developments in practice: it was even initiated by practice in 2016, specifically by primary care group 'Dokter Drenthe'. This is a good start to increase the chances that scientific research has a high societal impact. Dokter Drenthe received signals from affiliated general practices about increasing work pressure, while the accumulation of disease management programs did not enable professionals sufficiently to provide the right care and guidance to a growing group of people with one and multiple chronic illnesses. Although Dokter Drenthe is a frontrunner, the need to change the current organization of primary care was also acknowledged nationally. In the Woudschoten conference in 2019[2], initiated by a large coalition of general practitioner (GP) organisations, the core values of GP care were revised towards more 'integrated, person-centred care' in reaction to a growing burden on GPs. The value 'personal care' was changed into 'person-centred care' stressing a (more) active role for the patient. At the same time, 'jointly' was added as a core value because collaboration with patients as well as with professionals within and outside primary care is becoming increasingly important.

In a close collaboration between practice and science, with different steering groups and much interaction with Dokter Drenthe, the TARGET program was developed, consisting of several concrete tools and trainings to enhance professionals' skills to design care in an integrated way. The pilot study of TARGET has shown that this program has the potential to actually change and improve practice and make it more sustainable for the future, which is a first clear sign of societal impact of this dissertation. On a meso level, primary care professionals learned new skills due to the program's concrete tools and trainings, for instance to use and interpret a digital population segmentation tool. As this tool was well received, the Dutch software company Calculus, who is the founder of the widespread used software program (i.e. VIPLive) to facilitate reimbursements in general practice, is making efforts to integrate the tool into VIPLive or an equivalent existing program. As such, the segmentation tool will also be available for other regions, of which several showed great interest to use the tool as well. In addition, professionals' skills to engage in a comprehensive person-centred needs assessment (PCNA) were enhanced by the offered conversational training as well as the 'My Positive Health' tool. The PCNAs led and will lead to meaningful interactions between patients and professionals on micro level, which offer professionals new insights into patients. In addition, patients are encouraged to focus more on the positive aspects of their health and well-being, which is appreciated by both professionals and patients. Given that professionals need more holistic (conversational) skills to engage in integrated, person-centred care and that the type of information registered after holistic assessments such as TARGET's PCNA is different from regular consultations, this dissertation also gives reason for a debate about the future of primary care nation-wide. Especially practice nurses, who have an active role in holistic assessments, but are educated in a specialized way, may need more holistic skills. Moreover, practices should be given more freedom to design their own quality policy and decide what patient information is worth registering, not only for the quality and safety of care but also to support referral of patients and cooperation with other domains.

Furthermore, the close interaction with practice and policy (among others Dokter Drenthe and health insurer Zilveren Kruis) and the choice to design and evaluate TARGET according to realist evaluation (RE), supports structural embedding of the integrated care efforts in practice and avoids waste of scarce resources. This is a second sign of societal impact. The use of RE draws our attention to the preconditions for successful functioning and embedding of TARGET in practice, like team commitment to the implementation and strong network ties. Furthermore, instead of perceiving integrated care as a project, Dokter Drenthe perceives integrated, person-centred care as a long-term vision to make primary care sustainable. For example, Dokter Drenthe makes the TARGET trainings part of their regular education program. Also, the TARGET study was presented and discussed at several editions of the annual regional meetings of Dokter Drenthe. Zilveren Kruis also perceives the TARGET study as one of a few pilots around integrated care nationwide, which can be used as a source of inspiration and guidance for other regions. To this end, several meetings with Zilveren Kruis took place over the previous years to share and reflect upon new insights into integrated care. Together, Dokter Drenthe and Zilveren Kruis have already reached new agreements about the purchase and funding of care to people with chronic conditions, befitting a new integrated way of working.

A last sign of societal impact relates to the fact that insights into the design and implementation of TARGET were shared with other primary care groups (meso-level) and national branch organisations like InEen (macro-level). Over the years, TARGET insights were shared at several InEen theme meetings around integrated care and meetings with researchers involved in other, comparable Dutch integrated care initiatives called Ketenzorg Ontketend[3] and CO-PILOT[4] (in *Dutch*). Also, besides the scientific publications, results were disseminated to a Dutch audience in an accessible way: An article about the development of TARGET was published on online platform 'De Eerstelijns' and an infographic about high-need, high-cost patients was published in Skipr Quarterly Magazine. This helps other primary care groups to learn from the transferable insights into the TARGET program, without having to 'reinvent the wheel'. Moreover, InEen, who promotes the interests of care groups on a national level, can put the recommendations for integrated, person-centred care flowing from this dissertation high on the agenda of national policy makers. Also internationally, different stakeholders (e.g. health insurers) showed interest in the reorganization of primary care according to TARGET and insights were shared in seminars.

Scientific impact

The scientific impact of this dissertation is two-fold. Firstly, it contributes to the knowledge base about the need for integrated, person-centred care as well as the organizational innovations required to accommodate those needs. Secondly, it provides methodological guidance and inspiration for designing and implementing inherently complex integrated care programs.

With regards to the first source of scientific impact, this dissertation was one of the first that created insight into a Dutch high-need, high-cost (HNHC) population in primary care and subgroups within this specific population, based on a large and biopsychosocial dataset and by using a sophisticated analysis technique called latent class analysis (LCA). The US is a frontrunner in research on this small subgroup of the population accounting for a large degree of the care consumption in the healthcare system[5]. Insights into this HNHC population provide a scientific foundation for re-organizing care on the level of the general practice, but also regionally and even nationally. Furthermore, comparable integrated care programs also have used our HNHC-population insights for the implementation of their programs[4]. The quantitative HNHC-subgroups were interpreted qualitatively and made actionable by discussing – with primary care professionals – all healthcare strategies and interventions that were needed to accommodate their needs.

Not only the actionable subgroups, but also the scientific process used to develop these, can provide guidance and inspiration to other researchers in the field of integrated care.

A second way this dissertation impacts science, is related to the methodological guidance to perform a RE of integrated care. Too often, experimental studies of integrated care disappointingly lead to conclusions that evidence on outcomes is weak or inconsistent, leaving researchers with a 'black box' about how and why outcomes were only partly or not achieved[6]. For researchers to increase their insight into the working mechanisms and contextual dependency of complex programs, in relation to the achieved outcomes, RE offers a promising approach[7]. As RE is growing in use in social sciences but is still relatively new and as different ideas (including misconceptions) exist about RE and its concepts[8], this dissertation offers necessary guidance and inspiration for how to conduct a RE. With financial support from healthcare insurer Zilveren Kruis, next steps in the RE of TARGET are taken in the region of Drenthe, and the complete RE will be shared with other researchers in detail.

To share knowledge gained by this dissertation for scientific purposes, Chapters 2 to 6 were submitted to peer-reviewed, scientific journals, of which the majority (i.e. Chapters 2 to 5) has been published, in an open access way. Besides, various (poster) presentations were given at (inter)national scientific conferences, ranging from the annual research meeting of the Amercian AcademyHealth organization to the Dutch 'science day' of the scientific GP association called NHG.

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Addenda

Dankwoord

Als ik één ding geleerd heb in dit promotietraject is dat niks zo belangrijk is als omringd te worden door hele fijne collega's. Ook zoveel andere mensen, in mijn familie en vriendenkring, hebben ervoor gezorgd dat ik altijd met goede moed bleef doorgaan. Al die mensen wil ik in dit dankwoord eens flink in het zonnetje zetten.

Mijn dank gaat allereerst uit naar mijn promotieteam: Dirk Ruwaard, Arianne Elissen en Mariëlle Kroese. **Dirk**, je zei wel vaker: “Rowan komt uit het zuiden, maar ze is nogal calvinistisch van aard.” Daar heb je waarschijnlijk gelijk in, maar ook jij hebt duidelijk calvinistische trekjes☺. Ondanks je razend drukke baan, sloeg je geen feedbackronde over. En wanneer er (moeilijke) beslissingen gemaakt moesten worden, was jij diegene die alle argumenten op een rijtje zette, de overwegingen hardop liet horen en samen met ons knopen doorhakte. Duizendmaal dank, voor al je vertrouwen in mij, voor de keren dat je samen met Arianne en mij bent gaan zitten toen het me te veel werd, voor je wijsheid en relativeringsvermogen en de fijne persoon die je bent. **Arianne**, ik kende je al uit de Masterfase aan de UM. Die leuke, relaxte en héél erg kundige en interessante vrouw kwam ik weer tegen tijdens een sollicitatiegesprek voor een PhD-plek. Die indruk uit mijn studietijd maakte je helemaal waar en meer. Elk overleg wist jij weer net die dingen te zeggen die de boel ineens totaal voor mij ophelderden. Je barst van talent in je werk en ik kan alleen maar jaloers worden van de manier waarop jij schrijft, presenteert, met studenten omgaat en thuis ook nog eens alle ballen hooghoudt. Dankjewel lieve Arianne, ik hoop nog heel lang met je te werken. **Mariëlle**, aan het begin van mijn traject hebben we vaker samen de wereldreis naar Drenthe gemaakt. Tijdens die autoritjes viel er geen moment van stilte en zelfs toen we ’s avonds laat op weg naar Drenthe langs de snelweg strandden, zorgde jij ervoor dat we bleven lachen (al was het maar om de niet onknappe ANWB-meneer☺). Dankjewel voor je oog voor detail, het vertrouwen dat je mij gaf en je aandacht voor mij als persoon. Dan niet te vergeten: Dorijn Hertroijs en Niels Hameleers. Officieel waren waren jullie geen onderdeel van mijn promotieteam, maar dat voelde wel zo. **Dorijn**, voornamelijk in de laatste jaren, toen TARGET echt vorm had gekregen, zijn we nauw gaan samenwerken. Je vult mij perfect aan, met je humor, vrolijkheid en relativeringsvermogen. Binnen een mum van tijd kende jij het TARGET-onderzoek door en door. Wanneer ik bleef malen over het beste plan van aanpak, hielp jij me om keuzes te maken en door te gaan. **Niels**, in het begin van mijn promotieonderzoek hielp jij als data scientist bij het voorbereiden van de data voor mijn oh zo geliefde latente klassen analyse. Wat had ik zonder jou gemoeten! Je hebt bergen verzet en in duizend-en-een syntaxen toegewerkt naar een werkbare dataset. Niet gek dat je wel eens zei: “Als Rowan vakantie heeft, dan heb ik dat ook.” Je stond altijd klaar om te helpen en ik kon over werkelijk elk onderwerp met je sparren. Je hield me figuurlijk (maar soms ook letterlijk als echte gentleman☺) uit de wind (en de regen) en daarvoor mijn grote dank.

Dan wil ik mijn beoordelingscommissie bedanken, voor de tijd die ze vrij hebben gemaakt om mijn meer dan tweehonderd pagina's tellende proefschrift door te nemen en van een deskundige beoordeling te voorzien: prof. dr. **Jako Burgers**, prof. dr. **Jane Murray Cramm**, prof. dr. **Mieke Rijken**, prof. dr. **Aggie Paulus** en dr. **Bert Vrijhoef**.

A big thank you to dr. Ferdinand Mukumbang, with whom I cooperated with in the realist evaluation study. Dear **Ferdinand**, thank you for your expertise and support in taking our first steps in this (back then) completely new approach for us. The paper got so much more philosophical depth because of you. It even resulted in a Milbank Quarterly paper, which is still beyond my imagination.

Als ik mensen vertelde dat de opdrachtgever van mijn promotieonderzoek in Assen gevestigd was, kreeg ik altijd verbaasde reacties. Maar beste mensen van zorggroep **Dokter Drenthe** (Ik wilde bijna HZD zeggen…☺), jullie waren zo ambitieus en enthousiast, dat de grote afstand tot Maastricht jullie niks uitmaakte: als één van de eersten merkten jullie op dat 'die wildgroei aan ketenzorgprogramma's' niet langer kon doorgaan en er drastische verandering nodig was. Ik bewonder jullie innovatieve instelling: vanaf 2016 gingen jullie met ons 'een zoektocht' aan, zoals Ron het soms verwoordde. Die tocht was niet simpel, immers was er ons nog nooit iemand voorgegaan. Maar samen bouwden we stap voor stap een programma, jullie hielpen het in de praktijk te brengen en wij onderzochten het. Dit was allemaal nooit mogelijk geweest zonder de toewijding, het meedenken en meedoen van zoveel **zorgverleners en patiënten in de Drentse regio**, ontzettend bedankt! In het bijzonder wil ik natuurlijk **Ron Wissink**, **Stefan Meinema** en **Jan Schaart** bedanken, directeuren en respectievelijk voorzitter en leden van de raad van bestuur van Dokter Drenthe. Heren, in onze 'stuurgroepoverleggen' maakten jullie het ons niet altijd makkelijk, scherp als jullie waren. Maar altijd zat er een kern van waarheid in jullie boodschap en brachten jullie het project verder. Dank voor jullie vertrouwen al die jaren. Intensief heb ik daarnaast samengewerkt met Sophie de Reus-Spoorenberg en Ingeborg Weuring (die in het begin het stokje overnam van Siska van der Vlugt als ons aanspreekpunt). **Sophie**, toen jij ons eerste aanspreekpunt werd, kwam het project in een stroomversnelling. Op jouw initiatief planden we (jij, Dorijn en ik) lange tijd elke week een overleg in, vaak op maandagochtend, waardoor het bespreken van het weekend elke keer bovenaan onze agenda stond. Door je achtergrond in de wetenschap, je kundigheid en je warme persoonlijkheid was er direct een klik, en konden we altijd goed sparren. Ook jij hebt wat calvinistisch bloed en bent niet snel tevreden, maar weet wel: het TARGET-programma was zonder jou nooit zover gekomen. **Ingeborg**, je kon altijd rake en kritische vragen stellen over onze plannen en ideeën en combineert dat talent met warmte en inlevingsvermogen. Je voelde heel precies aan waar wij en de zorgverleners in de Drentse regio tegenaan liepen of juist enthousiast van werden. Dat heeft enorm veel voor het TARGET-programma betekend. Tenslotte nog een dikke merci aan de praktijkconsulenten van Dokter Drenthe, met name **Jeanet Scheper**, **Heidi Strijker** en **Janet de Boer**, die ik (letterlijk) te allen tijden om advies en hulp kon vragen en ervoor zorgden dat de onderzoeksplannen altijd even bekeken werden op haalbaarheid voor de praktijk.

Met financiering van zorgverzekeraar **Zilveren Kruis Achmea**, Stichting Achmea Gezondheidszorg (SAG), kregen we in 2020 de mogelijkheid om het TARGET-programma echt in de praktijk te brengen en gedegen te onderzoeken. Met name dank aan **Edmée van den Akker** en **Linda Raven**, beiden zorginkoper bij Zilveren Kruis, die enthousiast werden van het TARGET-project in Drenthe en ons met kritische reflecties scherp hielden en motiveerden om het onderste uit de kan te halen.

Het TARGET programma kreeg niet alleen concrete vormen door het meedenken van ‘interne’ betrokkenen zoals zorgverleners. Vanaf het begin van het traject dacht een **‘externe’ klankbordgroep** ook op regelmatige basis mee, waarvoor grote dank. Hierin waren de volgende partijen vertegenwoordigd: **InEen**, **Patiëntenfederatie Nederland**, **Stichting Kwaliteit en Ontwikkeling Huisartsenzorg**, **Nederlandse Vereniging van Praktijkondersteuners**, **Regionale Organisatie Huisartsen Amsterdam**, **PrimaCura Huisartsenzorg Midden-Brabant**, **Huisartsenorganisatie Noord-Kennemerland**, **De Ondernemende Huisarts**, **Zilveren Kruis Achmea**, **IQ Healthcare Radboudumc Nijmegen**, en het **Nivel**. Ook dank aan verschillende onderzoekers die aan vergelijkbare wetenschappelijke studies werken op het gebied van integrale zorg en met wie we regelmatig inzichten deelden: het **Ketenzorg Ontketend** project uit de Nijmeegse regio, het **CO-PILOT** project uit Zuid-Kennemerland en het **CHRODIS** project dat in een Europese samenwerking tot stand kwam.

Mijn (oud-)kamergenoten van 0.009 bij Health Services Research (HSR), Anne, Teuni en Marlot. Wat was ik in 2017 blij om met jullie op één kamer te belanden. Ondanks dat we niet allemaal dezelfde interne thermostaat hebben en even gelukkig werden van een hoop drukte op kantoor, zijn we allemaal harde werkers die van praatjes, gezelligheid én lekker eten houden. Niet zelden heb ik mijn zorgen en stress over mijn onderzoek met jullie mogen delen en altijd weer luisterden en hielpen jullie me. Dat zal ik nooit vergeten. Ondanks dat ik jullie niet allemaal meer even vaak spreek, hoop ik van harte dat we onze sterke band kunnen behouden! **Anne**, we zaten in dezelfde scriptiekring bij Silke en daar ontstond er meteen een klik tussen ons. Je bent ontzettend zorgzaam en ik mag je altijd (en in de aanloop naar mijn verdediging zeker☺) bellen voor advies. Hoewel ik een huismus ben, voelt onze huidige postdoc-kamer ook altijd als thuiskomen, met jouw rust, nuchterheid en vrolijkheid. Ik kijk op tegen je gestructureerde werken, je geduld om zaken tot op de bodem uit te zoeken en je talent voor vreemde talen (lees: Limburgs dialect). **Teuni**, lieve en warme Brabantse, jij bracht een hoop vrolijkheid en humor in onze kamer. Je bent een enorm sociaal dier en toont oprechte interesse in anderen. Jouw project was ontzettend ambitieus, maar jijzelf was dat nog meer: zowel op het werk als in jullie verbouwing thuis werd alles tot in het kleinste detail op orde gebracht. Maar ondanks dat perfectionisme wist jij steeds de vaart erin te houden en dat vind ik enorm knap. Het was een eer om jouw paranimf te zijn en te zien hoe sterk jij verdedigde, echt een voorbeeld voor mij! **Marlot**, jij was altijd de stille kracht van onze kamer. Soms vluchtte je als er een hoop drukte op kantoor was, maar je maakte ook tijd om uitgebreid met me te sparren als ik weer een vraag had over statistiek of – een onderwerp waar we beiden een haat-liefdeverhouding mee hebben – wetenschapsintegriteit. Ik kijk op naar hoe jij je hart volgt, altijd volledig jezelf bent en 'out of the box' durft te denken en doen. Na een tijdje kwam Lisanne op onze kamer als vijfde kamergenoot. **Lisanne**, door corona hebben we helaas niet zo intensief met elkaar gewerkt op onze kamer 0.009, maar als we elkaar zagen namen we altijd even de tijd om bij te praten en dat doen we gelukkig nog steeds!

Lieve **HSR-collega's**, wat heeft mijn tijd bij HSR altijd goed gevoeld! Ik kan bij iedereen aankloppen voor advies, dat heb ik dan ook vaak gedaan, en er is echt een gevoel van samenwerken en iets over hebben voor een ander. Ik ben blij dat ik nog mag blijven werken op deze warme afdeling. Mijn eerste kennismaking met HSR was tijdens mijn Masterthesis die ik met Silke als begeleider schreef. **Silke**, dankjewel voor de enorm leerzame periode die ik bij jou heb gehad. Door jou werd ik pas écht enthousiast over onderzoek en je hebt mijn onderzoeksvaardigheden in korte tijd enorm verbeterd. Ik ben blij dat we elkaar, ook al is het maar af en toe op de gang, nog steeds tegenkomen en spreken. Speciale dank gaat verder naar mijn **collega's van de Academische Werkplaats Duurzame Zorg (AWDZ)** en daarbinnen het **AWDZ-zwaartepunt 'population health management'**. Ik ben blij met zoveel getalenteerde onderzoekers om me heen binnen de AWDZ. We hebben elkaar de laatste jaren beter leren kennen, ondanks de coronabeperkingen. Ik voel me gewaardeerd binnen de club en gesteund om mijn eigen 'niche' te bouwen binnen het onderzoek. In het bijzonder, en zonder iemand te kort te doen, wil ik graag Arno noemen, als 'oude rot' in het vak, die – wanneer dit proefschrift verschijnt – de afdeling zal hebben verlaten om te genieten van zijn welverdiende pensioen. **Arno**, al in mijn studietijd wist jij mij te laten groeien, in je rol als ijzersterke tutor en docent. Hoewel we elkaar vaak maar eens in de zoveel tijd spraken, heb ik je altijd als een inspirerend iemand gezien die mij wees op mijn krachten. Dat zal ik niet vergeten. **Rose** en **Anna**, onderdeel van mijn AWDZ-zwaartepunt (naast Arianne, Dorijn en Anne), jullie heb ik de afgelopen tijd, zeker nu we wekelijkse updates hebben met het zwaartepunt, goed leren kennen. We zijn allemaal duidelijk 'kinderen van' (Arianne en Dorijn) en dat maakte onze samenwerking vanaf moment één soepel en leuk. Ik kijk met een glimlach terug op onze congresreis naar Odense in Denemarken (en dat wil iets zeggen gezien mijn voorliefde voor buitenlandse congressen, ahum…☺). Ook merci aan de altijd gezellige kamer 0.058, **Robin**, **Lise**, **Svenja** en **Ines**: Jullie zijn veel beter in mijlpalen vieren dan ik en hebben er dan ook op aangedrongen om heel bewust stil te staan bij de afronding van mijn proefschrift. Tijdens de lunch wordt er vaak heel wat afgelachen en dat maakt mijn werk altijd een stuk luchtiger. Verder wil ik verschillende onderzoeksmedewerkers van onze afdeling bedanken, met name Ine, Suus en Brigitte. **Ine** en **Suus**, jullie hebben mij de laatste jaren ontzettend veel werk uit handen genomen, in onder andere het vragenlijstonderzoek in Drenthe en het Career Event aan de UM. Jullie hebben steeds met mij meegedacht in elk stap die we zetten en zorgden ervoor dat we flink de vaart konden houden in verschillende grote projecten. **Brigitte**, voor duizend-en-een praktische zaken kon ik bij je aankloppen. Je hielp altijd (en snel) en had ook aandacht voor mij als persoon. En niet alleen voor werk gerelateerde zaken, maar ook als het mijn hond betrof, stond jij klaar om te helpen en we deelden vaak grappige verhalen over onze viervoeters. Last but not least: **Emmelie**, werkzaam als PhD-kandidaat bij sociale geneeskunde. Je kantoor zat vlak bij dat van ons en daarom maakten we regelmatig een praatje. In ongeveer dezelfde periode als ik kreeg jij een puppy en dat gaf nog een extra reden om elkaar te zien en spreken. Ik kijk altijd uit naar de momenten dat we elkaar op Dub30 zien, je bent altijd geïnteresseerd en ik kan nog iets leren van hoe sterk jij in je schoenen staat.

Lieve vriendinnen, **Karin** en **Linda**. We kennen elkaar al ons hele leven en samen met mijn zus Shannen hebben we een hele sterke en bijzondere band, van twee tweelingen. Jullie waren vast niet verbaasd dat ik in Maastricht ging werken, want vroeger op de basisschool vertelde ik jullie vaker dat ik toch zo graag Maastrichts wilde leren praten (?!?). Ik neem aan jullie alle drie een groot voorbeeld, omdat jullie heel goed (en veel beter dan ik) kunnen genieten van het leven én mij leren hoe je na te vallen toch weer kunt opstaan. Tijdens mijn promotietraject hebben we nogal wat speciale momenten gedeeld en gevierd: jullie specialiseerden allebei in de verpleegkunde, huizen werden gekocht, verbouwd en soms helaas weer verkocht en maar liefst twee gezonde meisjes werden geboren! Dankjewel Kaatje, Lin en Sjen!

Mijn twee gezusters, **Eva** en **Ankie**. Al meer dan 10 jaar kennen we elkaar nu. Ik denk met veel plezier terug aan het op stap gaan in Sittard en Nijmegen, en ons avontuur in Albufeira. Hoewel we elkaar nu meer om 3 uur ‘s middags dan om 3 uur ’s nachts zien, doet het mij altijd goed om jullie te zien. Na een afspraak (met vaak veel eten en drinken☺), ga ik altijd weer vrolijker naar huis. We kunnen over alles praten en jullie hebben altijd veel interesse getoond in mijn promotietraject. Merci leevekes!

De lieve **‘vrouwluuj van Munstergelaen’**, zonder namen te noemen, wil ik ook jullie bedanken, voor jullie interesse, de gezelligheid en alle bijzondere momenten die we al samen gevierd hebben.

Dan mijn vrienden die eigenlijk meer als familie voelen: de mensen van **de Paek**, oftewel mijn harmonie uit Sittard. Ik heb bij jullie ‘een plek om lief te hebben’. Mijn soms overvolle hoofd werd altijd weer leger tijdens de repetities. We hebben samen zoveel bijzondere momenten meegemaakt, van concertreizen heel ver van huis tot aan afterparty's op de Vijverweg. Bedankt allemaal, voor al het plezier dat we samen maken en alle steun die jullie geven. Hoewel dat altijd gevaarlijk is in een familie, wil ik een aantal mensen in het bijzonder noemen: **Thijs**, **Kelly**, **Bart & Suus**, **Wendy**, **Kim**, **Anne**, **Imme & Ramon** en **Ton**, oftewel 'de jeug' die inmiddels al voor 'nuuje jeug' bij het orkest aan het zorgen is. We organiseren samen feestjes, maar vieren doen we ze nog liever. Dat er nog maar heel veel tweede- of derde kerstdagborrels (met 30-Seconds) en BBQs mogen volgen. Toen ik begon na te denken over de kaft van mijn proefschrift, wist ik eigenlijk direct wie ik daarvoor wilde vragen, namelijk een creatief talent binnen onze vereniging: **Paul-Jean**. Leeve Paul-Jean, gelukkig was jij direct enthousiast en dat bleef je, ondanks mijn keuzestress en twijfels ('Du bes waal eine controlfreak he?'). Je dacht met mij mee en ik mocht van dichtbij zien hoe je – volledig met de hand – de tekening voor mijn kaft maakte. Ook om die tekening mooi op te laten maken, kon ik bij een Paek'er terecht: **Thijs**, dankjewel voor je tijd en moeite. Je zag precies wat er nodig was om de tekening van Paul-Jean helemaal uit de verf te laten komen.

Mijn lieve schoonouders, **Rie** en **Kitty**, en natuurlijk **oma** (van Richard)! Jullie zijn heel betrokken bij mij en zorgzaam voor mij, Richard, onze hond Lou en zoveel andere mensen. We hebben al veel gezellige reisjes gemaakt en jullie houden net als Richard en ik van lekker eten en terrasjes pakken. Ook onze liefde voor (blaas)muziek en spelen bij een vereniging hebben we gemeen. Ik weet dat ik altijd bij jullie kan aankloppen en jullie oprecht blij zijn voor mij als er goed nieuws is.

Mijn zussen en broertje: tweelingzus Shannen, Milou en Kay. Lieve **Shannen**, Sjen, vroeger was ik de dapperste (en bazigste☺) van ons twee, maar dat is snel gedraaid. Je bent heel wat stoerder dan ik en als ik nuchter advies nodig heb, kan ik altijd aankloppen. Op de middelbare school dachten mensen vaak dat we vriendinnen in plaats van zussen waren en dat is ook altijd mijn gevoel geweest. **Milou** en mijn schoonbroer **Dario**, jullie zijn een beetje ons showbizz-koppel. Jullie weten alles af van de laatste films en pikante details van BN'ers, en dat leidt vaak tot hilarische situaties bij ons thuis. Af en toe (en dat moeten we eigenlijk vaker doen) gaan we met de 'meisjes van Smeets' iets doen en dan is er altijd gezelligheid en kunnen we goed praten. **Kay** en mijn schoonzus **Eva**, net als Richard en ik zijn jullie echte Bourgondiërs, die geen moment voorbij laten gaan om lekker te eten en drinken. Jullie hebben altijd een luisterend oor voor mij en ik kan niet wachten om over een tijdje bij jullie over de vloer te komen in jullie eigen huis!

Pap en **mam**, jullie willen altijd álles weten over mij, mijn werk, Richard, de hond enzovoorts. Hoewel we inmiddels bijna allemaal het nest hebben verlaten, zorgen jullie nog heel goed voor jullie vier kinderen – en sinds kort 'harig kleinkind' ook wel 'schaapje' Lou. Als ik een paar dagen niks van me heb laten horen, appt mam altijd wel eventjes, om mijn reactie vervolgens aan pap door te geven. Jullie zijn altijd geïnteresseerd in goed nieuws dat ik te melden heb, maar ook als het moeilijk gaat zijn jullie er voor mij en herinneren jullie mij eraan dat 'er meer is dan alleen maar hard werken'. Mijn 'calvinistische bloed' heb ik toch echt van jullie. Maar ondanks dat ook jullie heel bescheiden zijn, weet ik zeker dat jullie heel trots zijn, op mij en op al jullie kinderen én de 'aanhang'.

Mien leeve sjat, **Richard**. Wat ben ik blij dat je me de afgelopen jaren veel op sleeptrouw hebt genomen naar heel wat ontspanningsmomenten. Je bent mijn reisleider, letterlijk en figuurlijk, en zoekt de mooiste B&Bs uit in heel Europa, waar we 's avonds volop genieten van 'mee eten met de pot'. Ik heb zoveel aan jouw nuchterheid, jouw positieve instelling, en – hoewel het ook wel eens tot discussies leidt – ben ik stiekem zo blij dat je totaal niet materialistisch bent. We zijn even ambitieus in ons werk: het moet altijd goed zijn en we zullen nooit helemaal tevreden zijn. Naast de (blaas)muziek, hebben we allebei een voorliefde voor Vlaamse series (en eten☺) en doen we niks liever dan een aflevering van 'FC de Kampioenen' kijken na een lange werkdag. Je herinnert me er altijd weer aan dat ik minder moet nadenken en van het leven mag genieten. En dat doen we, ook al moeten we dat in ons drukke leven soms goed plannen. Sinds een jaar hebben we Lou, het liefste hondje dat er bestaat, waar we allebei knettergek op zijn en dagelijks om moeten lachen. Danke, miene leeve, op nog heel vööl jaore same!

Addenda

About the author

Rowan Goswina Monique Smeets was born on December 8, 1993, in Sittard. In 2012, she received her high school diploma (Gymnasium) at Trevianum Scholengroep in Sittard. Rowan continued her education at Maastricht University, where she obtained her Bachelor's degree in Health Sciences in 2015, with a specialization in Prevention and Health. From 2015 onwards, she simultaneously followed two Master programs, i.e. Healthcare Policy, Innovation and Management (HPIM), and Health Education and Promotion (HEP). In 2017, she obtained both Master's degrees. During her time studying in Maastricht, she participated in several extra-curricular excellence programs, such as the Maastricht University Research Based Learning Program (MaRBLe) and the PREMIUM program. Additionally, she worked as a trainer in qualitative research in the Bachelor of Health Sciences.

Rowan started her PhD program at the department of Health Services Research, Maastricht University, in 2017. Her research was aimed at advancing the field of integrated, person-centred care for people with chronic conditions. She worked on the development and first implementation of an innovative program for integrated care called TARGET. This work was commissioned by and in close interaction with a large care group in the north of the Netherlands, i.e. 'Dokter Drenthe'. Rowan presented the insights gained during her PhD at several national and international conferences, such as the Annual Research Meeting of Academy Health (Washington, US) and the NHG-Wetenschapsdag. Besides her research activities, she was a tutor in the HPIM master program and coordinated the Career Event for, amongst others, HPIM students. Rowan gained interest in science communication and an innovative evaluation philosophy called 'realist evaluation'. Therefore, she followed different courses during her PhD: 'Journalistiek en Effectief Schrijven' provided by Observant and different realist evaluation courses provided by the CARES centre.

From November 2022 onwards, Rowan started working as a postdoctoral researcher at the same department. She will combine research with educational activities and science communication for the Living Lab for Sustainable Care (AWDZ in Dutch). She aims to make strong connections between those three fields, with the overarching aim to make research more meaningful by sharing insights with a broad audience and equipping students with new knowledge and skills.

Addenda

List of publications

List of publications

Scientific articles in international journals

Smeets RGM, Hertroijs DFL, Mukumbang FC, Kroese MEAL, Ruwaard D, Elissen AMJ. First things first: How to elicit the initial program theory for a realist evaluation of complex integrated care programs. Milbank Q. 2022;100(1):151-189.

Smeets RGM, Hertroijs DFL, Kroese MEAL, Hameleers N, Ruwaard D, Elissen AMJ. The Patient Centered Assessment Method (PCAM) for Action-Based Biopsychosocial Evaluation of Patient Needs: Validation and Perceived Value of the Dutch Translation. Int J Environ Res Public Health. 2021;18(22).

Smeets RGM, Kroese MEAL, Ruwaard D, Hameleers N, Elissen AMJ. Person-centred and efficient care delivery for high-need, high-cost patients: primary care professionals' experiences. BMC Family Practice. 2020;21(1):1-9.

Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N, Ruwaard D. Identifying subgroups of high-need, high-cost, chronically ill patients in primary care: A latent class analysis. PloS one. 2020;15(1):e0228103.

Smeets RGM, Kempen GIJM, Zijlstra GAR, et al. Experiences of home-care workers with the 'Stay Active at Home' programme targeting reablement of community-living older adults: An exploratory study. Health & Social Care in the Community. 2020;28(1):291-299.

Submitted articles

Smeets RGM, Hertroijs DFL, Ruwaard D, Spoorenberg SLW, Elissen AMJ. Supporting professionals to implement integrated, person-centred care for people with chronic conditions: The TARGET pilot study. (submitted)

International scientific conference contributions

Smeets RGM, Elissen AMJ, Spoorenberg SLW. Country practice example II: the Netherlands Coordination of chronic care management via care groups (networks in primary care). Seminar on skill-mix innovations by l'Assurance Maladie and The European Observatory on Health Systems and Policies, 16 September 2022, online (oral presentation).

Hertroijs DFL, **Smeets RGM**, Spoorenberg SLW, Ruwaard D, Elissen AMJ. Towards a focus on the person behind the patient: Is the TARGET integrated care program feasible and acceptable for general practice? International Conference on Integrated Care, 23-35 May 2022, Odense, Denmark (oral presentation).

Smeets RGM, Hertroijs DFL, Kroese MEAL, Hameleers N, Ruwaard D, Elissen AMJ. Action-based, holistic patient consultations to inform integrated care: validation and value of the Dutch Patient Centered Assessment Method (PCAM). International Conference on Integrated Care, 23-35 May 2022, Odense, Denmark (oral presentation).

Smeets, RGM, Hertroijs DFL, Mukumbang FC, Kroese MEAL, Ruwaard D, Elissen AMJ. Learning how integrated primary care works: first steps towards a realist evaluation of the Dutch TARGET program. WONCA Europe Conference, 6-10 July 2021, online (oral presentation).

Smeets RGM, Kroese MEAL, Ruwaard D, Hameleers N, Elissen AMJ. Experienced barriers and potential solutions with regards to care delivery to high-need, high-cost patients: a qualitative study in primary care. NHG-Wetenschapsdag, 5 & 11 February 2021, online (oral presentation).

Smeets RGM, Kroese MEAL, Ruwaard D, Hameleers N, Elissen AMJ. Primary care professionals' experiences with care delivery to high-need, high-cost, patients: a qualitative study. EHMA Annual Conference, 17-19 November 2020, online (oral presentation).

Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N, Ruwaard D. Identifying subgroups of high cost, high need chronically ill patients in primary care: a Latent Class Analysis. Annual Research Meeting Academy Health, 2-4 June 2019, Washington DC, US (poster presentation).

Metzelthin SF, **Smeets RGM**, WAG Hanssen, Zijlstra R, van Rossum E, de Man-van Ginkel JM, GIJM Kempen. Experiences of home care staff with the Stay Active at Home Program. GSA Annual Scientific Meeting, 14-18 November 2018, Boston Massachusetts, US (oral presentation).

Smeets RGM, Elissen AMJ, Kroese MEAL, Hameleers N, Ruwaard D. Exploring the potential of a risk stratification tool to move forward in integrated, person-centered primary care. International Conference of Integrated Care, 23-25 May 2018, Utrecht (poster presentation).

National conference contributions

Smeets RGM, Elissen AMJ, Spoorenberg SLW. Presentatie target - resultaten tot zover. InEen themabijeenkomst: Integrale en persoonsgerichte zorg, 7 April 2022, Utrecht (oral presentation).

Smeets RGM, Elissen AMJ, Spoorenberg SLW. Aan de slag met zorgzwaartemodellen. InEen themabijeenkomst: Integrale en persoonsgerichte zorg, 7 April 2022, Utrecht (workshop).

Ruwaard D, **Smeets RGM**, Elissen AMJ, Kroese MEAL, Hameleers N. Integraal Programma Chronische Zorg: op weg naar een implementatie en evaluatie in co-creatie met de praktijk. Sandwichcursus HZD, november 2019, Dalfsen (oral presentation).

Smeets RGM, Elissen AMJ, Weuring II. 'Doelgroepbepaling en scope van het geïntegreerde zorgprogramma'. InEen themabijeenkomst: Integratie chronische zorgprogramma's, 8 oktober 2019, Baarn, (workshop).

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