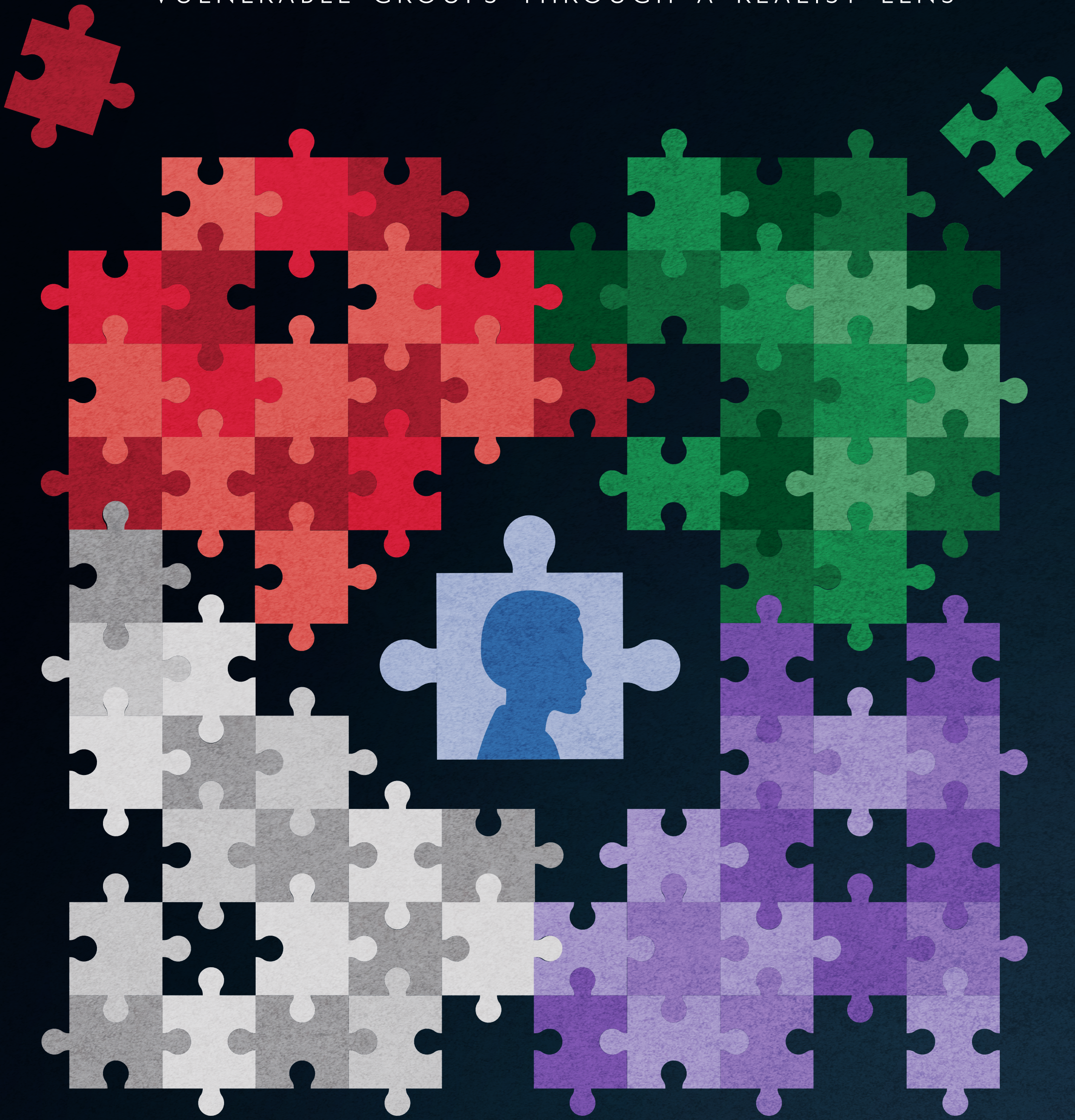
INSIDE THE BLACK BOX:

EXAMINING THE INTERCONNECTIVITY OF COMPONENTS OF INTEGRATED PERSON-CENTRED CARE FOR VULNERABLE GROUPS THROUGH A REALIST LENS



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Inside the black box: examining the interconnectivity of components of integrated person-centred care for vulnerable groups through a realist lens

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رَبِّ زِدْنِي عِلْمًا

“My Lord, increase me in knowledge”
[Quran 20:114]

TABLE OF CONTENTS

LIST OF ABBREVIATIONS

C	Context
CMO-C	Context-mechanism-outcome-configuration
FGD	Focus group discussion
GP	General practitioner
HCP	Healthcare provider
HRQoL	Health-related quality of life
ICP	Integrated care programme
I(C)T	Information (and Communication) Technology
IPCC	Integrated person-centred care
M	Mechanism
O	Outcome
RAMESES	Realist And Meta-narrative Evidence Syntheses: Evolving Standards
RCT	Randomized controlled trial
RRR	Rapid realist review
WHO	World Health Organization
WHO-IPCHS	World Health Organisation framework for integrated person-centred health services

CHAPTER 1

General introduction

BACKGROUND

Vulnerability and health inequity

Vulnerable groups in healthcare are those at a heightened risk of encountering poor health outcomes and limited access to healthcare services (1-3). Various factors can contribute to their vulnerability, including physical, mental, socioeconomic circumstances or their limited health literacy skills (4-12). Additionally, certain populations, such as racial and ethnic minorities, may face health disparities due to migration and/or discrimination that further contribute to their vulnerability (13, 14). Older people are particularly susceptible to vulnerability as aging is a recognized risk factor for the development of multiple chronic diseases and disabilities, impacting their well-being and independence (15-18). Across Europe the number of older people has been growing and is expected to grow even further in the future with the life expectancy being ±69 years in 1960 and ±81 years in 2017 (19-22). The Netherlands is dealing with the phenomenon 'double ageing' of the population, implying that not only the number of older people (i.e., people aged 65 years and older) in the total population is increasing, but also the proportion of people aged 80 years, posing unique challenges for healthcare systems (23-26). Individuals belonging to vulnerable groups often experience significant health challenges and frequently present a range of complex health needs. The complexity of care is determined by factors associated with patients, as well as the care process, such as the involvement of multiple healthcare providers (HCPs) (27). Health inequalities stem from differences in social, economic, and environmental factors, leading to disparities in health status among individuals or groups (28, 29). Addressing the needs of vulnerable populations, including older adults, requires comprehensive medical support, as well as social assistance to adopt a holistic approach to their well-being (30-34).

Integrated person-centred care

Due to the increasing (complex) care needs, current healthcare systems are confronted by various problems, such as increasing pressure on care (35), shortages of health personnel (36), and an increase in healthcare costs (37). Multiple developments show that healthcare systems, still largely focused on single diseases and acute problems, no longer fit to deliver health (and social) care for the entire population (38-43). What is currently being offered by healthcare systems and what they should offer to meet existing and new developments emphasize the need for transforming the way health and care services are organized, managed and delivered. These developments include:

- An increasing number of older people and people with chronic illnesses (38, 39, 44-47);
- An increasing number of (older) people with co- and multi morbidities (38, 39);
- Shifting away from the biomedical model towards a more holistic care model with more attention being paid to the psychological, social and meaningful living

aspects in organising care and support, in addition to the physical domain of health and functioning (48, 49);
- From supply-oriented system, where the dominance of the perspective of the healthcare professional used to define the care and services, to a value-driven approach (50, 51);
- Due to less distinctive boundaries between intramural and extramural work the existence of new professions (e.g., case managers, nurse practitioners or care coordinators) is rising. Traditional healthcare organisations increasingly integrate 'vertically', 'horizontally', or both and offer multiple and/or complementary services (52-54);
- Fragmented financial and legal systems in the fields of acute, chronic, social and informal care do not unite and promote the needs of clients, and often make coordination and cooperation more complex (38, 55).

In order for healthcare to be effective in which the efforts of multiple HCPs and organisations, the role of clients and their carers, together with the best available professional knowledge and a seamless organisation of care, all need to contribute to high quality care (27). Integrated person-centred care (IPCC) is considered the most effective and appropriate care delivery model for maximizing health, function, and well-being across the life course especially for older people and people with multiple chronic conditions (21, 56, 57). IPCC focuses on the total care needs of client, in addition to the services provided by a network of HCPs and organisations (58, 59). This type of care ensures that people "receive a continuum of services including health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation, and palliative care at different levels and sites within the health system, and that care is provided according to their needs throughout their life course" (60, p. 2). Integrated care delivery has shown to have a positive impact on patient satisfaction (61, 62), psychological health (63), perceived quality of care, and access to services, but evidence on how integrated care impacts quality of life and health care costs is mixed (64, 65). The expectation of integrated care is that it is recognised as a strategy to support the Quadruple Aim of health care (i.e., improving health of populations, improving patient experiences, reducing costs and improving the experience of the workforce) (66). The principle of integrated care programs (ICPs) is the intent to provide adequate care to patients, at the proper time by the right service provider, where traditional sectorial segregations (e.g., between health and social care) will be transcended (67). Even though, there is widespread recognition about the need to move towards IPCC, there is large variation in what integrated care entails for different stakeholders. Integrated care appears in a variety of forms, there is no uniform and accepted definition, nor are there clear boundaries of the underlying concepts. Definitions of integrated care vary from a narrow, disease-oriented perspective (58) to a complex population-oriented whole system perspective (53, 59, 65, 67-69).

The World Health Organization (WHO) developed a global strategy on people-centred and integrated health services to encourage “a fundamental paradigm shift in the way health services are funded, managed and delivered so all people have access to health services that respond to their preferences, are coordinated around their needs, and are safe, effective, timely, efficient and of an acceptable quality” (57, p. 34). It offers a framework and guiding principles to facilitate the coordination of care across various healthcare settings, including primary, specialty, acute, and long-term care. Person-centredness in integrated care is a key component to maximize outcomes. Common elements that define person-centred care are:

- Empowering and encouraging people to participate actively, as equal partners, in the decision-making process regarding their own care, and/or to manage their own health and care;
- Establishing an accommodating, cooperative and ongoing relationship between the professional, the person receiving care and the informal caregiver, including respectful communication and active listening;
- Having an understanding of the specific (health) concerns of the person, and their individual needs and preferences;
- Addressing all domains of health (i.e., the physical, cognitive, psychological, and social health domains);
- Providing coordinated care to achieve continuity and coherence of care and support (70).

Primary care

Primary care has been shown to be the most efficient setting for delivering high-quality, cost-effective care and has a central role in the delivery of care within an integrated person-centred healthcare system (21). A recent National Academies report defines high-quality primary care as “the provision of whole-person, integrated, accessible, and equitable health care by interprofessional teams that are accountable for addressing the majority of an individual’s health and wellness needs across settings and through sustained relationships with patients, families, and communities” (21, p. 173). High-quality primary care is critical for health, and requires functional partnerships across systems to maximize the capacity of individuals by addressing social determinants of health, improvements across the board and demands measurable improvement in health outcomes for multiple conditions” (71). While primary care systems rely on financing, policies, workforce, and core functions, there is a lack of evidence regarding implementation strategies for establishing sustainable systems in different contexts. Also, limited evidence was found for the value of population health management, facility management, safety, and improving quality of service delivery (21). To foster integrated systems, countries will need to embrace a comprehensive approach that invests in the overall healthcare infrastructure. In the Netherlands, primary care serves as the initial and accessible point of contact for individuals seeking information and support regarding their health and well-being (72). An effective primary care system ensures that people receive appropriate care at the right time, preventing premature or delayed utilization of costly and complex healthcare services, and facilitating referrals to non-care organizations when necessary. For many years, the Netherlands has been regarded as an exemplary model internationally, showcasing key features such as the comprehensive registration of citizens under individual general practices and the structured access to specialized care through a gatekeeping function (73).

Key-challenges concerning integrated person-centred care

Despite the widespread acknowledgement and desirability of IPCC, the implementation has proven to be a difficult task (74, 75). Current care for older people and people with complex health needs is inadequate (21). Especially for people with low health literacy levels, care is insufficiently person-centred (76, 77). Models for IPCC are abound, but there has been limited success in their widespread adoption. Key-challenges related to IPCC that have been reported are:

- Lack of coordination and of sustainable agreements between different care providers (health and social domain) and agencies, and roles and responsibilities of different health and social care providers involved not being clearly defined;
- Lack of training and education opportunities of HCPs and heavy workloads of staff;
- Lack of information sharing within and between organisations and providers, and incompatible information technology (IT) systems of organisations that hinder information sharing;
- Lack of person-centredness in cure with insufficient involvement of patients and informal caregiver in the care process, and lack of tailoring of services to the needs and preferences of (older) people;
- Lack of (sustainable) financial resources, confined staffing levels, and unsupportive legal frameworks (78).

Recurrent issues across the five areas include collaboration issues, technical issues, resource issues (i.e., funding, workforce, time), and care delivery issues (i.e., delivering care that is tailored to what is important to older people and their informal caregivers) (78). There is a lack of primary care research focusing on person-centred care for “hard-to-reach or underserved” groups such as migrants, ethnic minorities, individuals with low educational levels, or low health literacy (79-82). Consequently, their expectations and needs remain unclear, and it is evident that the current healthcare services are often not well-suited for their specific requirements (83-85). Scientific literature on the effectiveness of IPCC is inconclusive, partly due to the heterogeneity in outcomes (86-93). Traditional research often only indicates whether IPCC is more effective than standard of care, however, does not contain information on why it was more effective and how it has led to its results given the circumstances (94, 95). Insights into when IPCC programmes (do not) work, for whom, why and how, are lacking, the underlying mechanisms and the contextual influence often remain underexposed. Consequently, it remains unclear how, why, for whom and in what circumstances a complex intervention such as IPCC, leads to its results. To maximize the potential of care to patients and to set up and implement a proactive and strong policy, knowing why and how IPCC leads to positive results is important for various stakeholders such as HCPs, policy makers, and for people with low health literacy skills and people with a diverse ethnic and socioeconomic background.

Realist research

To provide a more detailed understanding of the interrelatedness of relevant factors that influence the effectiveness of IPCC, the realist research approach is used in this thesis. Realist research was first described by Pawson and Tiley (1997) as a theory-driven approach to synthesize and evaluate complex interventions or programmes (96-100). Theory-driven may be defined as any approach or strategy that integrates the use of theory in the conceptualization, design, conduct, interpretation and application of research (101). An essential aspect of the realist research approach is the belief that complex interventions or programmes may have different outcomes in different contexts, implying that complex interventions, such as IPCC, may work and be successful in one context but not or to a lesser extent in the other. The question realist research aims to answer is: “What works, for whom, in what respects, to what extent, in what contexts, and how?” (98, 100). This can be accomplished by providing a more in-depth understanding of the causal relationships by identifying and examining the underlying generative mechanisms related to a complex intervention or programme, that are triggered by contextual influences and the pattern of outcomes produced (102-107). The realist methodology aims to highlight the impact that interactions between the contextual factors and the mechanisms have on the intervention outcomes (100).

Definitions within realist research

Several terms that are fundamental to realist research have been explained below (100, 108-111):

- *Context* refers the contextual background of a complex intervention or programme. It can be described as the wider external factors, conditions, or aspects that trigger or modify the behaviour of a mechanism. It can include e.g., cultural norms and values, history aspects of an organisation or community, financial conditions, political aspects, geographical effects, pre-existing processes, the infrastructure in which the programme is built;
- *Mechanisms* describe what produce the programme effects and relate to causality. Mechanisms are considered the enablers, the real triggers of change that are sensitive to alterations in context and lead outcomes;
- *Outcomes* are the (un)intended or (un)expected results of a programme;
- A *context-mechanism-outcome-configuration (CMO-C)* explains the causal relationship between a context items, whether (or not) a mechanism of interest is triggered by it, and the outcomes produced. CMO-Cs can comprise a whole programme or only certain aspects of a programme. Configuring CMOs is the basis for generating or refining programme theories.

Programme theories

One of the main objectives of realist research is to develop a programme theory (8). A programme theory is a hypothesis explaining how, why, and for whom the complex intervention or programme is expected to work in what circumstances. In realist synthesis or evaluation the initial programme theory, middle-range programme theory, and refined programme theory represent different stages of developing and refining the understanding of how a program works. The initial programme theory is developed at the beginning of the process and represents the initial assumptions or hypotheses about how the programme is expected to work, based on existing knowledge and theories. As the synthesis or evaluation progresses and data is collected, the middle-range programme theory is developed. This theory represents a more refined understanding of how the program works and it involves analysing the data and identifying patterns, mechanisms, and context items that contribute to the outcomes observed. The refined programme theory is the final version of the theory, developed after considering all the evidence and feedback from stakeholders. It represents a comprehensive understanding of how the program works, including the underlying mechanisms, contextual influences, and the specific conditions necessary for achieving the desired outcomes.

A realist synthesis aims to provide a transferable theory that suggests that a certain complex intervention or programme is more or less likely to work in certain settings, for certain subjects, in certain kinds of circumstances (112, 113).

Traditional research versus realist research

Traditional research methods, such as systematic literature reviews and meta-analyses, commonly associated with the dominant positivist research, use the so-called ‘black box’ approach. They mainly focus on the outcomes and draw conclusions without providing an explanation or understanding with regard to how the outcomes were achieved or how a program may operate in different settings or under different circumstances (106, 114, 115). Unlike realist research, traditional research methods focus on aggregating effectiveness and providing an estimate of programme effectiveness by examining one or more outcomes, often established a priori (106, 116). This represents an oversimplification of both the environment and the intervention (117). However, in the real world this oversimplified representation provides little information about the effectiveness of complex interventions within uncontrolled, context-specific settings, and may be inadequate to contribute to future implementation of complex interventions (in practice) (106, 117-119). Realist research provides an alternative to the black box approach as it examines the internal components of a complex intervention and the possible causes and contextual factors associated with change (100, 102, 103, 120). Results of a realist review are context dependent with the generalizability of the results to other settings depending on the operation of similar mechanisms to generate outcomes. Due to the white box approach, realist reviews do not solely rely on peer-reviewed journals, but also utilize mixed methods.

RATIONALE OF THIS DISSERTATION

The overarching objective of this dissertation is to examine the relationships between the context in which IPCC for vulnerable groups in the Netherlands is applied, the mechanisms by which the complex interventions or programmes (do not) work, and the outcomes resulting from this interaction, by establishing a programme theory. To achieve this objective, this dissertation addresses the following research questions:

1. What context items, mechanisms and outcomes can be identified in international literature concerning integrated care programmes for community-dwelling frail older people?
2. What is the level of consensus among healthcare providers on the relevance of the context items, mechanisms, and outcomes of integrated care programmes for community-dwelling frail older people, as identified in international literature, for the ‘Dutch setting’?
3. What works (or not), why, and in what circumstances concerning person-centred care in primary care for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, according to international literature?
4. How relevant are the identified context items, mechanism, and outcomes of person-centred care in primary care, according to people with low health literacy skills and healthcare providers in the Netherlands?

The studies in this dissertation were instigated by the National Health Care Institute in the Netherlands. The National Health Care Institute is an advisory and implementing organisation which, among others, encourages good healthcare by helping all parties involved to continually improve healthcare quality and by helping patients find their way to high-quality care.

Outline of the thesis

This thesis consists of six chapters: the general introduction (Chapter 1), four chapters reporting the studies (Ch. 2-5), and a general discussion (Ch. 6).

Chapter 2 provides insight into the results of a rapid realist review (RRR), namely the relationships between the context in which ICPs for community-dwelling frail older people are applied, the mechanisms by which the programmes do (not) work, and the outcomes resulting from this interaction, by establishing a programme theory. The programme theory was then examined in relation to the five strategies of the WHO framework for integrated person-centred health services (IPCHS) (60). As the RRR provides an international perspective on the items that play an important role in ICPs for older people, and considering that ICPs need to fit the local setting, in **Chapter 3** it is was determined which items are relevant for the ‘Dutch setting’. The consensus on the relevance of context items, mechanisms, and outcomes of ICPs for community-dwelling frail older people for the ‘Dutch setting’ was assessed by means of a Delphi study and the programme theory for the ‘Dutch setting’ was refined. **Chapter 4** aims to explain how and why person-centred care in primary care works (or not) among others for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background. This was achieved by conducting a realist review and constructing a middle-range programme theory. Since the application of person-centred care in primary care in the ‘Dutch setting’ is expected to differ from other countries, **Chapter 5** looks into the validation of the items resulting from the RRR for the ‘Dutch setting’. By assessing consensus on the relevance of the items among different stakeholders, the middle-range theory from the RRR was refined. **Chapter 6** discusses the main findings and conclusions of this thesis and addresses their implications for practice policy and research in the field of IPCC.

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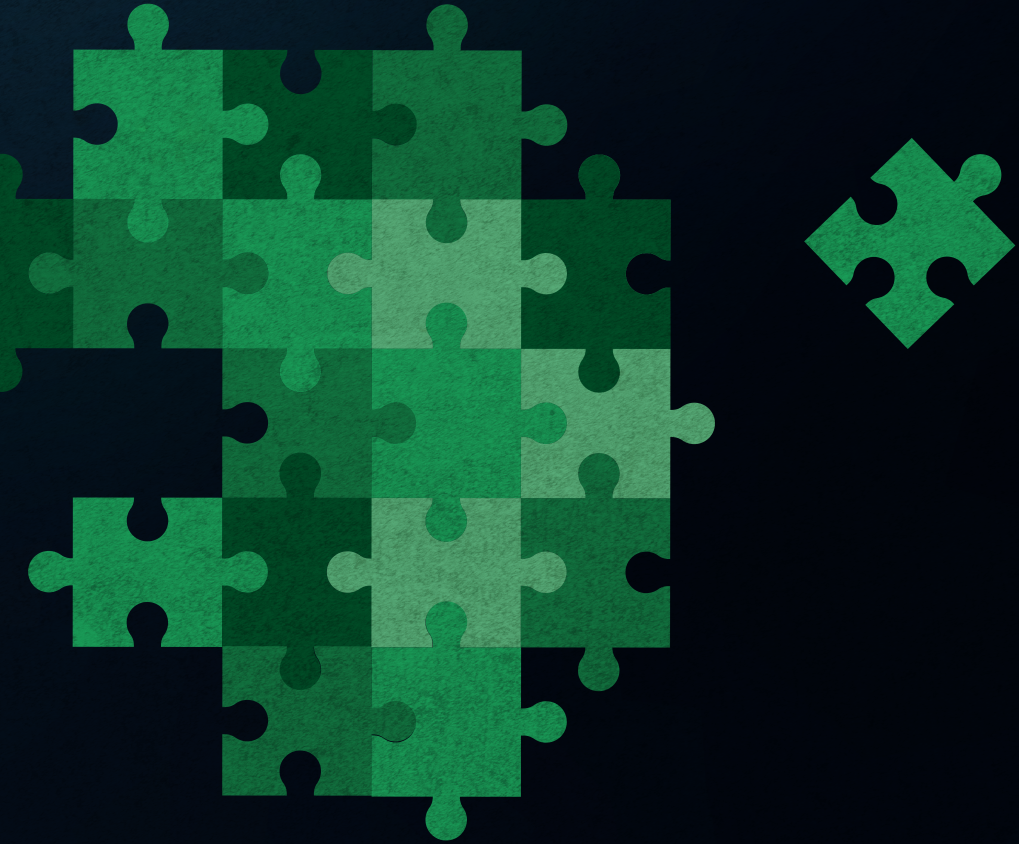

CHAPTER 2

Untangling the inter-relatedness within integrated care programmes for community-dwelling frail older people: a rapid realist review

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ABSTRACT

Objective

To identify the relationships between the context in which integrated care programmes (ICPs) for community-dwelling frail older people are applied, the mechanisms by which the programmes do (not) work and the outcomes resulting from this interaction by establishing a programme theory.

Design

Rapid realist review.

Inclusion criteria

Reviews and meta-analyses (January 2013–January 2019) and non-peer-reviewed literature (January 2013–December 2019) reporting on integrated care for community-dwelling frail older people (≥60 years).

Analysis

Selection and appraisal of documents was based on relevance and rigour according to the Realist And Meta-narrative Evidence Syntheses: Evolving Standards criteria. Data on context, mechanisms, programme activities and outcomes were extracted. Factors were categorised into the five strategies of the WHO framework of integrated people-centred health services (IPCHS).

Results

27 papers were included. The following programme theory was developed: it is essential to establish multidisciplinary teams of competent healthcare providers (HCPs) providing person-centred care, closely working together and communicating effectively with other stakeholders. Older people and informal caregivers should be involved in the care process. Financial support, efficient use of information technology and organisational alignment are also essential. ICPs demonstrate positive effects on the functionality of older people, satisfaction of older people, informal caregivers and HCPs, and a delayed placement in a nursing home. Heterogeneous effects were found for hospital-related outcomes, quality of life, healthcare costs and use of healthcare services. The two most prevalent WHO-IPCHS strategies as part of ICPs are ’creating an enabling environment’, followed by ‘strengthening governance and accountability’.

Conclusion

Currently, most ICPs do not address all WHO-IPCHS strategies. In order to optimise ICPs for frail older people the interaction between context items, mechanisms, programme activities and the outcomes should be taken into account from different perspectives (system, organisation, service delivery, HCP and patient).

INTRODUCTION

Most older people develop care needs in multiple domains (i.e., physical, mental and social at some point), and require coordinated care by multiple disciplines (1-4). The framework of integrated people-centred health services (IPCHS) by the WHO describes the complex nature of care for those with multiple needs. The challenge is to manage and deliver *'health services, so that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease-management, rehabilitation and palliative care services, coordinated across the different levels and sites of care within and beyond the health sector, and according to their needs throughout the life course'* (5, p. 2). Despite the existence of this international framework for the delivery of people-centred and integrated care (IC), European healthcare systems face several issues, such as a lack of coordination and interprofessional collaboration, poor person-centredness of care and insufficient resources and support (6). Existing reviews on the effectiveness of integrated care programmes (ICPs) for (frail) older people have shown heterogeneity in outcomes (7-11). Insights into when ICPs do (not) work, for whom, why and how are lacking, and the mechanisms (M) and the influence of contextual factors often remain underexposed. The heterogeneity in the effectiveness of ICPs thus far has only been explained to a limited extent. Therefore, a more detailed understanding of the inter-relatedness of all factors that influence the effectiveness of ICPs for community-dwelling frail older people is needed.

Realist research is a way to offer such an understanding, as it aims to reveal the inner mechanisms by which a complex intervention operates (12). In addition to outcomes (O), this approach examines the internal components of a care programme, unlike the traditional 'black box' approach, which mainly focuses on the outcomes, rather than how these outcomes were achieved. Thus, when applying a realist approach the specific aspects of the context (C) that influence the effect of a complex programme and the mechanisms that may create the change can be identified (13, 14). In this study, a rapid realist review (RRR) was conducted. The term 'rapid' refers to applying a realist approach within a relatively short time frame (15).

Initial programme theory

The aim of realist research is to test and refine an initial programme theory (PT) (a hypothesised explanation of how a complex intervention or programme is expected to work) in order to determine how, when and for whom the intervention or programme will work in a particular setting (16). In this RRR, the initial PT was based on the WHO-IPCHS framework. When developing the WHO-IPCHS framework, the WHO obtained experience and evidence on different levels (global, regional and national) from three different types of country settings (low, middle and high income countries), and countries facing special circumstances (e.g., conflict). In the framework, the WHO proposes five interdependent strategies that need to be adopted for health service delivery to become more integrated and people centred (5).

The five interconnected strategies are:

1. Engaging and empowering people and communities;
2. Strengthening governance and accountability;
3. Reorienting the model of care (i.e., ensuring that efficient and effective healthcare services are designed, purchased and provided through innovative models of care);
4. Coordinating services within and across sectors;
5. Creating an enabling environment (i.e., in order for the four previous strategies to become an operational reality, it is necessary to create an enabling environment that brings together all stakeholders to undertake transformational change).

In Supplementary file 2.1, a summary and explanation of the strategies of the WHO-IPCHS framework is provided.

Objectives

An RRR was performed with the objective of gaining insight into the relationships between the context in which ICPs for community-dwelling frail older people are applied, the mechanisms by which the programmes do (not) work and the outcomes resulting from this interaction by establishing a PT on the effectiveness of IC for frail older people. Based on the WHO-IPCHS framework, this study also aims to explore to what extent the five strategies are applied in ICPs as reported in the literature.

METHODS

The methods were established prior to conducting the RRR and no deviations from the methods occurred.

Rapid realist review

An RRR was conducted to identify the mechanisms (enablers, underlying entities, processes, structures, reasoning, choices, collective beliefs) of ICPs that operate in particular contexts (wider external factors concerning implementation contexts, opportunities and resources to enact decisions, broad conditions and participant conditions) to generate outcomes (intended and unintended) (16). This RRR was the first stage of a larger study in which insights of the literature will be assessed on their relevance in the Netherlands by a Delphi expert panel. For the larger study, a steering committee was established, consisting of experts in the field of IC for older people (for more details on the steering committee, see the Acknowledgements section). The involvement of experts working in the field is of great importance to realist research for providing input throughout the research process, as well as for being able to use the insights from the study to improve the quality of care in daily practice (17, 18). The members of the committee provided feedback and guidance on the methods and the interpretation of the results. The steering committee was put in place by AA, METCM and HJMV and consisted of senior researchers in the field, a primary care practitioner and representatives of IC organisations.

Search strategy

Searches were conducted in PubMed, EMBASE, CINAHL, Web of Science and the Cochrane Library. All types of reviews (narrative, rapid, realist, scoping or systematic) and meta-analyses on ICPs for (frail) older people were included (19). In this review, an overarching/non-specific definition of frailty was adopted in order to include various populations of frail older people. This implies that studies reporting on frailty were included, without operationalising a new definition of frailty in this study. English or Dutch papers published between January 2013 and January 2019 were included. As IC for (frail) older people has changed rapidly in recent years, programmes from before 2013 were not considered relevant. Programmes included patients who were frail older people with a minimum age of 60 years, corresponding to the WHO definition of an 'older adult' (20). Programmes needed to describe ICPs that consist of at least two of the five strategies of the WHO-IPCHS framework. Supplementary file 2.2 provide an overview of the search terms used. The search took place in January 2019. We also searched the reference lists of the eligible papers identified for the review. An additional search of non-peer-reviewed literature was conducted using Google to identify relevant context, mechanisms and outcomes data. The key search terms of publications were similar to the ones of the peer-reviewed literature search. Non-peer-reviewed literature published between January 2013 and December 2019 was included. Due to time constraints, and to capture the most relevant hits and ensuring a feasible quantity to screen, the first 10 pages (representing a total of 100 'best match' results) were examined. The non-peer-reviewed literature search took place in December 2019.

Selection and appraisal of documents

The titles and abstracts were screened by one author (AA) and supervised by a second author (HJMV). In case of even a slight doubt on selecting an article, the screener presented the article to the supervisor to ensure that articles were not overlooked or not included incorrectly. During full-text screening, the selection and appraisal of the papers was conducted by two authors (AA and JCM) based on their relevance (contribution to the development of the PT) and on their rigour (credible and trustworthy methods to generate data) in line with the Realist And Meta-narrative Evidence Syntheses: Evolving Standards quality standards (21). Disagreements were resolved by discussion resulting in consensus.

Data extraction and analysis

Data on context items, mechanisms, programme activities (PA) and outcomes were extracted and analysed. Per source publication, context-mechanism-outcome configuration(s) (CMOc(s)) were aimed to be identified. In case this was not possible due to the lack of data, overall common patterns in terms of context, mechanisms and outcomes in the source material were set out. In this review, the term ‘programme activities’ was used instead of ‘interventions’, as the term ‘intervention’ could cause confusion in relation to the composite nature of ICPs. Data extraction was performed by two authors (AA and HJMV). Disagreements about the category the extracted data belonged to (context, mechanism, programme activities or outcome) were resolved by discussion. Each context item, mechanism, programme activity and outcome that were reported in at least four papers were included in the analysis. Given the international perspective of this study and the variety of context items, mechanisms, programme activities and outcomes, we chose four papers as the minimum, realising this number is arbitrary.

Programme theory

Based on the CMOcs the PT was refined, describing the underlying relationships between context, mechanisms, programme activities and outcomes. Subsequently, two authors (AA and HJMV) individually categorised the context items, mechanisms, programme activities and outcomes into one (or more) of the five strategies of the WHO-IPCHS framework. The extent to which the strategies of the WHO-IPCHS framework were applied in the design and implementation of ICPs for community-dwelling (frail) older people was analysed. Categorisation was based on whether the context items, mechanisms, programme activities and outcomes corresponded to the strategic approaches and potential policy options and interventions provided by the WHO-IPCHS framework (5). Disagreements about which WHO-IPCHS strategy factors belonged to were resolved by discussion.

Patient and public involvement

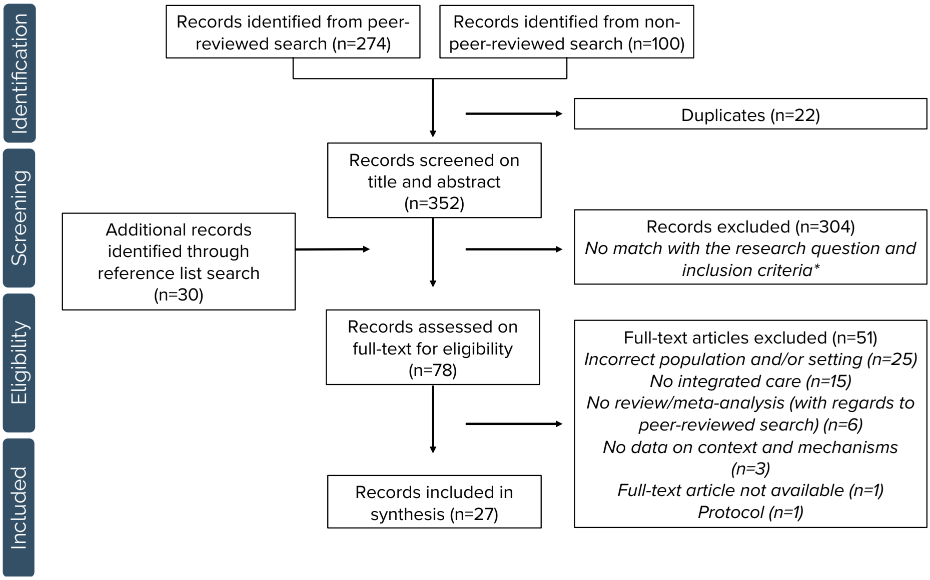
This study was instigated by the National Health Care Institute, an advisory and implementing organisation who, among others, encourages good healthcare by helping all parties involved to continually improve healthcare quality and by helping patients find their way to high-quality care. A stakeholder dissemination meeting was held during the course of the study (April 2019). This meeting was held with the objective of sharing the results of the RRR and to consider stakeholder perspectives to test and refine the initial PT derived from the RRR. Among others, (representatives of) patient organisations attended this meeting.

RESULTS

A total of 374 papers were identified. After exclusion of the duplicates, 352 papers were screened on titles and abstracts. An additional 30 records were identified through a reference list search and added. After exclusion of 304 papers, the remaining 78 papers were screened on their full text. In this step, 51 papers were excluded (see Figure 2.1 for more details). Finally, a total of 27 papers (15 papers from the peer-reviewed literature search and 12 papers from the non-peer-reviewed literature search) were included in the review (Figure 2.1). The peer-reviewed papers included eight systematic reviews (10, 22-28), five non-systematic reviews (29-33), one meta-analysis (34), and one paper consisting of both a systematic review and meta-analysis (35). The non-peer-reviewed papers included four (policy) reports (6, 36-38), four guides (for practitioners) (39-42), three websites/online articles (43-45), and one journal article (46). In Supplementary file 2.3, an overview of the included papers is provided.

Patient populations

The patients included in the papers had chronic diseases or multimorbidity (n = 8) (22, 24, 25, 27-30, 34), heart conditions (n = 7) (22-25, 29, 32, 34), or dementia (n = 3) (23, 25, 28). Papers often did not specify exclusion criteria (n = 11) (22-24, 26, 29-35).



* Studies focus on irrelevant interventions, instruments, pharmaceuticals, disease-specific approaches, populations and/or settings or a combination of the aforementioned.

Figure 2.1 Flowchart of paper selection

Programme theory

In Table 2.1, the context items, mechanisms, programme activities and outcomes reported in the literature and their explanation are shown in ascending order of how often they were reported. Based on the identified factors, CMOcs were established (Figure 2.2). In Figure 2.2, each set of coloured arrows represents a CMOc, which indicate that mechanisms of action get triggered within a specific context and that these mechanisms lead to particular outcomes. The dashed arrows indicate incomplete configurations, where either a context factor is linked with a mechanism or an outcome, or a mechanism with an outcome. Findings in the form of CMOcs are described in the following PT for effective IC for older people. Based on the needs of older people, the focus of IC should be on treating older people as individuals rather than a collection of diseases (M). In order to realise an appropriate approach and a successful use of risk prevention programmes, it is essential that the right patient population is identified and selected, for example, by use of a risk stratification tool (PA). Treatment approaches need to match the broad health issues/illness processes of frail older people by focusing on all life domains (i.e., physical, mental and social), instead of single disease-related aspects (M) in order to achieve desired results, such as an improved quality of life of older people (O). Health education and training (C) for older people and their informal caregivers could stimulate their active involvement in the care process (M), leading to the patient and the healthcare providers (HCPs) understanding each other better, as well as the patient having more insight into the importance of his/her treatment (M). Their involvement is important in setting up tailormade individual care plans (PA), leading to an improvement in functionality of the older person (O), but also for managing medication treatment (PA), and planning follow-up support (e.g., after hospital discharge) (PA) in order to have a reduced hospital (re)admission rate (O). To provide care in line with the vision of IC, it is essential to work with multidisciplinary core teams (C, M). These teams should consist of HCPs of various disciplines each having their own expertise (and include, for example, a case manager, a general practitioner, a geriatrician and an advanced nurse practitioner) (C) to meet the complex and diverse care needs of older people (O). Team members need to have clearly defined roles and responsibilities and need to be aware of each other's expertise (C) to work closely together effectively (M) and to establish a well-working collaboration (M), leading to higher satisfaction of older people, informal caregivers and HCPs (O). Training and education of HCPs in, for example, shared decision-making, patient empowerment, interprofessional collaboration and communication (C) needs to be an integral part of the healthcare system, as it is beneficial to enhance their skills and knowledge (C) to improve the quality of healthcare (O). With the help of training (C) and by means of customised communication (M), PAs such as having (preventive) home visits (PA) and performing extensive geriatric assessments (PA) can be conducted in a more competently matter resulting in a delay in nursing home placement (O) and a reduced use of healthcare services (O). However, it is important that organisational alignment (C) on all levels and the provision of sufficient financial resources (C) is in place to realise the aforementioned activities. Since frail older people are hospitalised relatively often, it is important that the core team includes a HCP (C) with expertise in hospital discharge planning (PA). This expertise entails developing an (early) extensive discharge plan (PA) in collaboration with the patient, informal caregiver(s) and HCPs (C), as well as assessing hospital discharge (PA) and ensuring collaboration among all disciplines (M) involved in caring for the respective older person (PA). In the long term, it may entail reduced healthcare costs for the health system (O). Information technology (C) can support the collaboration, involvement and communication (M) of HCPs by enabling information sharing (PA) between, for example, professionals of different disciplines, older people and their informal caregivers (C); by enabling health-related social networks and patient–provider interactions; by supporting patient engagement; by providing electronic access to guidelines, protocols and other health information; and by sending reminders for providers and patients (C).

Table 2.1 Reported context items (C), mechanisms (M), programme-activities (PA), and outcomes (O)

Factor	Explanation	References	Related WHO-IPCHS strategy
Context (C)			
Multidisciplinary core team	Deployment of different types of professionals as a core team (ANP, case manager, specialized geriatric care provider, community nurse, GP; discharge planning expert); clearly defined roles and responsibilities; HCPs know each other's expertise; sufficient staffing levels.	6, 22, 23, 25, 27, 33, 35-39, 41, 42, 44, 45	3, 4, 5
Training and education of HCP	Training and education of HCPs for the required competences, skills and knowledge; optimization expertise of HCPs; provision of training on case management.	6, 23, 25, 27-31, 33, 35, 36, 38, 40, 41	5
Role older person and informal caregiver(s)	Providing health education and training to the older person and informal caregivers; clearly defined single contact point for the older person and informal caregivers; availability of social support.	22, 25, 28, 31-33, 37, 39, 40	1
Financial support	Offering remunerative support and financial incentives; alignment of incentives and performance indicators; means to invest in new approaches and their management; issue of fragmented funding; sustainable funding of IC.	6, 24, 30, 31, 33, 34, 36-38	2 and 5
Information technology	Use of smarter (information) technologies to facilitate clinical practice (e.g. administrative tasks); use of a web-based electronic record system; capturing and disseminating information electronically across the health and social care system; access to shared records/electronic patient records by all involved stakeholders.	6, 29, 33, 36-39, 43, 44	3 and 5
Organisational alignment	Organisational coordination on all levels; cultural change; lack of sustainable agreements between different health- and social care providers and agencies; well-connected networks to facilitate access to support; offering organisational supports.	6, 25, 37, 38, 41, 42	1, 2, 3, 4, and 5
Mechanisms (M)			
Collaboration within and between disciplines	Fully integrated multidisciplinary care team with structures of collaboration within disciplines as well as between disciplines.	6, 26, 27, 30, 33, 36-40, 42-46	4 and 5
Involvement older person and informal caregiver(s)	Active involvement of older person and informal caregiver(s) in the care process e.g. shared decision making, developing care plans, discharge plan etc.; involving the network of the older person as much as possible.	10, 22-25, 27, 31, 33, 34, 37, 39, 42, 44	1, 2, 3, and 4

Table 2.1 Reported context items (C), mechanisms (M), programme-activities (PA), and outcomes (O) (continued)

Factor	Explanation	References	Related WHO-IPCHS strategy
Mechanisms (M) (cont.)			
Person-centred care	A focus on possibilities, needs, wishes, and preferences of the older person (and informal caregivers) instead of the person's illness and/or disabilities; viewing the older person as a human being, rather than a collection of diseases; focusing on care processes instead of outcomes.	6, 10, 22, 24, 25, 27, 34, 36, 37, 40-42, 46	1, 2, 3, 4, and 5
Effective communication	Providing effective communication between all stakeholders (older person, informal caregiver(s), HCPs, organisations, sites etc.)	6, 22, 25, 30, 31, 36, 37	1, 2, 3, and 5
Programme-activities (PA)			
Individual care plans	Setting up, implementing, monitoring, evaluating, and adjusting individual care plans.	10, 22-29, 33, 34, 36-40, 43	1, 2, and 5
Geriatric assessment	Performing comprehensive multidimensional geriatric assessments (physical, social and psychological, functional social), ideally at the older person's home.	10, 24-26, 28, 33-37, 40-43	1 and 3
Case finding/ prevention	(Early) identification and selection of potentially frail older people (target group) e.g. in the GP practice by means of screening instruments (e.g. risk stratification tool); incorporating prevention programmes.	10, 28-30, 37-43	3 and 4
Hospital discharge planning	Developing an (early) extensive discharge plan in collaboration with the patient, informal caregiver(s), and HCPs; assessing hospital discharge.	22, 24, 25, 27, 31, 32, 34, 45	1 and 4
Follow-up appointments	Planning follow-up support and/or strategies; performing follow-up appointments at home and by telephone e.g. after hospital discharge.	10, 22-25, 32, 34	1, 3, and 4
Medication treatment	Adjusting and aligning medication treatment plans e.g. when discharged from the hospital; medication counselling; medication self-management; securing medication safety.	22, 24, 25, 29, 34, 40	1, 3, and 4
Home visits	Frequent (preventive) home visits and assessments.	23, 25, 27, 29, 30	1 and 3
Case management	Deployment of case manager/case management.	10, 27, 33, 45	4

Table 2.1 Reported context items (C), mechanisms (M), programme-activities (PA), and outcomes (O) (continued)

Factor	Explanation	References	Related WHO-IPCHS strategy
Outcomes (O)			
Healthcare costs	Heterogenous effects (mainly reduced healthcare costs and community costs)	10, 22, 23, 25-30, 33, 35, 41	2 and 5
Hospital-related outcomes	Heterogenous effects (mainly a reduced hospital (re)admission rate; a reduced length of hospital stay; reduced use of emergency care).	22, 24-26, 30-35, 43	2 and 5
Quality of life	Heterogenous effects (mainly an improved quality of life).	22, 24, 25, 27, 29, 32-34, 41, 42, 46	2 and 5
Satisfaction	Higher satisfaction older person, informal caregivers and HCPs.	10, 22, 25-27, 29-31, 33	2 and 5
Functionality	Improved functioning/functional status.	22, 25, 27, 29, 30, 33, 39	2 and 5
Use of healthcare services	Heterogenous effects (mainly reduced use of hospital services/healthcare system).	10, 22, 27-30, 33	2 and 5
Nursing home placement	Postponement of placement in institutions/nursing home; lower nursing home admission rates; shorter length of stay in nursing home.	10, 23, 28, 30, 33	4

ANP: advanced nurse practitioner; GP: general practitioner; HCP: healthcare professional; IC: integrated care

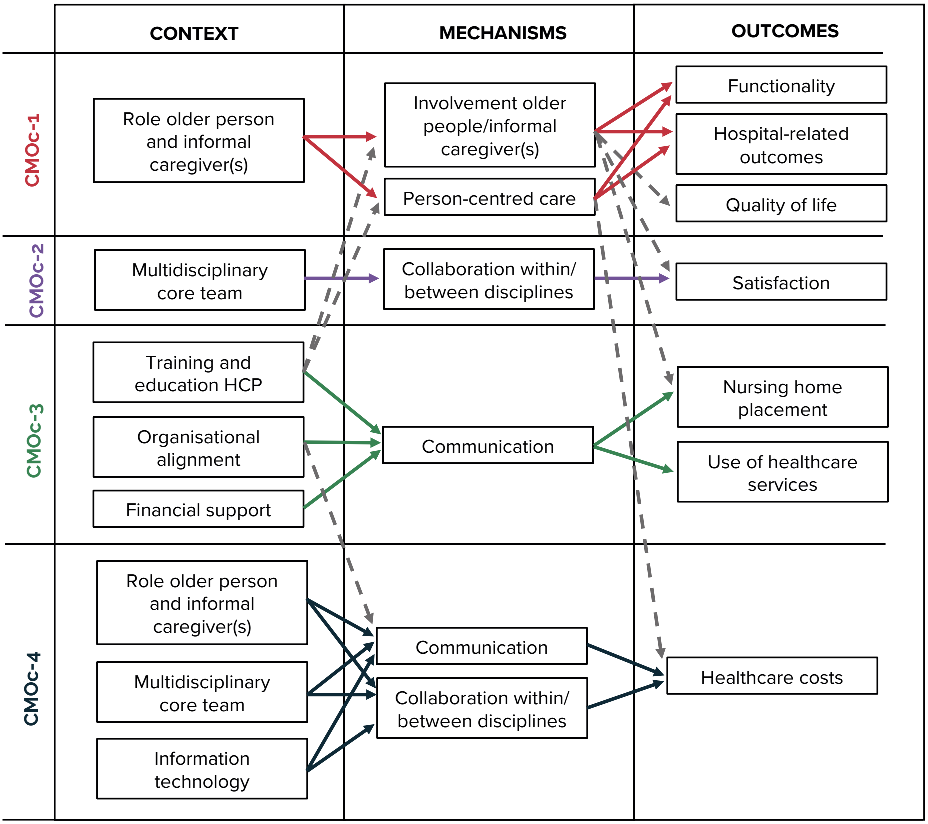


Figure 2.2 Context-mechanism-outcome configurations (CMOcs) of integrated care (IC) for community-dwelling frail older people. HCP: healthcare provider.

Link to the WHO-IPCHS framework

In Table 2.1 (rightmost column), the strategy/strategies of the WHO-IPCHS framework that relate to the extracted data are shown. These links with the WHO-IPCHS framework demonstrated that the most prevalent strategy to which most of the context items, mechanisms, programme activities and outcomes are categorised into was strategy 5 ‘creating an enabling environment’ (25%), followed by WHO-IPCHS strategy 2 ‘strengthening governance and accountability’ (20%). Three WHO-IPCHS strategies were linked with context items, mechanisms, programme activities and outcomes to the same extent (all 18%): ‘engaging and empowering people and communities’ (strategy 1), ‘reorienting the model of care’ (strategy 3) and ‘coordinating services within and across sectors’ (strategy 4). Linking the items to the WHO-IPCHS strategies shows that regarding context items, WHO-IPCHS strategy 5 ‘creating an enabling environment’ was most prevalent; regarding programme activities strategy 1 ‘engaging and empowering people and communities’; and regarding the outcomes both strategy

2 ‘strengthening governance and accountability’ and strategy 5 ‘creating an enabling environment’. Concerning mechanisms, all strategies were equally prevalent.

DISCUSSION

In this RRR, we provided a detailed overview of the interrelatedness of context items, mechanisms, programme activities and outcomes of IC for community-dwelling frail older people. Further, we linked these factors to the strategies of the WHO-IPCHS framework to explore to what extent the strategies are applied in ICPs and refined the PT. We developed a PT that explains how ICPs for community-dwelling frail older people work, for whom and why. The PT illustrated that it is essential to establish multidisciplinary teams of competent HCPs providing person-centred care, closely working together and communicating effectively with other stakeholders. Older people and informal caregivers should be involved in the care process in order to get a better picture of the patient’s wishes and needs, and shared decision-making can be established. Financial support, efficient use of information technology and organisational alignment are also essential. ICPs demonstrate positive effects on the functionality of older people, satisfaction of older people, informal caregivers and HCPs, and a delayed placement in a nursing home. Heterogeneous effects were found for hospital-related outcomes, quality of life, healthcare costs and use of healthcare services. Outcomes of IC for frail older people are the result of interactions of context items, mechanisms and programme activities, as identified in this study. The interaction of factors can only partly explain the effects of IC, as the focus in evaluating outcomes primarily lies on PAs and outcomes compared with context and mechanisms. Authors of papers included in this review reported that it was difficult to link ICPs to outcomes (n = 9) (10, 22, 23, 25, 27, 28, 31, 32, 35). According to the authors, this was attributed to the differences in populations, variations in the content and characteristics of programmes and their activities and, generally, a lack of robust programmes. This, however, made it impossible, as part of this RRR, to shed light on why ICPs do not work. The PT developed in this RRR should be considered a first step towards a more comprehensive PT. In this study, a linkage between the PT and the WHO-IPCHS framework shows that ‘creating an enabling environment’ (strategy 5) and ‘strengthening governance and accountability’ (strategy 2) seem to be prioritised in the way IC is currently delivered to older people, implicating that IC for older people still needs to be further developed, as not all five interconnected WHO-IPCHS strategies are equally prevalent in the current programmes. It must be noted that the WHO-IPCHS framework is transformative and given that healthcare systems are setting specific, its implications need to be aligned to the local context, values and preferences. In a follow-up study to this RRR, primary data on the relevance of the identified factors for the Dutch setting will be assessed. Context items, mechanisms, programme activities and outcomes reported in three papers or less, which are not included in the analysis of this study, will be included in the follow-up study. The categories (context, mechanisms, programme activities, outcomes) factors belonged to sometimes differed in the included studies depending on the function they held within a programme, as reported by the papers. For example, the factor 'home visits' was reported as a programme activity by five papers, and as a context item by three papers. This accentuates the importance of accurately indicating the meaning of each factor within a programme. It also emphasises that when programmes are compared, the varied meanings of identical items may partly explain differences in outcomes between programmes with apparently similar factors.

Depending on the type of literature (peer reviewed vs non-peer reviewed), either the interpretive meaning of factors was described or a statement was given. For example, regarding the context item 'financial support', papers reported a lack of financial incentives and resources, and no sustainable funding being in place (6, 31, 38). Regarding the context item 'multidisciplinary core teams', papers mentioned constrained staffing levels, unclarity of roles and responsibilities of team members, and mutual unfamiliarity of professionals from different disciplines/domains (6, 41). Also, the theoretical underpinning of the interrelatedness of factors and the level factors are operating on are lacking in the literature. It was difficult to identify CMOcs per publication and their corresponding level, as very limited to no information on the interaction of factors was found per article. Consequently, the current PT may give an oversimplified impression of the interplay of factors. Evaluating ICPs is considered challenging due to their complex nature (47).

Comparison with other literature

In line with this study, previous research demonstrated that the several components of ICPs for older people play a prominent role. However, the interaction of factors is underexposed as only one of the papers is a realist review (9), next to a scoping review (11), narrative review (48), and review of reviews (8), which mainly assessed components that contribute to IC. Studies reported the following components that correspond to the context items, mechanisms, PAs and outcomes found in this study: professional training of HCPs (8, 9, 11); incentives for integration and a funding system for IC (9, 11); patient education (8); organisational integration (11); effective communication (9, 11); person-centred care (11); comprehensive/geriatric assessment (8, 48); case management (8, 11, 48); home visits (8); medication review (8); developing care plans (9); and discharge planning (11). Favourable effects regarding care utilisation (reduced) and health outcomes (improved) were found (9, 48) and mixed results on costs (48). Similarly, the review of reviews by Briggs et al. also demonstrated that the focus of key elements of IC models for older people aligns with the WHO-IPCHS strategy 'creating an enabling environment' (strategy 5) (8).

Strengths and limitations

To the best of our knowledge, this is the first RRR that provides an overview of the interaction of context items, mechanisms, programme activities and outcomes and aligns them with the WHO-IPCHS strategies in order to explore to what extent the five strategies are applied in programmes. The strength of the realist approach lies in opening the black box, which leads to theory development explaining why ICPs (do not) work, for whom and under what circumstances. People from other countries may consider these findings useful to influence the effectiveness of ICPs for frail older people. Moreover, they are provided an overview of which WHO-IPCHS strategies are applied and which strategies are underexposed and deserve more attention. Another strength is the involvement of experts and (representatives of) patient organisations to test and refine the PT and to confirm findings. A limitation to be considered is the definitions of context, mechanisms, programme activities and outcomes. Within the realist approach this is often a challenge, as there may be some overlap, since an outcome from one ICP may be a contextual factor in another. However, in this study, disagreement about the category data belonged to was resolved by discussion between the authors. A second limitation was the use of an overarching/non-specific definition of frailty due to a lack of consensus on the term in international scientific literature, resulting in a broad patient population. Even though definitions of frailty and multiple instruments to measure frailty are available, these are rarely reported in research concerning IC for frail older people (49-55). Four papers included in this study mentioned the heterogeneity in the patient population as a striking finding (10, 26, 27, 35).

Recommendations

As the identified factors of ICPs for frail older people could not be aligned with all WHO-IPCHS strategies, ICPs need to have a more balanced application of all WHO-IPCHS strategies, as the realisation of all strategies in programmes ensures that health service delivery will be more people centred and integrated. Strategies most commonly reflected in ICPs are more administrative and planning focused, and less focused on the strategies that are related to actions associated with implementing new care models. In case one or more strategies are underexposed, it will affect progress in other strategies (5). To ensure that ICPs fulfil all five strategies, the WHO suggests implementation guidance support tools (56). Further research of ICPs should make use of the existing operationalisations of frailty to define clear and complete description of patient groups and their health problems. This would enable to offer tailor-made programme activities to the different degrees of frailty. Lastly, additional realist research is needed to establish a more comprehensive PT for IC for frail older people. As very limited to no information on the interaction of factors was found within each article, more focus on the theoretical underpinning of the interrelatedness of factors in the literature is needed by considering CMOc(s) within each article. Further setting-specific validation of context items, mechanisms, programme activities and outcomes of IC for frail older people needs to take place by involving older people and informal caregivers in the design and development of ICPs. As IC is in full development and needs to be defined more precisely than hitherto (57), this the study can be considered a valuable starting point for testing CMOcs and to use the study results as management information for the further application of IC.

CONCLUSION

In this RRR, we developed a PT that explains how ICPs for community-dwelling frail older people work, for whom and why. This study shows that ICPs for frail older people are still in development, as most ICPs do not address all WHO-IPCHS strategies. In order to optimise ICPs for frail older people, the comprehensiveness of the WHO-IPCHS framework and the interaction between context items, mechanisms, programme activities and the outcomes should be taken into account from different perspectives (system, organisation, service delivery, HCP and patient). Additional realist research is needed to establish more comprehensive PTs for IC for community-dwelling frail older people.

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SUPPLEMENTARY FILE 2.1

Summary of the WHO-IPCHS framework [1]

Strategy 1: Empowering and engaging people and communities

“Empowering and engaging people is about providing the opportunity, skills and resources that people need to be articulate and empowered users of health services and advocates for a reformed health system. This strategy seeks to unlock community and individual resources for action at all levels. It aims to empower individuals to make effective decisions about their own health and to enable communities to become actively engaged in co-producing healthy environments, and to provide informal carers with the necessary education to optimize their performance and support in order to continue in their role. Empowering and engaging people is also about reaching the underserved and marginalized groups of the population in order to guarantee universal access to and benefit from quality services that are co-produced according to their specific needs.” (p. 5, WHO framework on integrated, people-centred health services, 2016)

Strategy 2: Strengthening governance and accountability

“Strengthening governance requires a participatory approach to policy formulation, decision-making and performance evaluation at all levels of the health system, from policy-making to the clinical intervention level. Good governance is transparent, inclusive, reduces vulnerability to corruption and makes the best use of available resources and information to ensure the best possible results. Good governance is reinforced by a robust system for mutual accountability among policy-makers, managers, providers and users and by incentives aligned with a people-centred approach. Establishing a strong policy framework and a compelling narrative for reform will be important to building a shared vision, as well as setting out how that vision will be achieved.” (p. 6, WHO framework on integrated, people-centred health services, 2016)

Strategy 3: Reorienting the model of care

“Reorienting the model of care means ensuring that efficient and effective health care services are designed, purchased and provided through innovative models of care that prioritize primary and community care services and the co-production of health. This encompasses the shift from inpatient to outpatient and ambulatory care and from curative to preventive care. It requires investment in holistic and comprehensive care, including health promotion and ill-health prevention strategies that support people’s health and well-being. It also respects gender and cultural preferences in the design and operation of health services.” (p. 7, WHO framework on integrated, people-centred health services, 2016)

Strategy 4: Coordinating services within and across sectors

“Services should be coordinated around the needs and demands of people. This result requires integration of health care providers within and across health care settings, development of referral systems and networks among levels of care, and the creation of linkages between health and other sectors. It encompasses intersectoral action at the community level in order to address the social determinants of health and optimize use of scarce resources, including, at times, through partnerships with the private sector. Coordination does not necessarily require the merging of the different structures, services or workflows, but rather focuses on improving the delivery of care through the alignment and harmonizing of the processes and information among the different services.” (p. 8, WHO framework on integrated, people-centred health services, 2016)

Strategy 5: Creating an enabling environment

“In order for the four previous strategies to become an operational reality, it is necessary to create an enabling environment that brings together all stakeholders to undertake transformational change. This complex task will involve a diverse set of processes to bring about the necessary changes in leadership and management, information systems, methods to improve quality, reorientation of the workforce, legislative frameworks, financial arrangements, and incentives.” (p. 9, WHO framework on integrated, people-centred health services, 2016)

Reference:

1. World Health Organization. Framework on integrated, people-centred health services. 2016. Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA69/A69_39-en.pdf?ua=1&ua=1 (Accessed April 30th, 2020).

SUPPLEMENTARY FILE 2.2

Search terms and -strings

Database: PubMed

The first line covered the study population. The second line contained keywords related to care at home. The third line was aimed to identify IC programmes. The fourth line focused on the effectiveness.

Search lines	Search terms	Filtered by
1. Line	"Frail Elderly"[Mesh] OR "vulnerable populations"[MeSH] OR "Aging"[Mesh] OR "Aged"[Mesh] OR "elderly" OR "very elderly" OR "older adults" OR "older population" OR "senior" OR "frailty" OR "vulnerable" OR "frail older people" OR "vulnerable older people" OR "high risk"	Title/Abstract
2. Line	"Independent Living"[Mesh] OR "Home Care Services"[Mesh] OR "Primary Care Nursing"[Mesh] OR "Primary Nursing"[Mesh] OR "Physicians, Primary Care"[Mesh] OR "Primary Health Care"[Mesh] OR "Family Practice"[Mesh] OR "Family Nursing"[Mesh] OR "Ambulatory Care"[Mesh] OR "Ambulatory Care Facilities"[Mesh] OR "Community Integration"[Mesh] OR "Community Health Planning"[Mesh] OR "Community Health Services"[Mesh] OR "home" OR "home care" OR "home based" OR "home nursing" OR "homebound" OR "community dwelling" OR "independent living" OR "primary care" OR "primary health" OR "primary healthcare" OR "family practice" OR "family medicine" OR "ambulatory care" OR "outpatient care" OR "community care"	Title/Abstract
3. Line	"Delivery of Health Care, Integrated"[Mesh] OR "patient-centered care"[MeSH] OR "disease management"[MeSH] OR "patient care management"[MeSH] OR "case management"[MeSH] OR "Continuity of Patient Care"[MeSH] OR "integrated care" OR "integration of care" OR "care coordination" OR "collaborative care" OR "multidisciplinary care" OR "integrated health care system" OR "managed care" OR "health systems integration" OR "integrated service delivery systems" OR "integrated networks" OR "integrated healthcare delivery" OR "health services integration" OR "delivery system reform" OR "integrated health and social care models" OR "complex care" OR "care planning" OR "complex intervention" OR "continuing care" OR "care integration" OR "shared care" OR "transitional care" OR "patient care management" OR "synchronized care" OR "interdisciplinary care"	Title/Abstract
4. Line	"Cost-Benefit Analysis"[Mesh] OR "outcome" OR "cost-effectiveness" OR "effectiveness" OR "effects" OR "best practice"	Title/Abstract
5. Search string	#1 AND #2 AND #3 AND #4	

SUPPLEMENTARY FILE 2.3

Overview of included literature

Peer-reviewed literature

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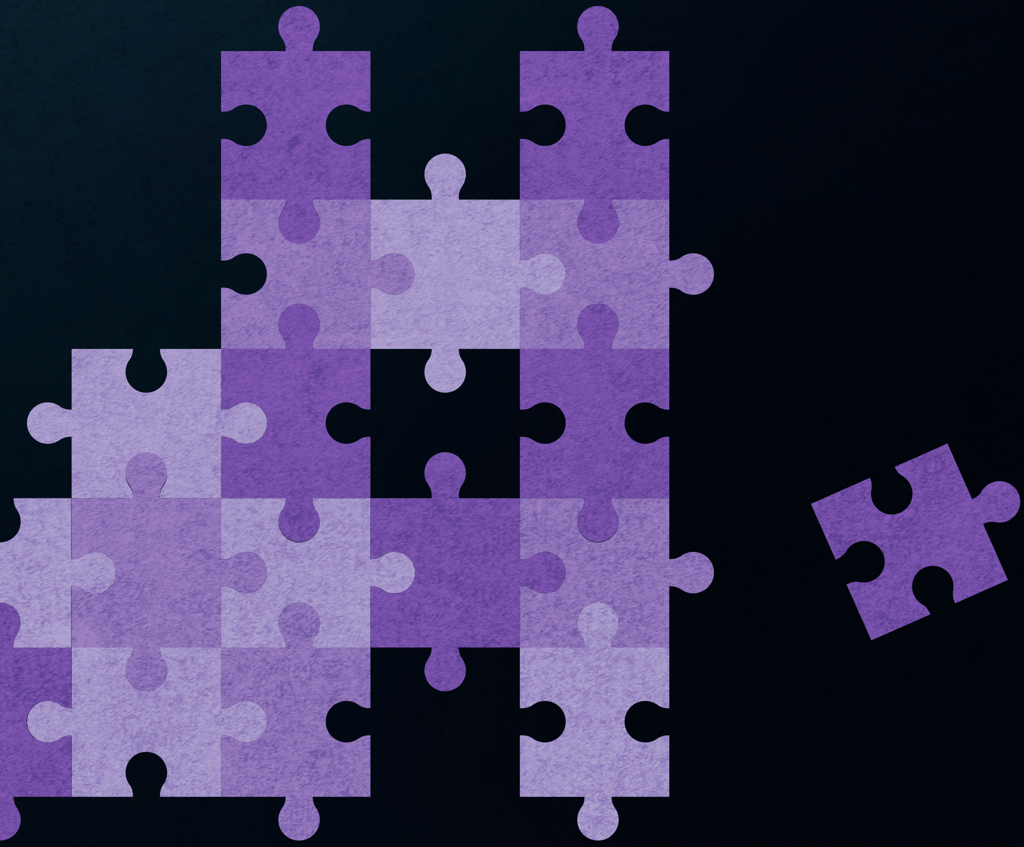

CHAPTER 3

Consensus on integrated care for older people among Dutch experts: a Delphi study

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ABSTRACT

Introduction

In a previous rapid realist review (RRR), an initial programme theory (PT) was established giving insight into the interrelatedness of context items, mechanisms, programme-activities, and outcomes that influence integrated care programmes (ICPs) for community-dwelling frail older people. As ICPs need to be tailored to their local setting, the objective of this study is to assess consensus on the relevance of the items identified in the RRR for the Dutch setting, and refine the PT, where appropriate.

Methods

A two-round e-Delphi study was carried out among Dutch experts to determine the relevance of 71 items.

Results

Consensus on relevance was reached on 57 out of 71 items (80%). Items added to refine the PT included: increasing number of older people, decreasing access to hospital beds, well-designed ICP implementation processes, case management, having a clear portfolio of patients, the role of the government, aligning existing health and social care systems, management and monitoring of care activities, strong relationship between older person and healthcare providers (HCP), and providing continuous feedback to HCPs.

Conclusion and discussion

The initial PT was refined for the Dutch setting. Items on which no consensus was found, need to be further investigated on the reason behind it.

INTRODUCTION

Aging is irrevocably accompanied by the loss of physical, mental, and social strength and capabilities (1-3). To address the diverse needs of older people for care and support, integrated care programmes (ICPs) are recommended. ICPs aim to provide a continuum of care for older people, where professionals in different domains cooperate and coordinate care taking into account the often complex care needs, and the individual preferences of older people within a broad range of (health and social) services over an extensive timeframe (4, 5). Notwithstanding the conceptual attractiveness of ICPs, the scientific literature shows heterogeneity in their outcomes (6-9).

Care for older people in the Netherlands

The Dutch government aims to help people grow old independently in their trusted environment among others by facilitating better support and care at home, support to informal caregivers and volunteers, and more suitable housing for older people at the mean time saving on costs for institutional care (10). General practitioners (GPs) and their specialised 'primary care assistant practitioners' are considered the main providers of complex care for older people. GPs, specialists in geriatric medicine and social geriatricians are partners in geriatric care who, together with pharmacists and home care providers, indicate what structure and resources are required to provide good care (11). Primary care assistant practitioners are regarded as essential players in identifying care needs of patients, organizing care and coordinating primary care (12).

Rapid Realist Review

This study is part of a larger study, commissioned by the National Health Care Institute. In the first part of this study, an international rapid realist review (RRR) (13) was conducted with the objective to provide insight into the relationships between the *context (C)* (wider external items) in which ICPs for community-dwelling older people are applied, the *mechanisms (M)* (enablers, underlying entities, processes, or structures) by which the ICPs (do not) work, and the *outcomes* (O) (intended and unintended) resulting from this interaction (14-16). As a result, the RRR established an initial programme theory (PT): a hypothesised explanation of how a complex intervention or programme is expected to work (17, 18). This initial PT demonstrated that it is essential to establish multidisciplinary teams (C) of competent healthcare providers (HCPs) (C) in order for them to provide person-centred care (M) and involve older people and their informal care giver(s) in the care process (M). This has a positive effect on the functionality of older people (O), hospital-related outcomes (O), and the quality of life of older people (O). Also, by means of a multidisciplinary core team (C) a strong collaboration within and between disciplines can be established (M), which has shown to increase the satisfaction levels of older people, informal caregivers and HCPs (O). Next to efficient use of information technology (C), organisational alignment

(C) on all levels, and the provision of sufficient financial resources (C) it is important that that training and education of HCPs (C) in e.g. communication skills takes place, for them to communicate effectively with all involved stakeholders (M). This can result in a delayed placement of the older person in a nursing home (O), reduced use of healthcare services (O), and reduced healthcare costs (O).

Setting ICPs

The environment plays an important role in the development and implementation of ICPs (19-21). Too often ICPs lack a theoretical underpinning and hence have been accused to jump to solutions and to do more harm than good (22). What may successfully work in one setting regarding ICPs, may not work in a different setting. Ideally, the appropriate combination of components of an ICP, needs to be developed and based on the values and preferences of the local setting, however this remains underexposed in the literature (19-21). So, notwithstanding the insights derived from the RRR, as mentioned previously, ultimately ICPs need to fit the local setting. The National Health Care Institute in the Netherlands indicated that, ideally, existing, often incidentally developed, local care initiatives should be replaced by conceptualised ICPs for community-dwelling older people. However, different stakeholders in different parts of the Netherlands may hold different beliefs about why, how and for whom an ICP may result in what outcomes and when.

Study objective

As the RRR provided an international perspective on the items that play an important role in ICPs for older people, but ICPs need to fit the local setting, it is essential to determine which items are relevant for the Dutch setting. Based on that, stakeholders are provided with evidence and practical guidance to establish effective ICPs. This can help to reduce the degree of heterogeneity present in outcomes of ICPs. The aim of this study is to assess consensus on the relevance of context items, mechanisms, programme-activities, and outcomes of ICPs for community-dwelling frail older people for the Dutch setting by various stakeholders and to refine the PT for the Dutch setting, where appropriate.

METHODS

An e-modified Delphi study was conducted to assess consensus for the Dutch setting on the context items, mechanisms, programme-activities and outcomes of ICPs for community-dwelling older people, which emerged from the RRR previously conducted (13). A Delphi study consists of multiple rounds in which data are collected by sending out a questionnaire that needs to be filled in by a panel of experts on a particular topic. The anonymous responses are aggregated and shared with the panel after each round in the form of a group result (20, 23, 24). In a classical Delphi study, the aim is to elicit opinion and gain consensus, may consist of three or more rounds, and has an open qualitative first round which allows Delphi panel experts to record responses. In this study, the term ‘modified’ refers to a Delphi study that consisted of two rounds, and where in round 1 Delphi panel experts were provided with items of the RRR, of which they are requested to assess their relevance for the Dutch setting (25, 26). A Delphi study is an efficient method for obtaining valuable input from multiple experts in a relatively short timeframe and clarifies which items are more/less relevant and why, or which items are missing from the theory presented, in this case the RRR. Information on consensus among experts is particularly useful in the process of refining the PT and explaining why integrated care does (not) work for (frail) older people, how, and in this specific context.

Selection of participants

A purposive sampling strategy was used to identify experts with relevant experience in the field of integrated care for older people, aiming for diversity regarding age, gender, profession, and the setting of the ICP(s) they were involved in. In order for the experts to be selected for the Delphi panel, they needed to be actively involved in the implementation of programmes regarding integrated care for (frail) older people at home which were being monitored or evaluated in the Netherlands. Their active involvement in the implementation of ICPs depended on their role as e.g. researchers, healthcare providers, policy advisors, managers etc. Participants for the Delphi expert panel were recruited across the Netherlands through the professional networks of various parties involved in this study, i.e. the commissioner of the current study, a steering committee established for the larger study (see Acknowledgements) and, the researchers of the current study. Experts who met the selection criteria were invited by email with information about the study objectives and details of the Delphi study. Those who gave informed consent were included in the study.

Delphi round 1

Participants were sent an electronic questionnaire via a weblink (SurveyMonkey). The questionnaire started with an introduction of the study, an explanation of the objectives, the structure of the questionnaire, and the definitions of the constructs: context, mechanisms, programme-activities, and outcomes. The questionnaire continued with six general questions regarding gender, age, highest level of education, current job position, number of years working within the position, and number of years of experience with integrated care for older people. The questionnaire contained another 71 questions related to ICPs (13). Participants were asked to indicate the relevance of 15 context items, 14 mechanisms, 20 programme-activities and 22 outcomes. Relevance was measured on a 9-point Likert scale (1 = very irrelevant, 9 = very relevant), with scores 1–3 considered as irrelevant, 4–6 as equivocal/ambiguous and, 7–9 as relevant. Context items included e.g. offering training and education to healthcare professionals, and having organisation support and coordination on all levels; mechanisms included e.g. involvement of older people and informal caregivers, and having effective communication between all stakeholders, programme-activities included e.g. performing comprehensive geriatric assessments, and deployment of case management; and outcomes included e.g. delayed move to nursing home, and quality of life (see Supplementary file 3.1 for the complete list). The questionnaire ended with two open questions. In this part, participants were able to provide additions to the context items, mechanisms, programme-activities, and/ or outcomes in the questionnaire. The participants were also asked for general comments/suggestions about items and the questionnaire itself. Data collection of round 1 took a total of two weeks.

Delphi round 2

In the second Delphi round, items on which dissensus was found during the first Delphi, were included. The questionnaire started with the same general questions as round 1. Subsequently, participants were asked to reassess the relevance of the context items, mechanisms, programme-activities, and outcomes on a 9-point Likert scale. At the end of the questionnaire, participants were asked for general comments/ suggestions on the items and the questionnaire. During the second round, participants were shown a summary of the group results from the first Delphi round, including 1) the median assessment results and interquartile range (IQR) on each item, 2) the level of (insufficient) consensus between the participants and, 3) whether consensus achieved. The IQR is the difference between the 3rd and 1st quartile in which 50% of core values lie (27). The IQR also shows the degree of convergence of the answers (28-31). A summary of the group results were shown to give insight into the level of (dis)agreement between experts in the first round and to generate additional insights about the specific item(s). It has been shown that providing feedback regarding the level of group agreement reached, influences the achievement of level of consensus subsequently (32). Data collection of round 2 took a total of two weeks.

Data analysis

The measures concerning the operationalization of the level of consensus among participants were determined in advance (33). In the literature, no standard threshold for consensus is offered (34), with thresholds for consensus ranging from 55%–100% (35). In this study, the 9-point scale was categorized into three ranges: 1–3 as irrelevant; 4–6 as equivocal; and 7–9 as relevant. The cut-off point for consensus among panel members was set on 75% (34, 36, 37), including the condition that less than 15% of the panel needed to have a scoring in the 1–3 range (38, 39). All items with scores in the 4–6 range and without consensus, were presented again to the expert panel in Delphi round 2. Table 3.1 demonstrates when an item was defined as irrelevant, equivocal, or relevant based on the overall median panel score in both rounds. The degree of consensus of the respondents on each context item, mechanism, programme-activity, and outcome was analysed based on the median scores of the group. Only fully completed questionnaires in both rounds were included in the analyses. The analyses were performed in MS Excel.

Table 3.1 Rules on consensus and dissensus in different point-ranges

		Overall panel median in 1-3 point range	Overall panel median in 4-6 point range	Overall panel median in 7-9 point range
Round 1	Dissensus (< 75%)	Equivocal → included in round 2	Equivocal → included in round 2	Equivocal → included in round 2
	Consensus (≥ 75%)	Irrelevant	Equivocal → included in round 2	Relevant
Round 2	Dissensus (< 75%)	Equivocal	Equivocal	Equivocal
	Consensus (≥ 75%)	Irrelevant	Equivocal	Relevant

Refined PT

Based on the findings of the Delphi study, the PT presented in the RRR was adjusted where appropriate. Consensus on items being relevant, remained part of the PT or were added to the PT. Consensus on items being irrelevant or no consensus on items were removed from the PT.

Ethics

As this study does not involve patients or study subjects, according to the Dutch Medical Research in Human Subjects Act (WMO) in the Netherlands, an ethical approval was not needed. However, all participants provided their consent and participation in the survey was anonymous.

RESULTS

Participants

A total of 35 people was approached to participate in the Delphi study, of which 21 people agreed (Figure 3.1). One person mentioned she did not have the time to participate, whereas the other 13 did not respond to our invitation and thus did not provide a reason not to participate. Of the 21 participants, three did not fully complete the questionnaire in round one (completion rate = 86%), and one in round two (completion rate = 94%). One participant in round one mentioned she found the questions too hard to interpret. Other participants did not provide a reason for not completing the questionnaire. The final data analyses included responses of 17 participants. In Table 3.2 the characteristics of the participants are shown.

Level of consensus

The results on each of the context items, mechanisms, programme-activities, and outcomes of the first and second Delphi round are shown in Supplementary file 3.1 and 3.2 respectively. Table 3.3 shows the total number of items per category (context, mechanisms, programme-activities and outcomes), the number of items on which consensus was achieved, and how many items were equivocal in both two rounds. In the first round, 51 of the total 71 items were considered relevant and consensus was achieved among the experts. The overall median rating by the experts was between the 7–9 point range with a consensus level over 75%. Twenty items remained undecided and were considered equivocal. The panel median for these items was in the 4–6 point range (eight items) and 7–9 point range (12 items) with consensus lower than 75% within the same 3-point region. Consensus on items being found relevant among the experts was observed in the mechanisms (86% of the items), followed by the context items (80% of the items), the outcomes, (68% of the items), and programme-activities (60% of the items).

Experts did not propose any additional items to include in round 2. In round 2, two participants indicated that the outcome factor ‘well-being of older person’ was missing in the questionnaire. In the second round, the 20 items that were rated as equivocal in round one were included. Of these items, consensus on six items was found among the experts. The overall median of the experts was between the 7–9 point range with a consensus level over 75%. For 14 items (70%) the degree of relevance remained undecided (equivocal). The overall median of the experts was in the 4–6 point range (three items) and in the 7–9 point range (11 items). Consensus on items being relevant among the experts was observed for the context items (67% of the items), followed by the mechanisms (50% of the items), programme-activities (25% of the items) and the outcomes (14% of the items). After two rounds, for 57 items of the total 71 items consensus was achieved among the experts whereby all the items were considered relevant.

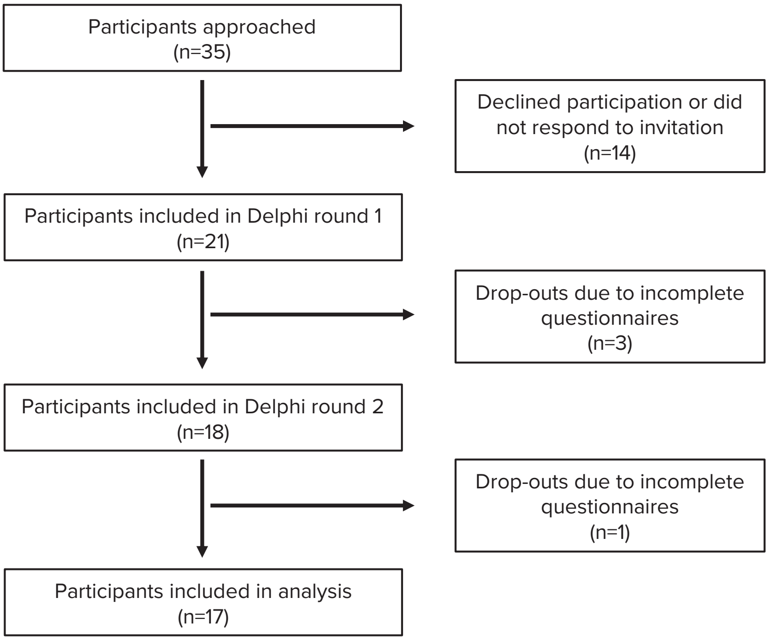

Figure 3.1 Flowchart of participant inclusion.

Table 3.2 Characteristics of the Delphi panel members

Characteristic		Participants (n = 17)
Gender (%)	Female	65
	Male	35
Age (years)	Min-Max	38-61
	Average (SD)	52.5 (7.3)
Highest level of education (%)	Bachelor	12
	Master	47
	PhD	41
Background (%)[#]	Research/academic	24
	Healthcare provider	41
	Other[^]	47
Years of experience	Min-Max	3-35
	Average (SD)	16.4 (10.8)

Several Delphi panel members had expertise in different backgrounds.
^ ‘Other’ included e.g. policy advisors, IC programme managers/project leaders, lecturers.

Table 3.3 Results of Delphi round 1 and 2

Category	Total number of items	Items found relevant (consensus), n (%)	Items undecided (equivocal), n (%)
Round 1			
Total	71	51 (72)	20 (28)
Context	15	12 (80)	3 (20)
Mechanisms	14	12 (86)	2 (14)
Programme-activities	20	12 (60)	8 (40)
Outcomes	22	15 (68)	7 (32)
Round 2			
Total	20	6 (30)	14 (70)
Context	3	2 (67)	1 (33)
Mechanisms	2	1 (50)	1 (50)
Programme-activities	8	2 (25)	6 (75)
Outcomes	7	1 (14)	6 (86)

Description of items

Context items

The context items that were found to be highly relevant for the Netherlands among the Delphi panel experts concern organizational support and coordination, (financial) resources and incentives to invest in integrated care for frail older people, the alignment of existing health and social care systems, and the smart use of (information) technologies. Experts agreed that training of professionals to be competent and highly skilled and having a multidisciplinary core team were context items of great importance. The integration of case management in a broader program or the healthcare system, as well as, offering guidance and support to older people and informal caregivers was also considered relevant. In light of the context item ‘offering remunerative and financial support’, experts mentioned that the financing of integrated care for older people should be led by patients’ needs. This entails that financing should not only be restricted to medical care, but also include social care and support for caregivers. The context items for which insufficient consensus was found after two rounds concerned the degree of integration of Advanced Practice Nurses (APN) in the healthcare system, for which no reason was provided.

Mechanisms

Among the Delphi panel experts there was agreement on the relevance of involving older people and their caregiver(s) (e.g. in shared decision-making, developing care plans) and of the importance of establishing a good relationship between the older person and the HCPs as mechanisms. Communicating effectively plays an essential role, not only between HCPs to ensure optimal interprofessional collaboration, but also between HCPs and older people and their informal caregivers. Enabling collaboration structures were considered very relevant for optimal functioning of a fully integrated interprofessional care team. Also, the HCPs need to provide person-centred care by putting the older person central and focus on the needs, preferences, and possibilities of the individual. Delphi panellists disagreed on the relevance of focusing on system goals (e.g. improved national system integration) for ICPs. A reason for not finding this mechanism relevant, was not provided.

Programme-activities

Experts considered the programme-activities identification and selection of the right target group, incorporating risk prevention in ICPs, performing comprehensive geriatric (home) assessments, and frequent (preventive) home visits to be highly relevant for the Dutch situation. Various care activities, such as the development and implementation of individual care plans, setting up a hospital discharge plan, medication adjustment and alignment (e.g. at care transition) were also considered programme-activities of high relevance. Supporting self-management of older people, the provision of case management, as well as empowerment of patients were found relevant too. The Delphi rounds also demonstrated that the degree of relevance was undecided for multiple programme-activities, such as the generic and disease-specific deployment of APNs, performing (telephone) follow-up appointments, having specialized clinics regarding memory/dementia care in primary care, standardization of processes, and the use of information technology (IT) for risk inventory and reminders. However, a reason on disagreement was not provided.

Outcomes

A high degree of relevance was found for increased functionality, improved self-management of the older person, quality of life (mixed results in the literature), improved (perceived) health, decreased decline in mental health (e.g. depression), a higher satisfaction of the patient, informal caregiver(s) and HCP(s). Moreover, the possibility for the older person to stay longer at home, and hospital-related outcomes (mixed results in the literature) were assessed to be of high relevance. Experts also agreed with high relevance being found on the outcomes of use of hospital services/health system (mixed results in the literature), improved access to healthcare and social care, and improved use of case management services. Dissensus on relevance has been found concerning the following outcome measures: increase in the performance frequency of early detection screening tests for certain conditions (e.g. diabetes, hypertension, vitamin B12 deficiency) and immunizations (e.g. influenza vaccinations) due to the highly clinical nature of the outcomes; reduced medication use by older people, improved timeliness of communication (e.g. to primary care), cost-effectiveness, and mortality. A reason for disagreement on the latter four outcomes was not found.

Refined PT

Based on the findings of the Delphi rounds, the PT was refined for the Dutch setting. In Box 1 this refined PT is shown, with the items that were added, being underlined.

Box 1. Refined PT on ICPs for community-dwelling frail older people in the Dutch setting

Considering the increase in the number of older people (C) and decrease in access to hospital beds (C), ICPs with well-designed implementation processes (C) offering continuity of care (PA) are needed. The national and local governments can play a role in facilitating (components of) ICPs by promotion via funding or policy (C) and by providing clarity on legislation and regulations concerning ICPs (C). By means of case finding the right patient population is identified and selected (PA) to deliver the right care at the right time. It is essential to establish well-skilled (C) multidisciplinary teams of competent HCPs (C) providing person-centred care (M) and self-management support (PA) and making sure that patients are empowered (PA) to achieve good health. HCPs need to work closely together (M) and communicate effectively with stakeholders from other domains e.g. primary care, community care, social/policy domain, medical specialist, informal caregivers (M). By education (C) and involving older people and informal caregivers in the care process (M), and trusting the general practitioner (M) and/or the primary HCP (e.g. home visiting professional) (M) a strong relationship between them and the HCP's (M) should be built. This way management and monitoring of care activities (M, PA) can be optimized with having a clear portfolio of patients (C) whereby continuous feedback to HCP's (M) needs to be provided. Several programme-activities may contribute to achieving the desired results, such as conducting extensive geriatric assessments/shared assessment processes (PA), setting up individual care plans (PA), having (preventive) home visits (PA), performing case management (PA), managing medication treatment (PA), hospital discharge planning (PA). Next to the alignment of health and social care systems and organizations (C), financial support (C) with e.g. incentives for active participation (M), efficient use of information technology (C), and integration of case management in ICPs (C) emerged also as key elements. ICPs demonstrate positive effects on the functionality (O), mental health (O), self-management skills (O), perceived health (O) of older people, hospital-related outcomes (O), quality of life (O), use of healthcare services including case management (O), and their access to healthcare and social care (O). Besides improved care processes (O), end-of-life discussions were increased (O), the burden on informal caregiver(s) was reduced (O), and there was a delayed placement in a nursing home (O) improving the satisfaction of older people, informal caregivers and HCPs with the care provided (O).

C = context; PA = programme-activity; M = mechanism; O = outcome

DISCUSSION

Principal findings

In this study we aimed to refine the PT for ICPs for community-dwelling frail older people for the Dutch setting by providing insight into the level of consensus on the relevance of context items, mechanisms, programme-activities, and outcomes identified in the RRR. Based on two Delphi rounds, consensus was reached on a set of 57 out of 71 items (80%) of the initial PT, derived from a previous conducted RRR using international literature. Based on the findings of the Delphi study, the initial PT was extended. The added items in the refined PT included increase in the number of older people, decrease in access to hospital beds, well-designed ICP implementation processes, case management, having a clear portfolio of patients, the role of the national/ regional governments, aligning existing health- and social care systems, management and monitoring of care activities, strong relationship between older person and HCPs with patients putting their trust in GP, providing continuous feedback to HCPs. These added outcomes were self-management, perceived and mental health, burden on informal caregiver(s), frequency of end-of-life discussions, healthcare access, and care processes. In the refined PT the items ‘having follow-up appointments’ (programme-activity) and ‘healthcare costs/cost-effectiveness’ (outcome) were removed. Also, not finding consensus on the relevance concerning the inclusiveness of APN may illustrate that there is unclarity about the APN role as part of ICPs in the Netherlands. As nowadays primary care assistant practitioners play an important role in primary care for older people, the main role of APNs in ICPs is not fulfilled like before. The main role of APNs seems to have changed over time from practitioner to consultant (12, 40).

Comparison to previous studies

When comparing our findings with those of other studies, it must be noted that there are not many Delphi studies on integrated care specifically for older people. Briggs et al. (2018) generated consensus on the actions required to implement the World Health Organization Integrated Care for Older People (ICOPE) approach (41). In line with our study, consensus was found on setting up individualised interdisciplinary care plans for patients, active case finding, incorporating prevention programmes, performing geriatric assessments, care delivery by interdisciplinary teams, educational support for formal and informal carers, and the use of data sharing platforms (41). Items on which no consensus was found by Briggs et al. (2018), were the use of provider report cards, traditional and complementary medicines, and the development of new work cadres (41). Zonneveld et al. (2020) investigated the values that underpin integrated health services delivery and found consensus on values such as ‘person-centred’, ‘co-produced’, ‘collaborative’, ‘preventative’, and ‘co-ordinated’, comparable to our findings (42). Regarding values related to IC, no consensus was found on ‘sustainable’, ‘innovative’, ‘proficient’, ‘safe’, and ‘realistic’ due to not being specific or essential enough for IC (42). They, however, did not focus on programmes for older people specifically.

Strengths and limitations

The strength of the current study lies in the use of the structured, electronic Delphi technique to further refine the PT in our RRR and explaining why IC does (not) work for (frail) older people, how, and in what context. To the best of our knowledge, we are one of the first to opt for a Delphi study following a RRR, whereas often individual interviews are conducted. Given the scarcity of resources, this appears to be an efficient method for obtaining meaningful input from multiple experts in a relatively short timeframe. This method makes it clear which items are more/less relevant, and/or which items are missing from a RRR and why items are considered less relevant. However, a few limitations need to be considered for this Delphi study. The first one being the size of the Delphi panel. We invited 35 experts to participate in the Delphi study, but not all responded to our invitation. Nonetheless, sufficient diversity in the Delphi panel was achieved, which is considered more important in terms of validity of study findings. Currently, there are no universally agreed criteria for the selection of experts, and the minimum or maximum number of experts on a panel (34, 43). A second limitation concerns the formulation of questions in the survey. Delphi panel members indicated that several questions were open for own interpretation and could be explained in more detail. The high level of consensus reached after two rounds given a diverse panel, is however very encouraging. To clarify questions in the second Delphi round, some were slightly reformulated or a brief explanation was included. A third limitation relates to the e-interaction between panel members. Exchange of arguments between experts and the authors was only possible digitally, which has hindered in not or partially being able to explain the lack of consensus. In order to acquire more information on the reasoning of members, a blended or ‘physical’ Delphi study could be more suitable.

Implications for practice and research

The findings of this study can be valuable for both HCPs, policymakers and researchers involved in the development, implementation and/or evaluation of ICPs for older people. Considering the interrelatedness of items, it is suggested to collectively implement the items mentioned in this study, to increase the effectiveness of ICPs. Developing a network in which various stakeholders (e.g. general practitioners, primary care assistant practitioners, pharmacists, community nurses, informal caregivers and older people) have good partnerships, can ensure a better connection between provided services and the needs and preferences of older people. Any forms of consultation to structurally exchange knowledge and expertise may support the (complex) care demand of individual older people. In an ideal situation, tailor-made interventions are offered depending on the different degrees of level of frailty of the older person. In addition, it is important to provide for a systematic risk inventory (e.g. by means of information technology), in which older people at risk are identified in an early stage and subsequently proactive policy can be pursued from the network. As in this study the context items, mechanisms, programme-activities, and outcomes have been assessed on their relevance, a next step in further research would be to see to what extent these have been implemented and reached the intended outcomes within their context. Also, items on which no consensus was found need to be further investigated on the reason behind it and to explore whether ICPs in the Netherlands are conceptually different than elsewhere or not. Additionally, further validation of context items, mechanisms, programme-activities, and outcomes needs to take place by involving the older people, informal caregivers, and federations for older people/ patients (44, 45).

CONCLUSION

In this study, consensus within the Delphi panel was reached on a set of 57 out of 71 items (80%) based on two Delphi rounds, with items being found relevant. Based on the findings of the Delphi study, the PT for ICPs for older people in the Dutch setting was refined. The added items in the refined PT included increasing number of older people, decreasing access to hospital beds, well-designed ICP implementation processes, case management, having a clear portfolio of patients, the role of the national/regional governments, aligning existing health- and social care systems, management and monitoring of care activities, strong relationship between older person and HCPs with patients putting their trust in GP, providing continuous feedback to HCPs. Further validation of context items, mechanisms, programme-activities, and outcomes needs to take place by involving the older people, informal caregivers, and federations for older people/patients. Additionally, items on which no consensus was found, need to be further investigated on the reason behind it.

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SUPPLEMENTARY FILE 3.1

Results Delphi round 1

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Context					
Increase in the number of older people	8 (1)	83	11	6	Relevant
Decrease in access to hospital beds	8 (2)	78	17	6	Relevant
Offering training and education to healthcare professionals (to enhance knowledge and skills)	9 (1)	94	6	0	Relevant
Having a clear portfolio of older people/patients	8 (3)	61	33	6	*Equivocal*
Having more focus on home visits through promotion by the government (through funding or policy)	6 (2)	39	56	6	*Equivocal*
Organisational support and coordination on all levels (with the required cultural change)	8 (1)	94	6	0	Relevant
Degree of integration of Advanced Practice Nurses (APN) in the system (organisation of care provision)	8 (2)	61	28	11	*Equivocal*
Integration of case management in a broader program/the healthcare system	8 (2)	94	0	6	Relevant
Clarity about legislation and regulations among healthcare professionals	8 (1)	89	11	0	Relevant
Aligning existing health and social care systems	9 (0)	100	0	0	Relevant
Offering education, guidance and support to older people and informal caregivers	9 (1)	100	0	0	Relevant
Offering remunerative supports to e.g. invest in a new approach and its management	9 (1)	89	6	6	Relevant
Having a good implementation process of IC programmes	9 (1)	94	6	0	Relevant
Having a multidisciplinary core team (deployment of general practitioner, geriatrician, community nurse, pharmacist, etc.)	9 (2)	89	11	0	Relevant
Using (information) technologies e.g. to facilitate clinical practice, enhance data exchange, improve access to electronic patient files	8 (2)	78	22	0	Relevant

Results Delphi round 1 (continued)

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Mechanisms					
Involvement of older people and informal caregiver(s) (e.g. in developing care plans, during hospital discharge, shared decision making etc.)	9 (0)	100	0	0	Relevant
Management and monitoring of care activities (continuity of contact between elderly and health professionals	8 (1)	94	6	0	Relevant
Effective communication between all stakeholders (older people, informal caregiver(s), healthcare professionals of different departments)	9 (0)	100	0	0	Relevant
Relationship between older person/informal caregiver(s) and healthcare professionals	9 (1)	100	0	0	Relevant
Availability of emergency telephone services after office hours	8 (2)	89	11	0	Relevant
Home visiting health professional is the designated primary healthcare provider	8 (2)	78	17	6	Relevant
Intensive collaboration of teams within and between different departments and domains with structures of collaboration	8 (1)	94	6	0	Relevant
Continuous feedback to HCP	8 (1)	83	11	6	Relevant
Challenges in mobilizing resources	8 (3)	78	22	0	Relevant
Focus on organisational goals (e.g. cost savings)	8 (2)	78	17	6	Relevant
Focus on system goals (e.g. improved system integration)	8 (2)	72	28	0	*Equivocal*
Incentives for active participation	7 (3)	56	39	6	*Equivocal*
Providing person-centred care (focus on the wishes and possibilities of the patient, focus on care process instead of outcomes, confidence in possibilities to improve well-being)	8 (1)	89	11	0	Relevant
Trust that GPs follow recommendations and benefit from collaboration	8 (1)	89	11	0	Relevant

Results Delphi round 1 (continued)

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Program activities					
Multidisciplinary interventions (offering patient health education, exercise programmes, and social activities close to home, adjusting medication treatments, and treatment plan)	8 (1)	94	6	0	Relevant
Focus on behavioural change and perception of older person's readiness	9 (2)	89	11	0	Relevant
Standardization of processes	8 (3)	72	22	6	*Equivocal*
Empowerment of older people	9 (1)	94	6	0	Relevant
Performing comprehensive geriatric (home) assessments (physical, social and psychological)	9 (1)	89	11	0	Relevant
Use of information technology (IT) for risk inventory and reminders	6 (2)	44	50	6	*Equivocal*
Development and implementation of individual care plans	8 (1)	89	11	0	Relevant
Disease specific deployment of APN's (control of risk factors and complications)	6 (2)	33	50	17	*Equivocal*
Generic deployment of APN's (improving patient autonomy)	8 (2)	72	22	6	*Equivocal*
Shared assessment processes	8 (2)	67	33	0	*Equivocal*
Discharge planning from hospital	9 (2)	89	6	6	Relevant
Performing (telephone) follow-up appointments	8 (2)	67	33	0	*Equivocal*
Frequent home visits (also for prevention)	8 (1)	78	17	6	Relevant
Supporting self-management of older people	8 (1)	94	6	0	Relevant
Monitoring the patient's care provision during transition e.g. from hospital to home	8 (1)	94	0	6	Relevant
Identification and selection of target group and incorporating prevention in integrated care interventions.	8 (0)	89	11	0	Relevant

Results Delphi round 1 (continued)

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Program activities (cont.)					
Adjusting and aligning medication treatment (e.g. at transition), medication counselling and self management	8 (1)	83	17	0	Relevant
Case management/deployment of case manager	8 (2)	67	33	0	*Equivocal*
Specialty clinics in primary care (memory/dementia)	6 (1)	17	72	0	*Equivocal*
Offering continuity by coordination among multiple health professionals	8 (1)	94	0	6	Relevant
Outcomes					
Increase in performance of early detection screening tests for specific diseases	5 (3)	17	61	22	*Equivocal*
Increase in performance of immunizations	5 (4)	6	67	28	*Equivocal*
Increased functionality/physical activity level	8 (1)	83	17	0	Relevant
Positive effect on goal attainment, empowerment and satisfaction with care process	8 (2)	94	6	0	Relevant
Improvement in self-management by patients	8 (1)	78	17	6	Relevant
Decreased decline in mental health (e.g. depression)	8 (1)	89	6	6	Relevant
Reduced medication use	7 (2)	61	39	0	*Equivocal*
Higher satisfaction older person, informal caregiver, and healthcare professional	8 (1)	89	6	6	Relevant
Improved perceived health	8 (1)	89	6	6	Relevant
Reduced burden on informal caregiver(s)	8 (1)	94	6	0	Relevant
Improved use of case management services	5 (2)	28	67	6	*Equivocal*
Increased frequency of end-of-life discussions	8 (2)	89	11	0	Relevant
Use of hospital/healthcare system (heterogenous effects in literature)	8 (1)	89	6	6	Relevant

Results Delphi round 1 (continued)

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Outcomes (cont.)					
Hospital related outcomes (less visits to emergency care, less (re)admissions, less bed days) (heterogenous effects in literature)	8 (1)	94	6	0	Relevant
Delayed move to the nursing home/less time in nursing homes	8 (1)	83	11	6	Relevant
Improved timeliness of communication (e.g. to primary care)	8(2)	72	22	6	*Equivocal*
Decreased frailty	8 (2)	83	17	0	Relevant
Improved access to healthcare and social care	8 (1)	83	11	6	Relevant
Improved care processes (clinical responsibility across phased and organisations, sharing of information, flexible use of resources, interdisciplinary working, shared financial responsibility)	8 (0)	89	6	6	Relevant
Healthcare costs/cost-effectiveness (heterogenous effects in literature)	8 (2)	67	28	6	*Equivocal*
Quality of life (heterogenous effects in literature)	9 (1)	89	6	6	Relevant
Mortality (heterogenous effects in literature)	6 (2)	22	61	17	*Equivocal*

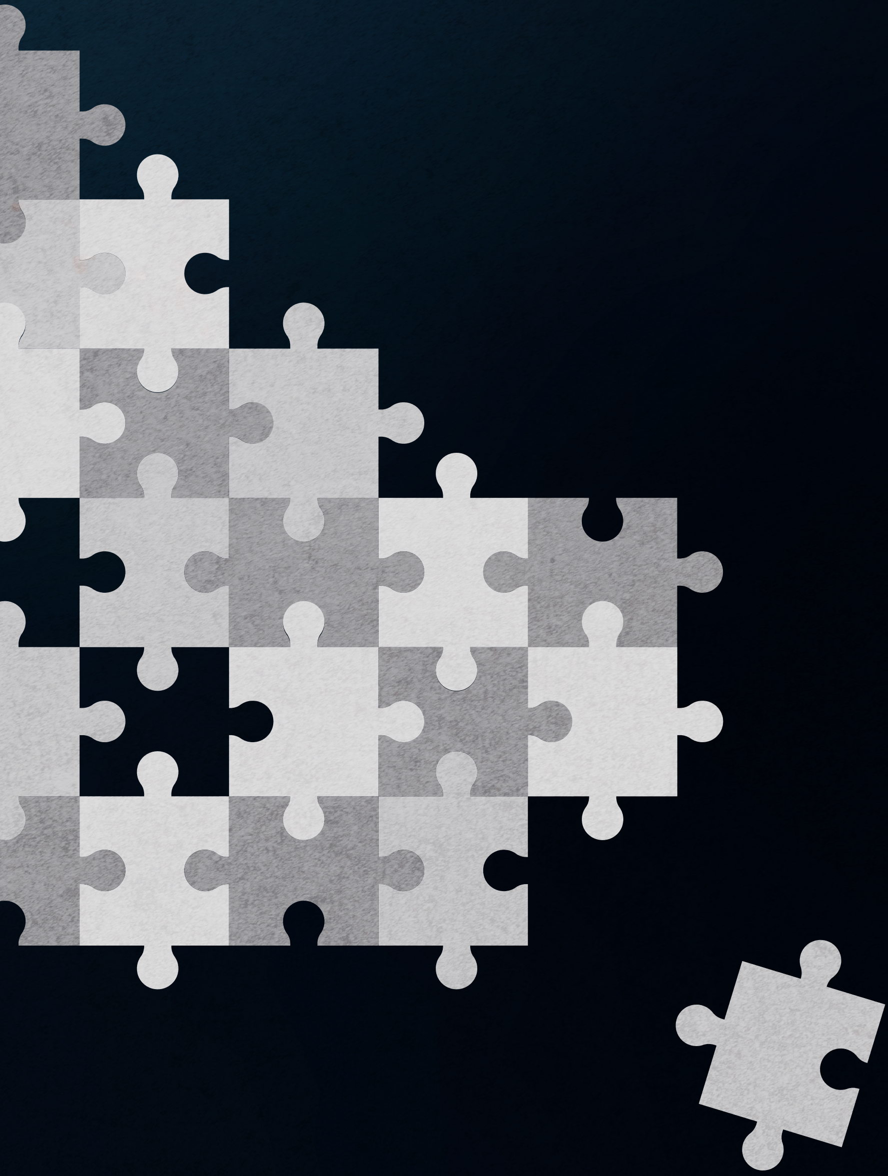
SUPPLEMENTARY FILE 3.2

Results Delphi round 2

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Context					
Having a clear portfolio of older people/patients	8 (1)	94	6	0	Relevant
Having more focus on home visits through promotion by the government (through funding or policy)	8 (1)	82	12	6	Relevant
Degree of integration of Advanced Practice Nurses (APN) in the system (organisation of care provision)	7 (3)	71	29	0	*Equivocal*
Mechanisms					
Focus on system goals (e.g. improved system integration)	7 (2)	59	41	0	*Equivocal*
Incentives for active participation	8 (1)	82	18	0	Relevant
Program activities					
Disease specific deployment of APN's (control of risk factors and complications)	7 (3)	59	29	12	*Equivocal*
Generic deployment (improving patient autonomy) of APN's	7 (3)	65	29	6	*Equivocal*
Standardization of processes	7 (2)	65	29	6	*Equivocal*
Use of information technology (IT) for risk inventory and reminders	7 (2)	71	29	0	*Equivocal*
Shared assessment processes	7 (1)	82	12	6	Relevant
Performing (telephone) follow-up appointments	7 (4)	59	29	12	*Equivocal*
Case management/deployment of case manager	8 (2)	88	12	0	Relevant
Specialty clinics in primary care (memory/dementia)	7 (3)	53	47	0	*Equivocal*

Results Delphi round 2 (continued)

Items	Median and IQR	Consensus in 7-9 range (%)	Consensus in 4-6 range (%)	Consensus in 1-3 range (%)	Overall consensus
Outcomes					
Increase in performance of early detection screening tests for specific diseases	5 (4)	24	47	29	*Equivocal*
Increase in performance of immunizations	5 (4)	29	41	29	*Equivocal*
Reduced medication use	7 (3)	71	24	6	*Equivocal*
Improved timeliness of communication (e.g. to primary care)	8 (3)	71	24	6	*Equivocal*
Improved use of case management services	7 (1)	82	18	0	Relevant
Healthcare costs/cost-effectiveness (heterogenous effects in literature)	7 (2)	53	47	0	*Equivocal*
Mortality (heterogenous effects in literature)	6 (3)	41	41	18	*Equivocal*



CHAPTER 4

Person-centred care in primary care: What works for whom, how and in what circumstances?

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ABSTRACT

This rapid realist review aims to explain how and why person-centred care (PCC) in primary care works (or not) among others for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, and to construct a middle-range programme theory (PT). Peered reviewed- and non-peer-reviewed literature (Jan 2013–Feb 2021) reporting on PCC in primary care was included. Selection and appraisal of documents were based on relevance and rigour according to the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) criteria. Data on context, mechanisms and outcomes (CMO) were extracted. Based on the extracted data, CMO configurations were identified per source publication. Configurations containing all three constructs (CMO) were included in the PT. The middle-range PT demonstrates that healthcare professionals (HCPs) should be trained and equipped with the knowledge and skills to communicate effectively (i.e. in easy-to-understand words, emphatically, checking whether the patient understands everything, listening attentively) tailored to the wishes, needs and possibilities of the patient, which may lead to higher satisfaction. This way the patient will be more involved in the care process and in the shared decision-making process, which may result in improved concordance, and an improved treatment approach. A respectful and empathic attitude of the HCP plays an important role in establishing a strong therapeutic relationship and improved health (system) outcomes. Together with a good accessibility of care for patients, setting up a personalised care plan with all involved parties may positively affect the self-management skills of patients. Good collaboration within the team and between different domains is desirable to ensure good care coordination. The coherence of items related to PCC in primary care should be considered to better understand its effectiveness.

INTRODUCTION

In healthcare, increasing attention is being paid to person-centred care (PCC). PCC put less focus on the medical conditions and more on the unique individual with an illness or impairment (1, 2). This type of care is particularly important for people suffering from chronic diseases. Each individual is recognised as a unique person with distinct goals, needs and preferences (2-4). PCC is the practice of caring for patients (and their families) in ways that are meaningful and valuable to the individual patient. It includes listening to, informing and involving patients in their care, whereby the focus is placed on the person in his personal and social context presenting the complaint or medical problem, rather than the complaint itself (2, 5). It also focuses on the social, mental, emotional and spiritual needs apart from diagnosis, physical and medical needs (3). PCC is considered a core value in providing high-quality (primary) healthcare (2, 6) and essential to achieving the universal health coverage goals by the World Health Organisation (WHO) (5, 7-11). To achieve these goals, focusing on the primary care sector is essential. A strong primary care can partly contain the rising costs, for example, in the Netherlands more than 90% of the care demands are treated in primary care for only 4% of the total budget for care (12, 13). Moreover, the primary care setting is especially important for PCC as primary care physicians are the initial contact point for patients, they play an important role in ongoing healthcare, and account for the majority of patient visits for conventional illnesses (14, 15). PCC has shown positive effects on healthcare outcomes including enhanced relationships between clinicians and patients (16), enhanced job satisfaction by clinicians (17, 18), enhanced patient satisfaction (19, 20), greater adherence to treatment improved concordance (19), improved quality of life (21), and lower health care costs (22). PCC also leads to increased self-reliance, less anxiety, pain and depression, fewer referrals or additional patient investigation (6, 23, 24).

Despite the global importance of PCC being generally acknowledged, the approach suffers from a lack of clarity. Traditional research, such as randomised controlled trials, meta-analyses and systematic reviews, often only indicate whether PCC is more effective than standard of care, but does not contain information on why it was more effective and how it has led to its results given the circumstances (25, 26). Consequently, it remains unclear how and for whom a complex intervention such as PCC, leads to positive results and under what circumstances. Diversity in age, gender, socioeconomic status (e.g. by income, education or occupation), migration background and multi-morbidity, is associated with large disparities in health and in quality of care (27). Primary care research on PCC including so-called 'hard-to-reach or underserved' groups, like non-native speakers, migrants or ethnic minorities, people with a low educational level, or a low health literacy level, is underrepresented (28), and therefore their expectations and needs are less clear, while it is known that existing care is often less suitable for them (29-34). Knowing why and how PCC leads to positive results, especially for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, is also relevant for professionals and for policymakers. To set up and implement a proactive and strong policy, it is important to have insight into the items of PCC in primary care that influence its effectiveness, considering their interrelatedness. To unravel which mechanisms are relevant for PCC in primary care and the influence of diversity on PCC, how they relate to each other, and which starting points there are to apply PCC in daily practice, a more detailed understanding of the relationship between the context in which PCC in primary care is applied and the underlying mechanisms that lead to effective PCC are needed (see 'Methods' section for definitions). Theretofore, the principles of realist research can be used, which focus on what works for whom, in which situation and why (35). Realist research is a theory-driven approach to review and/or evaluate complex interventions/programmes (24, 36-38). The objective of this study is to explain how and why PCC in primary care works (or not) among others for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, under what circumstances and to construct an overarching middle-range programme theory.

METHODS

The review methods were established prior to the conduct of the review and there were no significant deviations from the protocol.

Realist approach

A rapid realist review (RRR) was conducted that followed the standard Realist And Meta-narrative Evidence Synthesis: Evolving Standards (RAMESES) guidelines on quality and reporting (39, 40). The term 'rapid' refers to the use of a realist approach 'to a knowledge synthesis process and producing a product that is useful to policy makers in responding to time-sensitive and/or emerging issues where there is limited time and resources' (41, p. 2). The RRR focuses on explaining the relationship between the *context* in which PCC in primary care is applied, the *mechanisms* by which PCC work, and the *outcomes* that result from it. It assumes that all complex interventions have an underlying theory to explain how a particular intervention is meant to work.

Definitions

Several RRR terms are fundamental for understanding and assessing programmes: context, mechanisms, outcomes, context-mechanism-outcome configuration (CMO-C) and programme theory (PT). These terms are briefly explained below (35, 42-45). *Context* refers to any condition that triggers and/or modifies the behaviour of a mechanism. It can include cultural norms and history of the community in which a programme is implemented, scope and the extent of existing social networks or the infrastructure in which the programme is built. They can be trust-building processes, geographic location effects, funding sources, opportunities or constraints. *Mechanisms* describe what produces the effects of a programme and relate to causality. They are the agents of change and describe how the resources embedded in a programme influence the reasoning and action of programme 'subjects'. They are underlying enablers, entities, processes or structures which operate in specific contexts to generate outcomes of interest. *Outcomes* are the intended and unintended results of a programme. A *CMO-C* explains the causal relationship between a particular aspect of context, whether (or not) a mechanism of interest is triggered by it, and the outcomes produced. An *initial programme theory* is a hypothesised explanation describing how, why and for whom the complex intervention is expected to work in what circumstances. An initial PT is refined using primary or secondary evidence to a refined PT. A middle-range PT is a theory that lies between the initial and refined PT.

Literature search and selection

A peer-reviewed and a non-peer-reviewed literature search were conducted. The search for and the selection of literature took place in an iterative multi-step approach, making use of a 'purposive search' and 'snowball sampling'. Next to our own search, members of the steering committee were asked to share relevant key literature (see 'Patient and public involvement' for more information on the steering committee).

Peer-reviewed literature

Systematic reviews and meta-analyses were included to provide an extensive body of broad and high-quality evidence (46). The search was conducted in PubMed, Embase, Google Scholar, the Cochrane Database of Clinical Trials, and Web of Science. English and Dutch publications between January 2013 and February 2021 were included, as in older publications, most context variables were not considered presentable for current practices. Articles needed to discuss PCC in the primary care setting. Articles discussing PCC in the secondary or tertiary setting, a specific type of care (e.g. terminal care, end-of-life-care), a specific type of condition (e.g. dementia, cancer, depression) or a specific medical field (e.g. maternal health, psychiatry) were excluded. The following search terms were used (in various combinations): 'person cent(e)red care', 'client cent(e)red care', 'people cent(e)red care', 'shared decision making', 'implementation', 'barrier(s)', 'facilitator(s)', 'outcome(s)', '(cost-)effectiveness', 'best practice', 'diversity', 'gender', 'vulnerable groups', 'illiteracy', 'health literacy', 'underserved populations', 'migrant(s)', 'ethnic minorities' and 'minority health'. The reference lists of eligible papers identified for the review were also searched. All articles were screened by AA and half of them by HJMV. In case of doubt, a second researcher (MvdM) was involved to make a shared decision.

Non-peer-reviewed literature

The non-peer-reviewed literature was identified using Google. The search terms and timeframe of publications were similar to the ones in the peer-reviewed literature search. Due to time constraints, and to capture the most relevant hits and ensuring a feasible quantity to screen, the first 15 pages (representing a total of 150 'best match' results) were examined. All the selected literature was assessed on full-text by AA and half of them by HJMV. In case of doubt, a second researcher (MvdM) was involved to make a shared decision.

Appraisal of documents

According to the RAMESES quality standards, the articles were appraised based on two criteria: (1) relevance (can the data contribute to theory building and/or testing?); and (2) rigour (is the method used to generate that particular piece of data credible and trustworthy?) (47). Articles were evaluated by two authors: AA evaluated all articles and HJMV half of them. In case of even a slight doubt, the researcher presented the article to the other researcher to ensure that articles were not evaluated incorrectly. Disagreements were resolved by discussion resulting in consensus.

Data extraction and analysis

Data on CMO of the included articles and documents were extracted by one researcher (AA), whereas HJMV extracted data from a selection of articles. Data from both the peer-reviewed and non-peer-reviewed publications were considered of equal weight in the analysis. Context items, mechanisms and outcomes were assigned to the constructs by multiple researchers independently based on the definitions of the constructs and the interpretation of the function of the items within the source publication. Disagreements about the category to which the extracted data belongs (context, mechanism or outcome) were resolved in a discussion between the researchers. Each context item, mechanism and outcome that was reported in at least six papers were included in the analysis. Given the international perspective of this study and the variety of context items, mechanisms and outcomes, we chose six papers as the minimum, realising this number is arbitrary. Then, it was examined which CMO-C(s) could be formed based on the included context items, mechanisms and outcomes per source publication. It must be noted that since no source publication did explicitly report on the relationship between CMO and CMO-C(s), we identified CMO-Cs based on the items we categorised in the three constructs. Since there were also incomplete CMO-C(s), as various source publications only reported one or two constructs (context or mechanism or outcomes), we had chosen to only include those source publications that contained all three constructs (context, mechanism and outcome). Subsequently, we analysed per outcome item (O_1, O_2, O_3, etc.) which context items and mechanisms are associated with it. To report on the most described causal relation(s) per outcome item and to build a robust PT, context items and mechanisms in the CMO-C(s) needed to be present in at least half of the included publications. Based on these CMO-Cs, the middle-range PT was developed describing the underlying relationships between context, mechanisms and outcomes.

Patient and public involvement

This study was commissioned by the National Health Care Institute, the Dutch national advisory and implementing organisation who, among others, encourages good healthcare by helping all parties involved to continually improve healthcare quality. This RRR is part of a larger study for which a steering committee was established. The ten members of the steering committee were purposively selected based on their expertise in the PCC or primary care field and were primary care practitioners, senior researchers, medical specialists, policymakers, patient's representatives (specifically concerning people with limited (health-)literacy and a migrant background) (see Acknowledgements). Several meetings with the steering committee were held during the study (February 2018, December 2018, April 2019, and December 2019). These meetings were held with the objective to provide feedback and guidance on the methods, the interpretation of (interim) results, and providing overall advice regarding the research. Stakeholder perspectives were considered when testing and refining the PT derived from the RRR. Members of the steering committee were asked to discuss, and to indicate if the identified items on context, mechanisms and outcomes in the literature match with what they see in Dutch practice and to add anything that was possibly missing.

Initial programme theory

One of the objectives of realist research is to test and refine an initial PT in order to determine how, when and for whom the complex intervention will (not) work in a particular setting (45). To formulate an initial PT on applying PCC in the primary care setting, we organised a workshop with experts of the steering committee during a kick-off meeting (dated 28 February 2018). During the kick-off meeting, the study objectives and findings of the literature were shared. Participants were invited to discuss the proposed items and add relevant items. It was hypothesised that communication with the patient plays a crucial role in adequately applying PCC, especially for people with low health literacy skills or migrant background, and having sufficient time during the general practitioner (GP) consultation. The use of easy-to-understand language in conversations and forms (e.g. administrative, informative) when exchanging information would make the care process easier to understand for the person. It was also stated that currently the diversity aspect is not sufficiently considered when applying PCC. Also, by taking into account the context of the person, and their wishes and needs, shared decision-making and involvement of the person would improve. Practitioners need to advance their knowledge, develop new skills and need be conscious on how they themselves apply PCC. On a more macro level, it was mentioned that PCC needs to have a more central role in medical studies at university level and that guidelines need to be adjusted for vulnerable groups, such as people with low health literacy skills. Coordination of care can be improved, as not all healthcare professionals (HCPs) involved in a patient's care process are always up-to-date on the progress. General practice structures and payment models were thought to limit the delivery of PCC.

RESULTS

The search strategy and inquiry through experts yielded 748 peer-reviewed literature articles and 133 non-peer-reviewed articles. After duplicates were removed, 829 titles and abstracts were screened, and of these 709 publications were excluded as they did not match the inclusion criteria. The 120 remaining articles were assessed on full-text of which 65 publications were excluded. Fifty-five publications were included in the analysis (Figure 4.1). The design of the selected publications were:

- Seven reviews (48-54);
- Thirteen systematic reviews (SR) (55-67), of which one was a SR and a meta-analysis (59), one was a SR and concept analysis (65), one was a SR and qualitative meta-synthesis (67), and one was a SR and thematic synthesis (58);
- Seven scoping reviews (68-74);
- Six reviews of reviews (2, 75-79);
- One meta-analysis (80);
- Three (research) articles in international journals (81-83);
- Seven (research) articles in Dutch journals (84-90);
- Three guidelines (91-93);
- Two web pages (94-96);
- One study report (97, 98);
- One white paper (99);
- One information brochure (100);
- One PhD dissertation (97); and
- One commentary piece (101).

Relationships between context, mechanisms and outcomes

In Table 4.1 an overview is provided of the items interpreted as context, mechanisms and outcomes that were extracted from the included papers with their explanation (see Supplementary file 4.1 for corresponding references). Items are shown in ascending order of how often they were reported in the literature. The context items concern issues related to the system-level (macro-level) (accessibility of care, enabling sufficient time biomedical approach towards a holistic biopsychosocial approach in medicine), to the level of healthcare organisations (meso-level) (having a good collaboration of the team, equipping HCPs with the right skillset through training, foreseeing in the required capacity, have a supporting policy in place, using information technology (IT) and e-health initiatives), and to the level of HCPs (micro-level) (providing patient education, setting up a personalised care plan) or the patients (having social support (networks)).

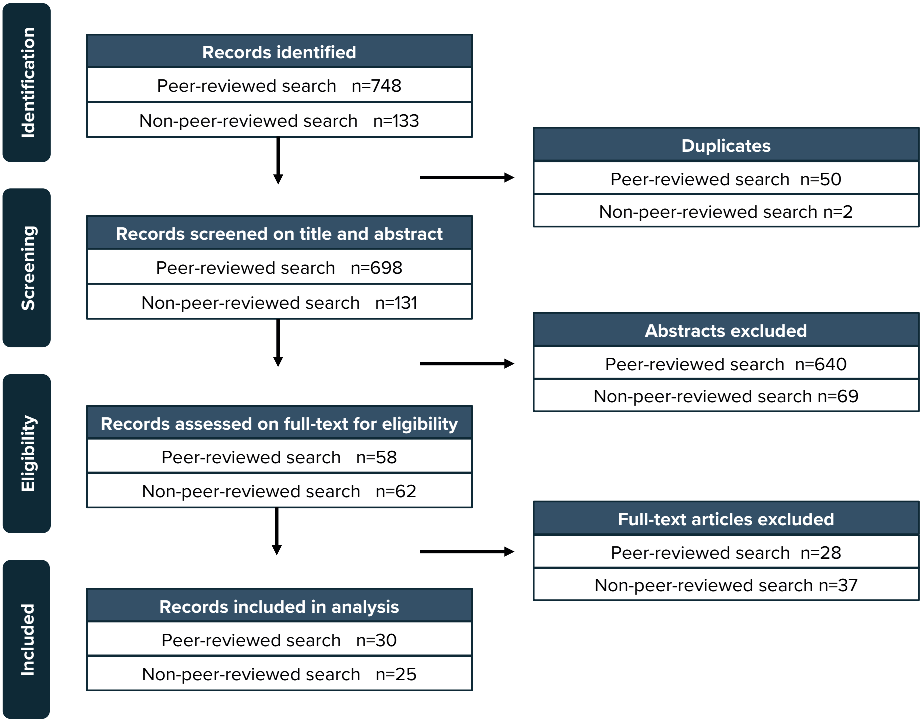


Figure 4.1 Flowchart article selection

Mechanisms related to behaviour of the HCP (micro-level) (providing effective communication, for example easy to understand words, checking whether the person understands everything, listening attentively, having a holistic focus, showing respect to the person, having an open and empathic attitude, providing self-management support, carry out shared decision-making and provide care coordination), and of the behaviour of the person (having an active role in their care process), as well as to their interaction (establishing a therapeutic relationship). Outcomes cover health system outcomes (macro-level), patient involvement, satisfaction of the patient, informal caregiver and/or HCP, concordance, self-management skills, psychological outcomes, improved treatment and better health outcomes (all micro-level). Next, CMO-Cs were aimed to be formed per source publication according to the categorisation of the items in the constructs. In Supplementary file 4.2, all (complete and incomplete) CMO-Cs as reported per source publication are shown. In Figure 4.2 the CMO-configurations are shown, that contained all three constructs (i.e. context, mechanism and outcome) and are used to refine the initial PT from the workshop. For all CMO-Cs identified, the most common context item reported in the literature was 'skills and training HCP' implying that HCPs need to be equipped with the knowledge and skills by means of professional training and education to perform PCC. Training of skills concern communication skills (verbal and non-verbal, related to shared decision-making, intercultural communication, communication tailored to the information needs and health literacy skills of the person, and teach-back), skills to provide PCC, skills to build a trustful relationship with patients, and empathic skills. HCPs also need to have knowledge of medical diseases and disease processes, social and cultural differences and cultural competences. A second essential context item is the accessibility of care that is appropriate and in line with people's preferences, meaning care that is conveniently located for the person, affordable and that can be accessed in time. It also includes accessibility to specialist care and services when a referral is made and (digital) access to information about care and electronic patient records. Also, personalised care planning in collaboration with patients including preparation, goal setting, action planning, documenting, coordinating, supporting and reviewing, was considered an important context item of PCC. Under the influence of these context items, the following mechanisms were identified: patients (and if applicable, their informal caregivers) need to be engaged, supported, involved and empowered to play an important role in their care process to improve care outcomes. Also, HCPs need to provide effective communication by being compassionate, being empathetic, they need to learn about their patients' situations through careful listening and observation, use easy language (avoid medical jargon), convey tailored and accessible information/materials, checking the person's understanding of the information and his or her reactions to it. Moreover, providing and empowering self-management (support and education) to the patient was considered an important mechanism. Important outcomes of PCC in primary care, as the result of the interaction between context items and mechanisms, are improved health outcomes, psychological outcomes and health system outcomes, improved self-management skills, improved concordance, higher satisfaction of the patient, informal caregivers and/or healthcare providers, more involvement of the patient in his/her care process, and a more adequate person-centred treatment whereby the right intensity of support is offered to the patient.

Table 4.1 Reported context items (C), mechanisms (M), and outcomes (O)

Construct*	**Explanation**
Context items (C)	
Equip HCPs with the right knowledge and skills by means of professional training and education.	Training of skills concerning verbal and non-verbal communication; 'shared decision-making'-related communication; intercultural communication; tailored communication; interpersonal capacities; providing person-centred care; to build trustful relationship with patients; empathic skills. Knowledge of medical affairs, diseases and disease processes, social and cultural differences, cultural competences. The specific knowledge and skills necessary for patients with low health literacy skills need to be included as part of the medical education.
Have a good collaboration/ team	Multidisciplinary teamwork; effective interprofessional collaboration; collaboration between different domains (e.g., social domain); collaboration between patient and HCPs.
Provide patient education	Promote and provide education/educational information to patients.
Foresee in sufficient time during consultation	Lack of time is often experienced during consultations to approach patients in a holistic wat and address psychosocial problems; limitations of time affect physician-patient relationship.
Patients having social support (networks)	Social support and social support networks, environmental support, more social support reduced sense of isolation and increased motivation and confidence.
Set up a personalised care planning	Personalised care planning in collaboration with patients (preparation, goal setting, action planning, documenting, co-ordinating, supporting, reviewing).
Foresee in the required capacity	Creating space for required time, people and resources and using this in a targeted manner to design person-centred care; sufficiently equipped to accommodate the biopsychosocial needs of patients; availability of sufficient women clinicians for female patients; appropriate and effective use of healthcare resources.
Applying IT- and e-health initiatives	Applying IT- and e-health initiatives; providing telehealth, teleconsultations, and telemonitoring; the use of online tools and technology; developing ICT to access audiotapes of consultations and patient-held records.
Need for shifting away from the dominance of biomedical approach in medical encounter	Too much focus on disease-oriented and complaint-oriented approach; too much focus on what is measurable and outcomes rather than what is necessary; evidence-based medicine leaves limited room for patient's own considerations; current medical practice strongly based on scientific guidelines.
Accessibility of care	Offering appropriate and preferred access to care, i.e. care that is conveniently located for the patient (e.g., decentralised services, availability of transportation), and that can be accessed in time. It also includes accessibility to specialists or specialty services when a referral is made and (digital) access to information about care and computerised records.
Have a supporting policy in place	Policy should structurally take into account (patients with) low health literacy skills, social and cultural differences.

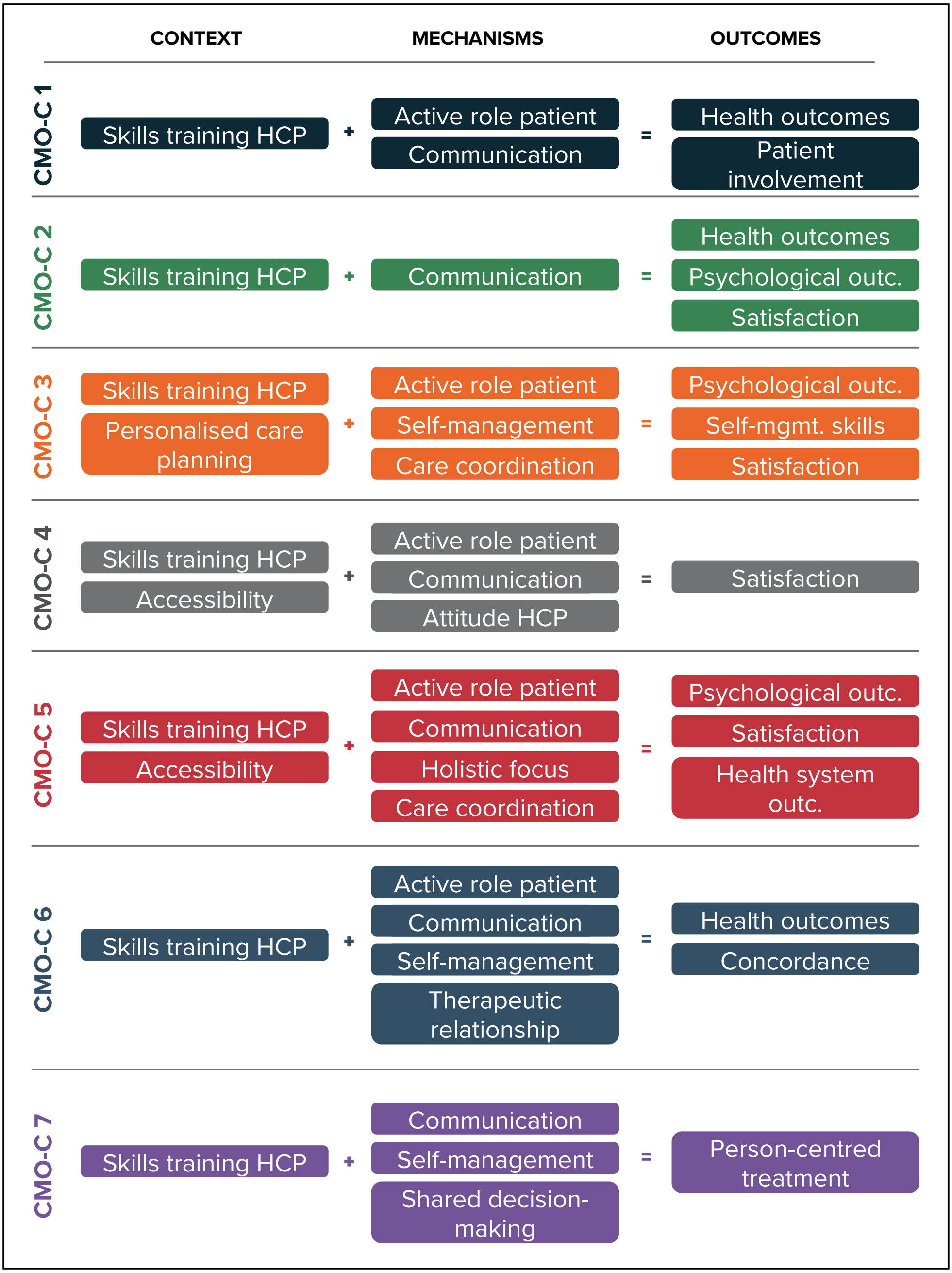
Table 4.1 Reported context items (C), mechanisms (M), and outcomes (O) (continued)

Construct*	**Explanation**
Mechanisms (M)	
Provide effective communication	HCPs need to provide effective communication by being compassionate, being empathetic, learning about their patients' situations through careful listening and observation, use easy language (avoid medical jargon), conveying tailored and accessible information/materials, checking the patient's understanding of the information and his or her reactions to it, deploying an interpreter.
Have a holistic focus	Understanding the whole person in addition to the presenting illness, treating the patient as a person and not a disease, nonmedical issues are considered relevant, supporting patients in their physical, psychological, social and existential needs, paying attention to the patient's life story, taking into account socio-economic health differences.
HCPs showing respect and having an open and empathic attitude	Having an open, friendly, empathic attitude with genuine interest in and compassion for the patient. HCP needs to respect the patient's beliefs, preferences, and values, and treat them with dignity.
Patients having an active role in their care process	Engage, support, involve and empower patients to play an important active role in their care process to improve health outcomes; patient participation; involvement patient's families and informal caregivers; encourage people to use question prompts to help them interact; having family support programmes; help create awareness for the patient, explore resilience and take a step in the direction he or she wants.
Establishing a therapeutic relationship	Establishing a longitudinal doctor–patient relationship, invest in therapeutic partnership building, mutual trust.
Provide self-management support	Provide, empower, enable self-management (support and education) to patient.
Apply shared decision-making	Seeking the patient's implicit or explicit involvement in the decision-making process; exploring the patient's ideas, fears, and expectations about the problem and possible treatments; providing a balanced view in the discussion of healthcare options; determine treatment goals together.
Ensure care coordination	Care that is planned and coordinated across health carers, situations, time, and across all elements of the health system; structuring service organisation to enable care continuity.

Table 4.1 Reported context items (C), mechanisms (M), and outcomes (O) (continued)

Construct*	**Explanation**
Outcomes (O)	
Health outcomes	Improvements in physical health, functional outcomes, and clinical outcomes (e.g., blood glucose levels, lung function, haemoglobin, cholesterol, blood pressure).
Patient involvement	Increased self-efficacy, higher participation in shared decision-making, enhanced patient autonomy.
Health system outcomes	Less referrals, less follow-up examination, reduced emergency department visits, reduced hospital (re)admissions.
Satisfaction	Higher satisfaction of patient, informal caregiver and/or healthcare providers.
Concordance	Higher treatment and medication concordance; improved health behaviour of patient.
Self-management skills	Improvements in self-management skills/capabilities/activities and self-management outcomes.
Psychological outcomes	Improvements in psychological health (e.g., depression, anxiety, distress).
Treatment approach	Improved patient-centred treatment approach, right intensity of support, more appropriate treatment, better connection of care for people with low health literacy skills.

* Items shown in ascending order of how often they were reported in the literature.



	CONTEXT		MECHANISMS		OUTCOMES
CMO-C 1	Skills training HCP	+	Active role patient Communication	=	Health outcomes Patient involvement
CMO-C 2	Skills training HCP	+	Communication	=	Health outcomes Psychological outc. Satisfaction
CMO-C 3	Skills training HCP Personalised care planning	+	Active role patient Self-management Care coordination	=	Psychological outc. Self-mgmt. skills Satisfaction
CMO-C 4	Skills training HCP Accessibility	+	Active role patient Communication Attitude HCP	=	Satisfaction
CMO-C 5	Skills training HCP Accessibility	+	Active role patient Communication Holistic focus Care coordination	=	Psychological outc. Satisfaction Health system outc.
CMO-C 6	Skills training HCP	+	Active role patient Communication Self-management Therapeutic relationship	=	Health outcomes Concordance
CMO-C 7	Skills training HCP	+	Communication Self-management Shared decision-making	=	Person-centred treatment

HCP: healthcare professional, outc.:outcomes, self-mngmt: self-management

Figure 4.2 CMO-Cs on PCC in primary care

Middle-range PT

It was found in both the initial PT and the RRR that communication (M) tailored to the needs and health literacy skills of the patient plays an important role in, among others in the extent to which patients are and feel involved in their care process (M), and also in the shared decision-making process (M). To communicate effectively and to acquire other necessary skills (M), HCPs need to be trained and educated (C) to have a PCC approach during treatment (M) instead of a biomedical, disease-oriented approach (M). HCPs should be provided with sufficient time (C) to discuss the wishes and preferences of patients (M). If several HCPs are involved in the care process, good collaboration within the team (C) and between different domains (C) is desirable to ensure good care coordination (M). Also, supporting policies (C) help to address the importance of PCC. Based on the RRR, the initial PT can be further complemented: respect and attitude of the HCP (M) play an important role in establishing a strong therapeutic relationship (M). Providing patient education (C) and setting up a personalised care plan (C) together with patient positively affects the self-management skills (O). Patients' social support networks (C) also help to improve the patients' health (O). In addition, having sufficient capacity (C), offering access to appropriate and preferred care (C), and providing IT and telephone initiatives (C) play a key role in practicing PCC in primary care. There were several items that were not observed in the RRR but were mentioned by experts when establishing the initial PT. These concerns take the diversity aspect more into account when applying PCC, PCC having a more central role in medical studies, and having general practice structures and payment models in place that facilitate PCC in primary care.

DISCUSSION

Principal findings

This study aims to explain how and why PCC in primary care works (or not) among others for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, under what circumstances and to construct a middle-range programme theory. In this RRR, the middle-range theory demonstrates that HCPs should be trained and equipped with the knowledge and skills to communicate effectively (in easy-to-understand words, emphatically, listening attentively, checking whether the patient understands everything) tailored to the wishes, needs and possibilities of the patient, which may lead to higher satisfaction. This way patients will be and feel more involved in their care process and in the shared decision-making process, which may result in improved concordance, and an improved treatment approach. A respectful and empathic attitude of the HCP plays an important role in establishing a strong therapeutic relationship causing improved health (system) outcomes. Together with a good accessibility of care for patients, setting up a personalised care plan with all involved parties may positively affect the self-management skills of patients. Good collaboration within the team and between different domains is desirable to ensure good care coordination.

Two items (i.e. the need for more attention to diversity in patients when practicing PCC and more teaching of PCC in medical education) that were not observed in the RRR, but mentioned by experts in the initial PT, may be party included in other context items found in the RRR. Concerning diversity, the RRR identifies the context items 'having a holistic focus' and 'HCP respecting the patient's beliefs, preferences and values', which implies understanding the whole person in addition to the presenting illness, treating the patient as a person and not a disease, non-medical issues being considered relevant, supporting patients in their physical, psychological, social and existential needs, paying attention to the patient's life story, taking into account ethnic and socio-economic health differences. This indicates that if HCPs work in a person-centred way, one automatically would have to pay attention to the diversity aspect. Also, the item PCC having a more central role in medical studies, which was included in the initial PT but not found in the RRR may be counterbalanced by the context item 'equipping HCPs with the knowledge and skills by means of professional training and education'. Regarding the identified context items, mechanisms and outcomes, it was observed that context items interpreted by us were reported on system-level (macro-level), the level of healthcare organisations (meso-level), and at the level of HCPS and patients (micro-level), whereas mechanisms were only reported on micro-level, and outcomes on macro-level and micro-level.

Strengths and limitations

To the best of our knowledge, this is the first RRR on the effectiveness of person-centred care in primary care, providing insight into the complex interplay of context, mechanisms and outcomes. Also, the coherence of items in relation to PCC in primary care has not been reported before. This study is in line with the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) quality and publication standards (40, 47), which focus on the objectives of Realist Review, understanding and applying a realist principle, realist review design, data collection methods, involving key stakeholders, data analysis and reporting a realist review. A methodological limitation, inherent to realist research, is that the instructions for performing a Realist Review are only partially crystallised. This can be both limiting and reinforcing, since during the process of reflection and decision-making, researchers can make adjustments to the realist constructs, but cannot estimate whether these adjustments will bring out the best result. A second limitation to consider, also inherent to realist research, is the lack of conceptual clarity of the constructs context (102, 103) and mechanisms (104, 105), which makes assigning items to the different constructs difficult (106). Our interpretation of items was based on the definition of context and mechanisms (see methods section), and information provided in the source publications, which was often limited. Also, several context items (e.g. providing patient education) and mechanisms (e.g. applying shared decision-making) can be considered independent interventions, as the source publication itself did not label the items as context or mechanisms, but we interpreted the items as context or mechanism. To ensure that items were assigned to the constructs correctly, multiple researchers independently examined the interpretation of the function of the items within the publication as closely as possible. Lastly, many of the included studies did not have complete data to construct the most optimal CMO configurations. This may have to do with the emphasis placed on outcome data in many studies, and to a lesser extent on mechanisms of action and context. A large part of the CMO configurations was incomplete only containing one or two constructs. To paint a valid picture of the most reported CMO configurations, incomplete CMO configurations were excluded meaning that a lot of information was lost.

Comparison with prior work

A previous realist synthesis which aimed to elicit an initial PT of how multispecialty community providers can achieve their outcomes has found strong evidence on multidisciplinary teams being an important mechanism provided that the teams include the relevant professions (107). Causal relations were also found with the uses and effects of health information technology (HIT) and care planning for individual patients (107). Contrary to what we found, they also reported on organisational culture, interorganisational network management, planned referral networks and the diversion of patients from inpatient to primary care (107). In line with our findings, a synthesis on person-centred models reported that patients (and their families) and caregivers valued three key features of PCC, namely strong communication skills among HCPs to facilitate shared decision-making and positive patient-provider relationships; having a certain level of control on health decisions and treatment plan(s); and patients being treated as an individual with their own preferences and needs, rather than simply as a patient with a disease. Also, team-based primary care was desirable due to the benefits of better collaboration among HCPs. HCPs educating patients on their illness was observed as a way to enhance PCC at the system, organisational and/or provider level (108). A framework on PCC approaches mentioned the core elements of communication (including communication between personnel at all levels in an organisation) and relationship-building skills as key players (109).

Recommendations

Further research needs to be conducted concerning the extent to which the items identified in this RRR are currently collectively being applied in practice. Ideally, to make the PT more robust, more studies with data on all CMO-items in the CMO configurations should be available to validate findings and the PT. This way, one can also analyse which combinations of CMO configurations concerning PCC in primary care do not take place and therefore, when PCC does not work. To be able to more accurately assess the items influencing PCC for understudied groups like ethnic minorities, or people with low (health) literacy skills, more data on health and healthcare use of these groups are necessary. To this end, registration of ethnicity and educational level should be included in databases on health and healthcare use. We also recommend to promote PCC in practice through actions on macro- meso- and micro level: at policy level we recommend: the development and implementation of quality indicators for PCC, comprehensible communication and accessibility of care (also for people with limited health literacy skills); setting requirements for training of HCPs and for guideline development, stimulating the development of integrated multidisciplinary care standards for multimorbidity instead of disease-specific standards; setting requirements for e-Health/IT activities ensuring that IT-systems in different settings can be integrated to enable collaboration and coordination between HCPs; and facilitating flexible consultation time and adjustment of care intensity to patient needs as well as interprofessional collaboration between healthcare and social care. On an organisation level (meso-level) PCC needs to be included in the vision and policy and be discussed with all employees how PCC can be achieved within their own practice; patients need to be involved in the design and organisation of practice and care; good accessibility of the practice needs to be ensured; interprofessional training of all HCPs needs to be stimulated and facilitated. On micro-level HCPs should educate themselves (in PCC, self-reflection, understandable communication) and apply what they have learned. They should approach each patient with an open respectful attitude, focused on the patient's questions, problems, wishes and values in addition to on the illness or medical complaint.

CONCLUSION

This RRR provides insight into the complex interplay of context, mechanisms and outcomes concerning PCC in primary care. The coherence of items related to PCC in primary care should be considered to better understand its effectiveness. HCPs should be trained and stimulated to communicate empathically, understandably and culturally sensitive, focused on the wishes, needs and possibilities of the patient, so that self-management can be realised as much as possible. In addition to requiring knowledge and skills, a good accessibility to care, as well as setting up personalised care plans with the active involvement of the patient (and his/her family) is required, so that these can result in improved health (system) outcomes, improved concordance, higher satisfaction and a more adequate person-centred treatment.

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SUPPLEMENTARY FILE 4.1

References of context items, mechanisms, and outcomes

Construct	References
Context items (C)	
Equip HCPs with the right knowledge and skills by means of professional training and education.	Brickley et al., 2020; Butterworth et al., 2019; de Been & van den Muijsenbergh, 2019; Derksen, Bensing, & Lagro-Janssen, 2013; Ekelmans, 2020; Filler, Jameel, & Gagliardi, 2020; Giusti et al., 2020; Heijmans, Zwikker, van der Heide, & Rademakers, 2016; Jager et al., 2019; King & Hoppe, 2013; Lafontaine, Bourgault, Girard, & Ellefsen, 2020; Lévesque, Hovey, & Bedos, 2013; Mutsaers, 2016; O'Donnell et al., 2016; Poitras, Maltais, Bestard-Denommé, Stewart, & Fortin, 2018; Rathert, Wyrwich, & Boren, 2013; Renzaho, Romios, Crock, & Sønderlund, 2013; Rochfort et al., 2018; Rocque & Leanza, 2015; Scholl, Zill, Härter, & Dirmaier, 2014; Sharma, Bamford, & Dodman, 2015; Smeets, Kroese, Ruwaard, Hameleers, & Elissen, 2020; The Health Foundation, 2018; Van den Muijsenbergh, 2013; van der Velden, 2018; van Weel-Baumgarten & Brouwers, 2018; Winsor et al., 2013
Have a good collaboration/team	Boshuizen, 2014; Constand, MacDermid, Dal Bello-Haas, & Law, 2014; DeRosa et al., 2019; Filler et al., 2020; Giusti et al., 2020; InEen, 2016; Jackson et al., 2013; Jager et al., 2019; John, Jani, Peters, Agho, & Tannous, 2020; Louw, Marcus, & Hugo, 2017; Mutsaers, 2016; Poitras et al., 2018; Scholl et al., 2014; Sharma et al., 2015; Smeets et al., 2020
Provide patient education	Boshuizen, 2014; DeRosa et al., 2019; Eikelenboom, 2017; John et al., 2020; Lafontaine et al., 2020; National Voices, 2014a, 2014c; Park et al., 2018; Scholl et al., 2014; Winn, Ozanne, & Sepucha, 2015
Foresee in sufficient time during consultation	Akseer et al., 2021; Brickley et al., 2020; Butterworth et al., 2019; de Been & van den Muijsenbergh, 2019; Giusti et al., 2020; Mutsaers, 2016; Rocque & Leanza, 2015; Sharma et al., 2015; Smeets et al., 2020
Patients having social support (networks)	Eikelenboom, 2017; Jager et al., 2019; Lafontaine et al., 2020; O'Donnell et al., 2016; Park et al., 2018; Smeets et al., 2020; Tomaselli, Buttigieg, Rosano, Cassar, & Grima, 2020; Winsor et al., 2013
Set up a personalised care planning	Coulter et al., 2015; InEen, 2016; NHG, 2017; Poitras et al., 2018; Rathert et al., 2013; Smeets et al., 2020; Wildevuur & Simonse, 2015
Foresee in the required capacity	Constand et al., 2014; Filler et al., 2020; Giusti et al., 2020; InEen, 2016; Jager et al., 2019; National Voices, 2014a; Smeets et al., 2020
Applying IT- and e-health initiatives	Boshuizen, 2014; InEen, 2016; Jager et al., 2019; National Voices, 2014a, 2014b, 2014c; Smeets et al., 2020; Wildevuur & Simonse, 2015; Winsor et al., 2013

References of context items, mechanisms, and outcomes (continued)

Construct	References
Context items (C) (cont.)	
Need for shifting away from the dominance of biomedical approach in medical encounter	Ekelmans, 2020; Engelberts, 2018; Mutsaers, 2016; Poitras et al., 2018; PoZoB, 2021; Rocque & Leanza, 2015
Accessibility of care	de Been & van den Muijsenbergh, 2019; Heijmans et al., 2016; Jackson et al., 2013; O'Donnell et al., 2016; Park et al., 2018; Scholl et al., 2014
Have a supporting policy in place	Boshuizen, 2014; de Been & van den Muijsenbergh, 2019; Heijmans et al., 2016; O'Donnell et al., 2016; Smeets et al., 2020; Van der Meulen, 2019
Mechanisms (M)	
Provide effective communication	Akseer et al., 2021; Boshuizen, 2014; Butterworth et al., 2019; Constand et al., 2014; de Been & van den Muijsenbergh, 2019; Derksen et al., 2013; Engels, 2019; Filler et al., 2020; Giusti et al., 2020; Heijmans et al., 2016; Jager et al., 2019; King & Hoppe, 2013; Muijsenbergh, 2019; National Voices, 2014a, 2014b; O'Donnell et al., 2016; Park et al., 2018; PoZoB, 2021; Rathert et al., 2013; Rocque & Leanza, 2015; Scholl et al., 2014; Sharma et al., 2015; Smeets et al., 2020; Van der Meulen, 2019; van der Velden, 2018; van Weel-Baumgarten & Brouwers, 2018; Wildevuur & Simonse, 2015
Have a holistic focus	Brickley et al., 2020; de Been & van den Muijsenbergh, 2019; Filler et al., 2020; Giusti et al., 2020; Håkansson Eklund et al., 2019; Jackson et al., 2013; Lafontaine et al., 2020; Louw et al., 2017; McMillan et al., 2013; Muijsenbergh, 2019; O'Donnell et al., 2016; Park et al., 2018; Poitras et al., 2018; PoZoB, 2021; Rocque & Leanza, 2015; Scholl et al., 2014; Schwartz, Weiner, Binns-Calvey, & Weaver, 2016; Sharma et al., 2015; The Health Foundation, 2018; Tomaselli et al., 2020; Van den Muijsenbergh, 2013; Van der Meulen, 2019
HCPs showing respect and having an open and empathic attitude	Akseer et al., 2021; Brickley et al., 2020; DeRosa et al., 2019; Ekelmans, 2020; Filler et al., 2020; Giusti et al., 2020; Håkansson Eklund et al., 2019; Lafontaine et al., 2020; Lundy et al., 2015; Mutsaers, 2016; Rathert et al., 2013; Rocque & Leanza, 2015; Sharma et al., 2015; Tomaselli et al., 2020; Van den Muijsenbergh, 2013; van der Velden, 2018; van Weel-Baumgarten & Brouwers, 2018
Patients having an active role in their care process	Akseer et al., 2021; Butterworth et al., 2019; Coulter et al., 2015; DeRosa et al., 2019; Eikelenboom, 2017; Ekelmans, 2020; Giusti et al., 2020; McMillan et al., 2013; National Voices, 2014c; Park et al., 2018; PoZoB, 2021; Rathert et al., 2013; Scholl et al., 2014; Sharma et al., 2015; The Health Foundation, 2014, 2018; Tomaselli et al., 2020; van Weel-Baumgarten & Brouwers, 2018; Wildevuur & Simonse, 2015

References of context items, mechanisms, and outcomes (continued)

Construct	References
Mechanisms (M) (cont.)	
Establishing a therapeutic relationship	Akseer et al., 2021; Brickley et al., 2020; Constand et al., 2014; Filler et al., 2020; Giusti et al., 2020; Håkansson Eklund et al., 2019; InEen, 2016; Lafontaine et al., 2020; Louw et al., 2017; Muijsenbergh, 2019; Mutsaers, 2016; Park et al., 2018; Scholl et al., 2014; Sharma et al., 2015; The Health Foundation, 2018; van der Velden, 2018; van Weel-Baumgarten & Brouwers, 2018; Winsor et al., 2013
Providing self-management support	Boshuizen, 2014; Butterworth et al., 2019; Coulter et al., 2015; Eikelenboom, 2017; Filler et al., 2020; Heijmans et al., 2016; InEen, 2016; Jager et al., 2019; John et al., 2020; National Voices, 2014b; Poitras et al., 2018; Rochfort et al., 2018; The Health Foundation, 2014, 2018; Winsor et al., 2013
Apply shared decision-making	Brickley et al., 2020; Butterworth et al., 2019; Coulter et al., 2015; Eikelenboom, 2017; Ekelmans, 2020; Engelberts, 2018; Giusti et al., 2020; Håkansson Eklund et al., 2019; InEen, 2016; Lafontaine et al., 2020; Mutsaers, 2016; Park et al., 2018; Sharma et al., 2015; Smeets et al., 2020; The Health Foundation, 2014
Ensure care coordination	Giusti et al., 2020; Håkansson Eklund et al., 2019; Jackson et al., 2013; John et al., 2020; O'Donnell et al., 2016; Park et al., 2018; Poitras et al., 2018; PoZoB, 2021; Scholl et al., 2014; The Health Foundation, 2014; Winsor et al., 2013
Outcomes (O)	
Health outcomes	Coulter et al., 2015; de Been & van den Muijsenbergh, 2019; Derksen et al., 2013; John et al., 2020; King & Hoppe, 2013; McMillan et al., 2013; Muijsenbergh, 2019; Park et al., 2018; Rathert et al., 2013; Renzaho et al., 2013; The Health Foundation, 2018; Tomaselli et al., 2020; Van den Muijsenbergh, 2013; van Weel-Baumgarten & Brouwers, 2018; Wildevuur & Simonse, 2015
Patient involvement	de Been & van den Muijsenbergh, 2019; Derksen et al., 2013; DeRosa et al., 2019; Muijsenbergh, 2019; National Voices, 2014a, 2014c; PoZoB, 2021; Rochfort et al., 2018; Rocque & Leanza, 2015; Winn et al., 2015
Health system outcomes	Butterworth et al., 2019; de Been & van den Muijsenbergh, 2019; Jackson et al., 2013; John et al., 2020; McMillan et al., 2013; O'Donnell et al., 2016; Park et al., 2018; Van den Muijsenbergh, 2013; van Weel-Baumgarten & Brouwers, 2018; Wildevuur & Simonse, 2015
Satisfaction	Brickley et al., 2020; Derksen et al., 2013; King & Hoppe, 2013; Lafontaine et al., 2020; McMillan et al., 2013; Park et al., 2018; Rathert et al., 2013; Rocque & Leanza, 2015; The Health Foundation, 2014

References of context items, mechanisms, and outcomes (continued)

Construct	References
Outcomes (O) (cont.)	
Concordance	Brickley et al., 2020; Coulter et al., 2015; King & Hoppe, 2013; National Voices, 2014a, 2014b; Rochfort et al., 2018; Rocque & Leanza, 2015; The Health Foundation, 2018; van Weel-Baumgarten & Brouwers, 2018
Self-management skills	Coulter et al., 2015; John et al., 2020; National Voices, 2014b; Park et al., 2018; Rathert et al., 2013; Rochfort et al., 2018; Winsor et al., 2013
Psychological outcomes	Butterworth et al., 2019; Coulter et al., 2015; de Been & van den Muijsenbergh, 2019; Derksen et al., 2013; John et al., 2020; Muijsenbergh, 2019
Improved treatment	Boshuizen, 2014; Eikelenboom, 2017; Heijmans et al., 2016; InEen, 2016; McMillan et al., 2013; O'Donnell et al., 2016; Park et al., 2018; Rocque & Leanza, 2015; van der Velden, 2018; van Weel-Baumgarten & Brouwers, 2018

SUPPLEMENTARY FILE 4.2

CMO-configurations per source publication

Overview context, mechanisms, and outcomes (CMO)

Context items	Mechanisms	Outcomes
C1: Equip HCPs with the right knowledge and skills by means of professional training and education.	M1: Patients having an active role in their care process	O1: Health outcomes
C2: Provide patient education	M2: Provide effective communication	O2: Psychological outcomes
C3: Have a supporting policy in place	M3: Providing self-management support	O3: Self-management skills
C4: Patients having social support (networks)	M4: Apply shared decision-making	O4: Concordance
C5: Accessibility of care	M5: HCPs showing respect and having an open and empathic attitude	O5: Satisfaction
C6: Foresee in the required capacity	M6: Have a holistic focus	O6: Patient involvement
C7: Applying IT- and e-health initiatives	M7: Ensure care coordination	O7: Treatment approach
C8: Foresee in sufficient time during consultation	M8: Establishing a therapeutic relationship	O8: Health system outcomes
C9: Need for shifting away from the dominance of biomedical approach in medical encounter		
C10: Have a good collaboration/team		
C11: Set up a personalised care planning		

Overview CMO-configurations per source publication

CMO-configurations			Source (first author, year)
C8	M1, M2, M5, M8	-	Akseer et al. (2021)
C2, C3, C7, C10, C11	M2, M3	O7	Boshuizen et al. (2014)
C1, C8	M1, M5, M6, M8	O4, O5, O6	Brickley et al. (2020)
C1, C8	M1, M2, M3, M4	O4, O5	Butterworth et al. (2019)
C6, C10	M1, M2, M5, M8	-	Constand et al. (2014)
C11	M1, M3, M4	O1, O2, O3, O4	Coulter et al. (2015)
C1, C3, C7	M2, M6	O1, O2, O6	De Been et al. (2019)
C2, C10	M1, M5	-	DeRosa et al. (2019)
C1	M2	O1, O2, O5, O6	Derksen et al. (2013)
C1, C9	M1, M4, M5	-	Ekelmans (2020)
C4	M3, M4	O7	Eikelenboom (2017)
C9	M1, M4	-	Engelberts et al. (2018)
-	M2	-	Engels (2019)
C1, C6, C10	M2, M4, M5, M6, M8	-	Filler et al. (2020)
C1, C6, C8, C10	M1, M2, M4, M5, M6, M7, M8	-	Giusti et al. (2020)
-	M4, M5, M6, M7, M8	-	Håkansson Eklund et al. (2019)
C3, C5, C1	M2, M3	O7	Heijmans et al. (2016)
C6, C7, C11	M3, M4, M7	O7	InEen (2016)
C10, C5	M6, M7	O8	Jackson et al. (2013)
C1, C4, C6, C7, C10	M3	-	Jager et al. (2019)
C2, C10	M3, M7	O2, O3, O8	John et al. (2020)
C1	M2, M4, M8	O1, O4, O5	King et al. (2013)
C1, C2, C4	M1, M4, M5, M6	O5, O7	Lafontaine et al. (2020)
C1	-	-	Levesque et al. (2013)
C10	M5, M6, M8	-	Louw et al. (2017)
-	M5	-	Lundy et al. (2015)
-	M1, M5, M6	O1, O5	McMilan et al. (2013)
C1, C8, C9, C10	M4, M5, M8	-	Mutsaers et al. (2016)
C7	M2, M3	O4	National voices (2014a)
C7	M1	-	National voices (2014b)
C2, C6, C7	M2	-	National voices (2014c)
C11	-	-	NHG (2017)
C1, C3, C4, C5	M2, M6, M7	O8	O'Donnell et al. (2016)

Overview CMO-configurations per source publication (continued)

CMO-configurations			Source (first author, year)
C1, C2, C5, C11	M1, M4, M6, M7	Patients: O3, O5, O8; family members: O2, O5; HCPs: O2	Park et al. (2018)
C1, C9, C10	M3, M6, M7	-	Poitras et al. (2018)
C9	M1, M6, M7	O6	PoZoB (2021)
C1, C11	M1, M2, M5	O1, O3, O5	Rathert et al. (2013)
C1	M1	-	Renzaho et al. (2013)
C1	M1, M3	O3, O4, O6	Rochfort et al. (2018)
C1, C8, C9	M1, M2, M5	O5, O6	Rocqueet al. (2015)
C1, C2, C5, C9, C10	M1, M2, M7, M8	-	Scholl et al. (2014)
-	-	-	Schwartz et al. (2016)
C1, C10	M1, M2, M6, M8	-	Sharma et al. (2015)
C1, C6, C7, C8, C10, C11	M2, M4	-	Smeets et al. (2020)
-	M1, M3, M4, M7	O5	The Health Foundation (2014)
C1	M1, M3, M5, M8	O1, O4	The Health Foundation (2018)
C4	M1, M5, M6	O1	Tomaselli et al. (2020)
C1	M5, M6	O1, O5	Van den Muijsenbergh et al. (2013)
C1	M2, M8	O1, O2, O6	Van den Muijsenbergh (2019)
C3	M2, M6	-	Van der Meulen (2019)
C1	M2, M5, M8	O7	Van der Velden (2018)
C1	M1, M2, M5, M8	O1, O4, O8	Van Weel-Baumgarten et al. (2018)
C2, C7, C11	-	O1, O8	Wildevuur et al. (2015)
C2	-	O6	Winn et al. (2015)
C1, C4, C7	M3, M7, M8	O3	Winsor et al. (2013)

CHAPTER 5

Person-centred care in the Dutch primary care setting: refinement of middle-range theory by patients and professionals

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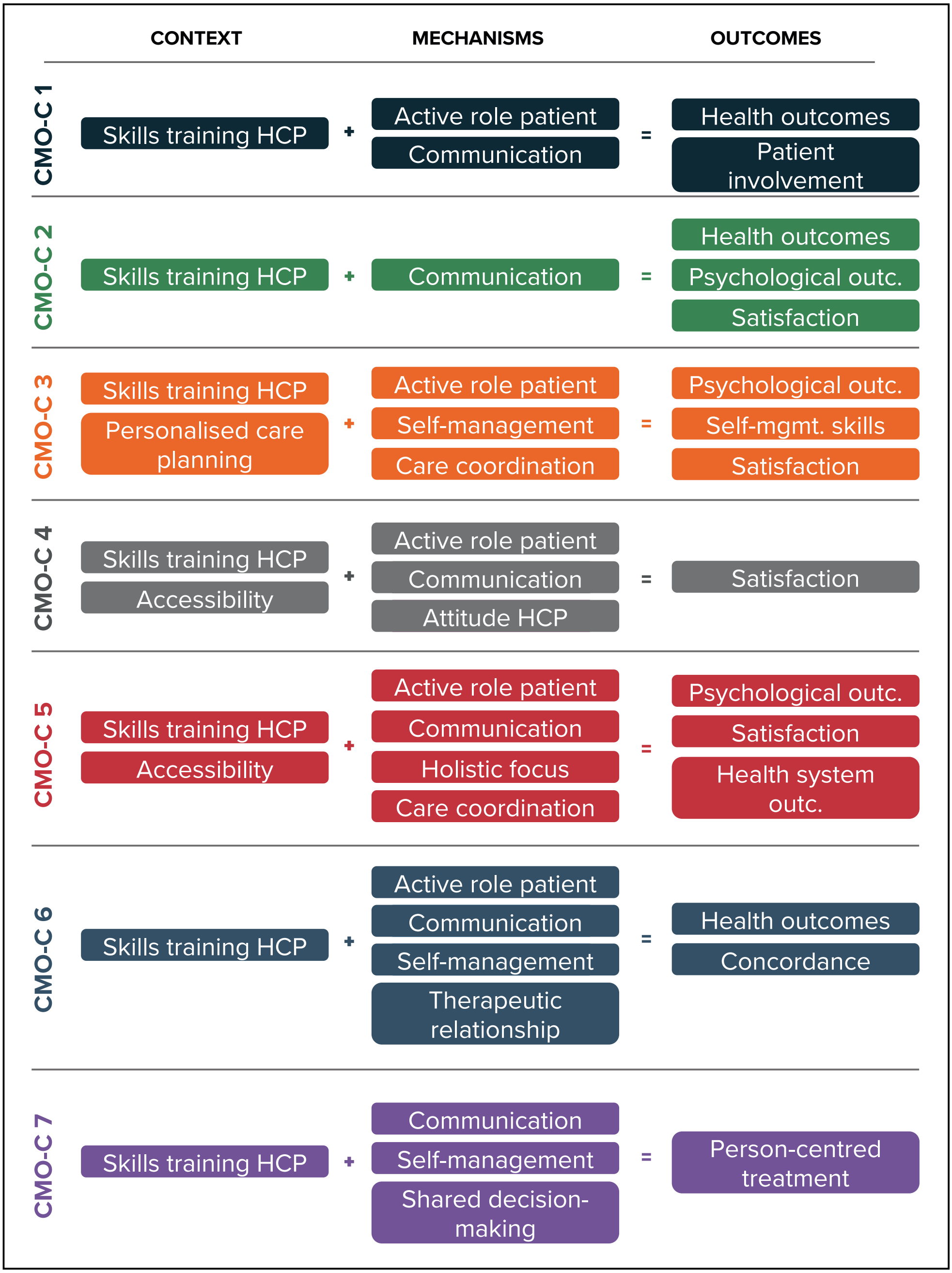
ABSTRACT

In a previous rapid realist review (RRR) of international literature insight was provided into how, why, and under what circumstances person-centred care (PCC) in primary care works (or not) among others for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, by establishing a middle-range programme theory (PT), which describes the relationship between context items, mechanisms, and outcomes. Since the application of PCC in primary care in the Dutch setting is expected to differ from other countries, the objective of this study is to validate the items (face validity) resulting from the RRR for the Dutch setting by assessing consensus on the relevance of items. Four focus group discussions with patient representatives and patients with limited health literacy skills (n = 14), and primary care professionals (n = 11) were held partly combined with a Delphi-study. Items were added to refine the middle-range PT for the Dutch primary care setting. These items indicated that in order to optimally align care to the patient tailored supporting material that is developed together with the target group is important, next to providing tailored communication. Healthcare providers (HCPs) and patients need to have a shared vision and set up goals and action plans together. HCPs should stimulate patient's self-efficacy, need to be aware of the patient's (social) circumstances and work in a culturally sensitive way. Better integration between information and communications technology systems, flexible payment models, and patients access to documents, and recorded consultations should be in place. This may result in better alignment of care to the needs of patients, improved accessibility to care, improved patient's self-efficacy, and improved health-related quality of life. On the long-term higher cost-effectiveness and a higher quality of healthcare can be realised. In conclusion, this study shows that for PCC to be effective in Dutch primary care, the PT based on international literature was refined by leaving out items and adding new items for which insufficient or sufficient consensus, respectively, was found.

INTRODUCTION

Healthcare systems are gradually transforming from biomedically-oriented systems towards more person-centred care (PCC) oriented systems (1, 2). To understand and adequately address a person's health problem(s) and experience of illness, having a disease-oriented perspective alone is not sufficient (3, 4). Worldwide, person-centredness has gained more recognition over the years and is considered a core element of high-quality healthcare (5-7). Driving factors behind this recognition are the growing and changing demand for care, more technological possibilities, and the rising healthcare costs (8). When PCC addresses also nonmedical causes of and solutions for physical distress, it could reduce costs of more expensive (hospital-based) medical specialist care. A core element of PCC is to create a partnership between the healthcare professional and the care recipient, in which the unique needs and beliefs of the latter are the starting point for the provision of care (9). PCC is considered a core value of primary care (10, 11). In the Netherlands general practitioners (GPs) have a central role in the healthcare system. As GPs are the first contact point for individuals experiencing health problems and an increasing number of patients with complex care needs ending up in primary care, it is especially important for GPs to provide appropriate support by applying a holistic and person-centred approach that contributes to the overall well-being of individuals (12). The Dutch healthcare system is recognised for its well-developed primary healthcare (13, 14). Important elements for this are GPs acting as gatekeepers for specialist care and hence the gradual accessibility of secondary medical specialistic care. The assumption behind this is that a well-functioning primary care setting takes over the care demand as much as possible, which otherwise would end up in the more expensive secondary care. The implementation of practice nurses in Dutch GP practices has increased the interdisciplinary character of care (15). In addition to the gatekeeping function, empanelment is also considered an important component or building or strengthening primary care (16). Literature advocating PCC is widespread (17) and the experiences gained with PCC in primary care in the Netherlands are increasingly shared, often in terms of best practices, barriers to implementation and conditions for success (18). However, despite the conceptual attractiveness of PCC, in daily practice PCC remains poorly understood and implemented (19). A previously published rapid realist review (RRR) of international literature aimed to provide insight into the question for whom, how and why PCC in primary care does (not) work under what circumstances (20). The resulting middle-range programme theory (PT) (Figure 5.1) demonstrated that healthcare providers (HCPs) should be trained and equipped with the knowledge and skills to communicate effectively (i.e., in easy-to-understand words, emphatically, checking whether the patient understands everything, listening attentively) tailored to the wishes, needs and possibilities of the patient, which may lead to higher satisfaction of patients, informal caregivers, and/or healthcare professionals. This way patients will be more involved in their care process and in the shared decision-making process, which may result in improved concordance, and an improved treatment approach. A respectful and empathic attitude of the HCP plays an important role in establishing a strong therapeutic relationship and improved health (system) outcomes. Together with a good accessibility of care for patients, setting up a personalised care planning with all involved parties may positively affect the self-management skills of patients. Good collaboration within the team and between different domains is desirable to ensure good care coordination.

However, since the application of PCC in primary care in the Dutch setting is expected to differ from primary care in other countries, it is deemed relevant to assess the relevance of the obtained items from the international RRR for the Dutch setting. In doing so, the active involvement of experts from the field is of great importance, both for providing input and for translating theoretical insights into suggestions for daily practice (21). Moreover, PCC should also take into account diversity in age, gender, socio-economic status, education, migration background, (multi)morbidity as well as personal preferences and needs (22). For example, approximately 25% of the Dutch population has a migration background (23), more than 18% are low-literate (24), and 30% have insufficient or limited health literacy skills (25). People from these groups often have poorer health, partly because the care provided insufficiently match their needs and possibilities. Existing treatment protocols and standards of care are largely based on scientific evidence usually obtained from study participants outside these groups and therefore do not or only partially apply to these groups (26). The objective of this study is to validate the items (face validity) resulting from the international RRR for the Dutch setting by assessing consensus on the relevance of the items among different stakeholders.



	CONTEXT		MECHANISMS		OUTCOMES
CMO-C 1	Skills training HCP	+	Active role patient Communication	=	Health outcomes Patient involvement
CMO-C 2	Skills training HCP	+	Communication	=	Health outcomes Psychological outc. Satisfaction
CMO-C 3	Skills training HCP Personalised care planning	+	Active role patient Self-management Care coordination	=	Psychological outc. Self-mgmt. skills Satisfaction
CMO-C 4	Skills training HCP Accessibility	+	Active role patient Communication Attitude HCP	=	Satisfaction
CMO-C 5	Skills training HCP Accessibility	+	Active role patient Communication Holistic focus Care coordination	=	Psychological outc. Satisfaction Health system outc.
CMO-C 6	Skills training HCP	+	Active role patient Communication Self-management Therapeutic relationship	=	Health outcomes Concordance
CMO-C 7	Skills training HCP	+	Communication Self-management Shared decision-making	=	Person-centred treatment

HCP: healthcare professional, outc.: outcomes, self-mngmt: self-management

Figure 5.1 Middle-range PT from the RRR (20)

METHODS

Patient and public involvement

This study was commissioned by the National Health Care Institute, who, amongst others, encourages good healthcare by helping all parties involved to continually improve healthcare quality. This study is part of a larger study for which a steering committee was established. The ten members of the steering committee were purposively selected based on their expertise in the PCC or primary care field and were primary care practitioners, senior researchers, medical specialists, policy makers, patient's representatives (specifically concerning patients with limited (health-) literacy and a migrant background) (see Acknowledgements). Several meetings with the steering committee were held during the study (February 2018, December 2018, April 2019, December 2019). These meetings were held with the objective to provide feedback and guidance on the methods, the interpretation of (interim) results, and providing overall advice regarding the research. Stakeholder perspectives were considered when testing and refining the PT derived from the RRR. Members of the steering committee were asked to discuss, and to indicate if the identified items on context, mechanisms and outcomes in the literature match with what they see in Dutch practice.

Programme theory

One of the key elements in doing realist research is to establish a PT. A PT explains what mechanisms will generate the outcomes and what features of the context will affect whether or not those mechanisms operate (27, 28). Context items refer to wider external factors, and mechanisms are considered enablers, underlying entities, processes, structures, reasoning, choices, or collective beliefs). The interaction between context and mechanisms lead to outcomes (intended and unintended). In the international RRR we established a middle-range PT (see Introduction and Figure 5.1), which we aimed to refine based on the findings of this study in the Dutch setting.

Study design

In this qualitative study, four focus group discussions (FGDs) were held with the objective to encourage group interaction between participants and to explore and clarify individual and shared perspectives (29). FGD 3 and 4 were combined with a Delphi-study. The four FGDs were held with different stakeholders to validate the findings from the international RRR for the Dutch setting. A FGD lasted approximately 90 minutes. All FGDs were held at a neutral place that participants already knew (i.e., at a research organisation), and where they felt comfortable. Participants of FGD 1 and 2 were patient representatives and patients with limited health literacy skills. Participants of FGD 3 and 4 were various primary care professionals. Due to the different target groups, a target group-specific approach was used. The different approaches are explained in more detail below.

Recruitment

Participants of FGD 1 and 2 were recruited through purposive sampling. Adult participants were approached using trusted network organisations. These organisations are the Network of Organisations of Older Migrants (NOOM), which focus on diverse groups of migrant older people in the Netherlands, and the ABC foundation, a volunteer organisation for low-literate people throughout the Netherlands. During the recruitment process maximum variation in gender, age, ethnic background, educational level and level of health literacy was aimed to achieve. FGD 1 and 2 were led by a researcher (AA) and another moderator experienced in leading FGDs with people with low (health) literacy skills (NHvR). FGD 1 and 2 took place in August 2018. Participants of FGD 3 and 4 were various primary care professionals, members of care organisations, policy makers, and researchers. Participants of FGD 3 and 4 were recruited (purposive sampling) through the expert network of the researchers of this project, aiming for variation in gender, age, professional background, and experience with person-centred care. To be included in the FGD, participants needed to have scientific (research) experience and/or practical work experience in a professional or service organisation regarding person-centred care in primary care. FGD 3 and 4 were led by two researchers (AA and HJMV or MvdM). FGD 3 and 4 took place in December 2018.

Data collection

For FGD 1 and 2 an open-ended semi-structured topic guide was used by the moderators, which was compiled based on the context items, mechanism, and outcome variables from the RRR (Figure 5.1). Only patient-related items were included and were presented in the form of simple formulated questions during the FGDs (Figure 5.2 and Supplementary file 5.1). Participants could also ask other questions and/or share their own story or experiences. This facilitated the researchers to collect additional data. Participatory learning and action (PLA) techniques were applied to facilitate equal input from participants, thereby stimulating the active participation of participants. PLA is a form of participatory research, which emphasizes the need for stakeholders' active engagement across the full range of research activities, including data generation and data analysis, and is specifically suitable for meaningful involvement of stakeholders with limited power or skills (30, 31). Field notes were made during the FGDs. In FGD 3 and 4 validation of the CMO-items by participants took place by means of an e-Delphi questionnaire (Supplementary file 5.2) and a FGD during the second round (Figure 5.2). The Delphi technique is a widely used research method, which consists of several rounds of data collection to capture and structure the knowledge and opinions of a panel of participants on a topic in which they have expertise (32). Field notes were made during the FGDs.

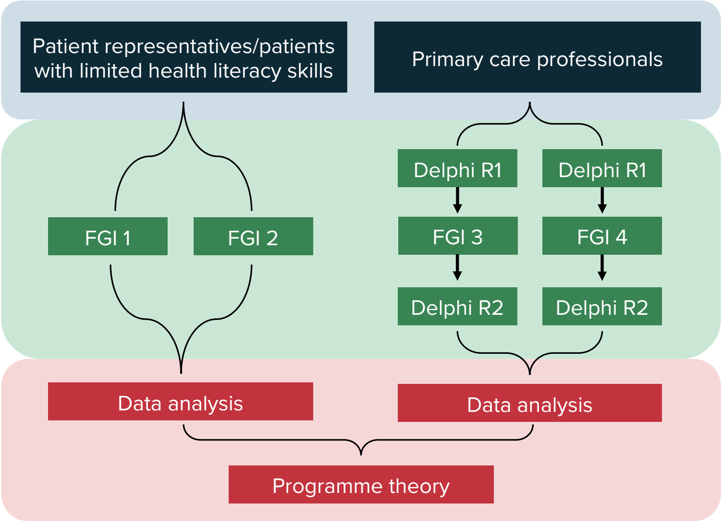


Figure 5.2 Overview of participants, data collection, and data analysis

Delphi round 1

Participants received a web link to an online version of the questionnaire in SurveyMonkey (version 2018). The questionnaire started with an introduction of the study and its objectives, the structure of the questionnaire, and the definitions of the constructs: context, mechanisms, programme-activities, and outcomes. The questionnaire continued with six general questions regarding gender, age, highest level of education, current job position, number of years working within the position, and number of years of experience with PCC. The questionnaire contained another 63 questions related to CMO-data derived from the RRR. Experts were asked to assess the relevance on a 9-point Likert scale (1 = very irrelevant to 9 = very relevant) of PCC-related items in primary care in the Netherlands of context items (n = 30), mechanisms (n = 19), and outcomes (n = 14) identified in the RRR. The questionnaire ended with two open questions, namely possible additions to the stated context items, mechanisms, and/or outcomes based on personal experiences, and participants were asked if they had any additional comments/suggestions about the questionnaire. The answers of the participants were completely anonymised. The respondents were given a total of two weeks to complete the questionnaire.

FGD (second round)

Before the second round of the Delphi questionnaire was completed, a FGD was held (Figure 5.2). The aim of this FGD was to discuss the context items, mechanisms and outcomes for which insufficient consensus/dissensus was found in round 1. During this FGD, the group results from the first Delphi round were provided, including 1) the median assessment results and interquartile range (IQR) on each item), 2) the level of (insufficient) consensus between the participants and, whether consensus was achieved (32, 33). The IQR is the difference between the 3rd and 1st quartile in which 50% of core values lie (34) and also shows the degree of convergence of the answers (35-38). The items, for which dissensus was found, were presented and discussed during the FGD to give insight into the level of (dis)agreement between experts in the first round and to generate additional insights about the specific item(s). Providing feedback on the level of group agreement reached, influences achieving the level of consensus subsequently (39). Misinterpretation on item(s) needed to be clarified.

Delphi round 2

An online version of the questionnaire was sent including the context items, mechanisms, and outcomes for which no consensus was found in round one (33). The questionnaire started with the same general questions as round 1. Then, participants were asked to indicate the degree of relevance of context items, mechanisms and outcomes for PCC in primary care in the Netherlands on the same 9-point Likert scale. At the end of the questionnaire, participants had the possibility to add items that were not included in the questionnaire and could also provide general comments/suggestions on the questionnaire. For round 2, the respondents were given a total of two weeks to complete the questionnaire.

Data analysis

All FGDs were audio-taped and transcribed verbatim manually. Using thematic analysis techniques (40), text segments were assigned a code if they related to a specific theme/topic, using an inductive, iterative process. Categories with similar content were investigated for inter-relationships, and further refined. Half of the data was coded independently by two researchers (AA, MvdM) to maximise credibility and trustworthiness (40). Any differences in code application were resolved by discussion with a third researcher (HJMV). Data were analysed both descriptively and exploratively. For the Delphi rounds in FGD 3 and 4 a 9-point Likert scale (1 = very irrelevant to 9 = very relevant) was used to indicate the degree of relevance of the CMO-items. To collect data from participants in a most sensitive matter, use was made of a 9-point Likert scale. For analysis, data were recorded into: irrelevant (1–3), equivocal (4–6) and relevant (7–9). Recoding enabled us to assess consensus on these meaningful levels and hence derive recommendations for improvement. To determine the level of consensus within the Delphi panel, many studies use a predetermined level of consensus among the experts (41). However, the literature does not describe a standard threshold for reaching consensus (42), with thresholds for consensus varying from 55–100% (43). In this study the level of consensus was 75% or more (42, 44, 45), with the condition that less than 15% of participants scored in the opposite range of that scale namely the 1–3 range (46, 47). All items with scores in the 4–6 range and without consensus, were presented again to the Delphi panel in round 2. Respondents' overall consensus on each context, mechanism, and outcome was analysed based on the median of the group's scores. The analysis was performed in MS Excel 2018. Consensus on items being found relevant by FGD 1 and 2 and/or FGD 3 and 4, remained part of the PT or were added to the PT. Consensus on items being irrelevant or no consensus on items were removed from the PT.

Trustworthiness

This study largely complies with the COnsolidated criteria for REporting Qualitative research (COREQ) Checklist, a checklist for explicit and comprehensive reporting of qualitative studies (in-depth interviews and focus groups) (48). To increase the credibility of this study multiple FGDs were held, multiple stakeholders' perspectives were included, and triangulation of data collection methods took place. Regarding transferability, sampling strategies, detailed descriptions of participants, a description of the topic list, and the procedure of methods were included. With respect to confirmability, (interim) results were presented to the commissioner of this study and the steering committee of this study. Regarding dependability, multiple authors independently coded the transcripts, interpretation of the results took place individually by multiple authors, and participants quotations were included to accurately report their perspectives.

Ethics

As this study does not involve patients or study subjects, according to the Dutch Medical Research in Human Subjects Act (WMO) in the Netherlands, an ethical approval was not needed. However, all participants provided their (verbal) consent and participation in the survey was anonymous.

RESULTS

FGD 1 and 2 with patient representatives

FGD 1 and 2 consisted of a total of 14 participants. In Table 5.1 the participants' characteristics are shown. Participants who were not originally born in the Netherlands have been in the Netherlands for on average of 44 years (SD: 11.4 years). All context items, mechanisms, and outcomes presented to participants were found relevant for PCC in primary care in the Netherlands. This concerns the context items: patients having social support (networks), a good collaboration between HCPs, patient education being provided, sufficient time during consultation, setting up a personalised care planning, and making use of e-health options. The mechanisms deemed relevant for PCC in primary care in the Netherlands are HCPs providing effective communication (including listen attentively), HCPs having a holistic approach, HCPs showing respect and having an open, friendly, and empathic attitude, patients having an active role in their care process, establishing a therapeutic relationship, self-management support, and shared decision-making. The outcomes considered relevant concerned health outcomes, patient involvement, satisfaction of the patient, therapy concordance, self-management skills, and an improved treatment approach. On the items below participants had additional comments next to them being considered relevant.

Table 5.1 Characteristics of participants.

Characteristic		FGD 1 and 2 (n = 14)	FGD 3 and 4 (n = 11)
Gender (%)	Female	36	45
	Male	64	55
Age (years)	Average (SD)	66 (9.7)	50.1 (10.2)
Highest level of education (%)#	Elementary education	57	-
	Intermediate vocational education	21	-
	Bachelor	7	27
	Master	14	45
	PhD	-	27
Background (%)	Research/academic	-	36
	Healthcare provider	-	36
	Other	100*	27^
Years of experience	Average (SD)	N/A	13.6 (11.1)

Basic education also includes special basis education (e.g., visual/hearing impaired, disabled, chronically ill)
* 'Other' includes e.g., a chef/cook, retirees, a stay-at-home mom, IT-teacher,
^ 'Other' includes e.g. (policy) advisors, managers/project leaders

The participants reflected on these items based on their own experience, indicating that they are relevant for PCC in primary care, but not always carried out properly in practice.

Communication

According to the participants, HCPs did not (yet) adapt their communication sufficiently to the needs and wishes of the patients. Participants stated that *“in the communication by the care provider more attention should be paid to diversity”* (P1 and P2). One participant expressed that *“communication is extremely important when you visit the GP. Often older migrants cannot communicate well in Dutch, but they do know what they want to ask in their own language. They often bring their son or daughter to the GP together with them to ask questions [related to medical health of patient]”* (P1). In addition, the use of aids (pictures, attributes, etc.) during the consultation could support communication, which is currently very limited done. Also, patients often had difficulties understanding health information and medical terms, while most of them did not indicate this. This is particularly the case for low-literate people and migrants, who had difficulty with the (Dutch) language and were therefore limited in their communication options. One participant mentioned that *“people still don’t have the guts to say they are illiterate, and that’s just because of the shame associated with it”* (P3). Reinforcing patients’ language skills and using interpreters can improve communication.

Consultation time

An important barrier of PCC in primary care according to the participants was the consultation time with the GP, which is too short to actually explain their problem. A participant mentioned that: *“In my own GP practice, I am experiencing the third generation of GPs, I noticed that doctors have less and less time. The consultation really just takes 10 minutes, so you can just ask one question. If you have more questions and your time is up, you will be cut off. It becomes very clear that there is no time left”* (P4). Patients often felt unheard or misunderstood, because there was insufficient time during the consultation to discuss all relevant matters or to explain everything properly. As a result, the HCP was also unable to provide adequate support based on the patient’s context and to discuss any underlying problems. Participants said: *“I would like that he [the GP] gives extra time to people who have difficulties with reading and writing. He [the GP] has knowledge in the medical field, but he should also know which patient have difficulties with reading and writing. Also, it should be pointed out what the rules and regulations are here in the Netherlands compared to other countries [regarding time]”* (P5). Patients making a double appointment with the GP could be helpful. Moreover, patients at home writing down points to discuss as preparation of the consultation could contribute to a more efficient use of consultation time. One participant stated that *“healthcare is commercialising in such a way that everything is expressed in Euros. The GP would like to take half an hour herself [for* *the consultation], but the health insurer, which is focused on the money, plays a very important role here. And it's getting worse, I feel. Sufficient time and attention for the patient are the building blocks of a relationship of trust, and this is at odds with the available time"* (P4).

Shared decision-making

Participants experienced that shared decision-making in practice was not conducted properly. Partly because of the short consultation time, the pros and cons of different treatment options were not always explained well by the HCP. Some participants stated that due to insufficient insight of patients into the disease and treatment options, as well as the expectation that the HCP is the expert in the medical field, this resulted in both parties being reluctant to make shared decisions. Therefore, the choice of HCP often played a decisive role. The wishes and preferences of the patient often remained underexposed. Overall, participants mentioned that *"I really like it when a GP asks you if you want to do something [which is part of care process] and whether you agree [with a treatment plan]"* (P6).

Collaboration between HCPs

The collaboration between HCPs (e.g., between practice nurse and GP or HCPs between primary and secondary care) could be improved. Participants often experienced that the different HCPs involved in the care process were not always well informed. As a result, patients often had to repeat their story, at the expense of the limited time available. For example, (electronic) information transfer often fell short and relevant (medical) documents were insufficiently shared. The HCPs involved also often gave different advices, which led to confusion among patients. Better coordination between HCPs of the agreements and advices made, is necessary to provide PCC.

Active role patient

In certain groups, such as people with low health literacy skills, patients often lacked confidence to ask questions to the HCPs and take an active role for the benefit of their health. This was partly because patients assigned a high status to the GP and placed him/her on a pedestal. These patients often did not want to bother the GP with their questions. In addition, they did not indicate by themselves that they had low (health) literacy skills because of past unfortunate events (e.g., bullying, bad experiences with HCPs 'not knowing who the patient is'). The patient was also rarely asked by the HCP whether they had low (health) literacy skills, with the result that the HCP had insufficient knowledge about the patient's background. As one participant stated: *"it would be good if the GP knew the background of the patient and what to consider. It is very important that the doctor knows what is going on behind the person in front of him/her"* (P7). Solutions for patients having an active role could be to schedule an intake interview for every new patient in the practice; inform other involved HCPs of important characteristics of the patient (e.g., low literacy); give sufficient room to patients to ask questions, check whether patients have asked all their questions and whether they have understood the answers. On the other hand, patients can go into the consultation better prepared by writing down their discussion points and questions in advance.

FGD 3 and 4 with care professionals

A total of 18 experts received the invitation to participate in the FGDs, of which eleven experts agreed. In Table 5.1 the characteristics of the participants are shown.

Quantitative description of consensus level

In round 1 consensus was achieved for 46 items out of a total 63 items (73%) among experts. All items were found relevant for the Dutch setting with the overall median lying in the 7-9 range. On 18 out of the 30 context items consensus was found (60%), 17 out of 19 mechanisms (89%), and 11 out of 14 outcomes (79%) (Figure 5.3). On 17 items dissensus was found with a panel median in the 4-6 point range (3 items) and 7-9 point range (14 items). These items were included in round 2.

In the second round, consensus was achieved among experts for 6 out of 17 items (35%), of which 4 out of 12 context items (33%), 1 out of 2 mechanisms (50%), and 1 out of 3 outcomes (33%). The overall median was in the 7-9 range. For 11 items, the relevance remained undecided. The overall median was in the 4-6 range (5 items) and in the 7-9 range (4 items), 2 items equally fell in the 4-6 range and 7-9 range. After both rounds, for 52 items out of 63 items (83%) consensus was found with all items being considered relevant.

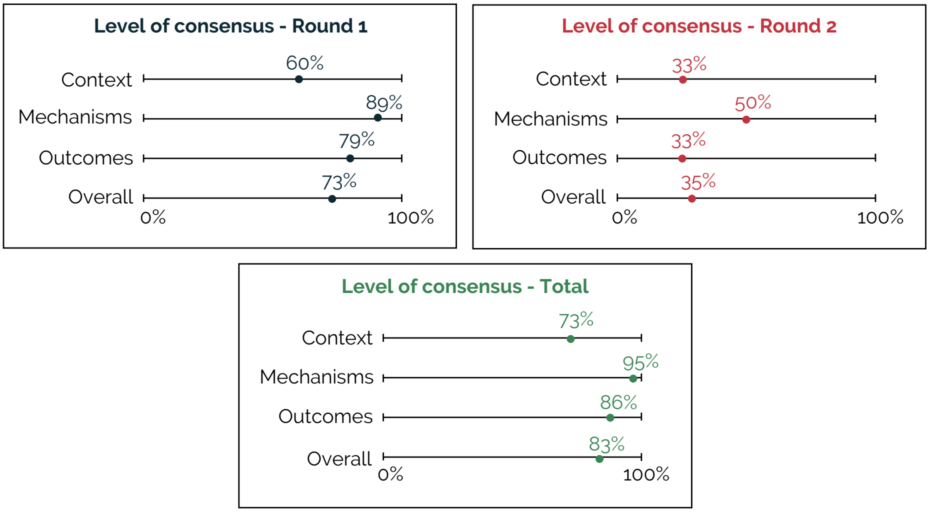


Figure 5.3 Level of consensus found in round 1 and 2.

Qualitative description of context items, mechanisms, and outcomes.

The outcomes on every context item, mechanism, and outcome of the first and second Delphi round are shown in Supplementary files 5.3 and 5.4 respectively. The items from round 1 that were found to be equivocal, were included in the second round.

Consensus

Context items – Based on both rounds, context items that were considered relevant for PCC in primary care in the Netherlands on macro-level were shifting the focus from a disease- and complaint-oriented approach to a more holistic approach, using evidence-based guidelines, foreseeing in sufficient capacity and time for patients during consultation, offering (more) space and resources to HCPs to experiment, and having flexible payment systems. Participants believed that *"experimenting in its broadest sense should be taken into account to improve PCC towards patients"* (P10, P13, P18). *"For example, if you have patients with a chronic conditions and you want them to take more control of their health themselves, and as a care provider you have learned a new conversation technique to be applied during consultation in which you approach the person openly and let him/her decide for themselves what they want to change [in their care process], then you have to have the space to try out the new technique, practice with it, and to improve it"* (P16).

On an organisational (meso) level, experts found that improving accessibility (e.g., to healthcare organisations, to documents, recorded consultations), having a good collaboration between HCPs and having a shared vision, having a supportive policy in place which strengthens the quality of PCC especially concerning low health literacy, and better integration between information and communications technology (ICT) systems are relevant items. Of the latter a participant mentioned: *"Better integration between ICT systems promotes cooperation, care is then better coordinated and it becomes more person-centred. Now everyone works according their own way"* (P12).

On an individual (micro) level HCPs having PCC skills (e.g., regarding communication, shared decision-making, providing culturally sensitive care) possibly through training or acquired during their medical education was found relevant. In addition, HCPs providing patient education, patients having social support (networks), and patients being involved in organising care was considered relevant.

A participant mentioned that *"HCPs setting goals and making action plans is also very relevant, because often patients don't know this by themselves. They often have questions during the consultation, and when the care provider reaches the bottom layer of those questions, you discover why the patient finds that important. Also, other things that are important for the patient emerge"* (P10).

Mechanisms – On meso-level experts found a focus on care coordination and achieving effective collaboration between patient and HCP(s) relevant. On micro-level, it is key that HCPs provide effective communication (e.g., simplifying treatment strategies and information for patients, encouraging patients to ask questions), have an open and empathic attitude, are aware of the patient's social circumstances, have a holistic focus, respecting the wishes and preferences of patients, applying shared decision-making together with patients, provide self-management support, and establishing a therapeutic relationship. Also, the involvement of patients and their family/informal caregivers in the care process was found relevant.

Outcomes – The following outcomes were considered relevant for PCC in primary care: an improved treatment approach with a more accurate intensity of support provided, higher therapy concordance, increased patient involvement, improved (psychological) health outcomes, improved health-related quality of life (HRQoL), higher satisfaction of patient, informal caregiver and/or HCP(s), improved relationship between patient and HCP(s), more accessible care, higher quality of care, and a higher cost-effectiveness of healthcare. One participant mentioned: *"Intensity of the support provided by the HCP is very important as an outcome. You could consider it as a success factor of PCC, it is tailored support to the patient"* (P12).

Dissensus

Context items – After two rounds, a lack of agreement on the relevance of some items for PCC in primary care in the Netherlands was observed, such as the application and efficient use of ICT and e-health initiatives. *"The information in e-health applications needs to be in line with what the healthcare provider says. Only if the information is in line and explained well, it will reinforce each other, otherwise it will lose its function."* (P13) *"E-health applications may not work for low-literate people or non-native speakers. Moreover, there are also people that are digitally illiterate"* (P14).

There was also dissensus on the item having sufficient male and female HCPs per practice, as participants found that *"there are people who would like to have a male or a female care provider, it's nice that people have that choice. But whether you choose a male or female doctor, they both have to provide PCC, regardless of their gender"* (P15).

Some participants believed that providing better administrative support for HCPs might positively influence PCC, but is not considered relevant to provide PCC. *"Providing better administrative support for caregivers can reduce administrative barriers to increase working in a person-centred way. The [consultation] time you can spend on a patient is already limited, so if you can spend less time on administrative things such as electronically saving or capturing what has been discussed with the patient such as setting the goals, you have more time to provide PCC to the patient. But it is not a precondition to provide good PCC and therefore, not relevant"* (P16).

Regarding the item preparation of consultation by patient it was mentioned that *"the preparation of a consultation by the patient is not by definition relevant for the provision of person-centred care by the care provider"* (P9). *"It is nice if a patient prepares a consultation, it can be very helpful. The question is also whether each patient can prepare the consultation, whether he/she is competent enough to do so. Someone who actively thinks about his/her health makes the conversation easier, but it is not a condition for the provision of PCC, that is the task of the care provider"* (P8).
About the item patients having a high/low socioeconomic status (SES), some mentioned that *"having a high or low SES is not relevant for providing PCC. Most of the time it does require more effort to provide PCC to people with a low SES. But providing care to people with a high SES, such as expats, can also be challenging, as they are not familiar with the systems [in the country], but are highly educated at the same time. SES is not decisive for PCC"* (P12, P15).
Dissensus was also found on the items setting up a personalised care planning and, HCPs stimulating patient empowerment.

<u>Mechanisms</u> – There was no agreement on the relevance concerning HCPs stimulating self-monitoring by patients. It was mentioned that *"It is important that the patient can monitor his own medical condition. However, a person with low health literacy skills with for example severe rheumatism may need someone else to monitor him/her. Stimulating by the care provider is important, but you have to take into account what someone is able to do. I don't think everyone can and will monitor their own health. It is beneficial for those who can"* (P11).

<u>Outcomes</u> – No consensus was found on the items self-management skills of patients and health system outcomes (reduced use of healthcare system, less referrals, less follow-up examinations, reduced emergency department visits, reduced hospital (re) admissions) for PCC in primary care in the Netherlands.

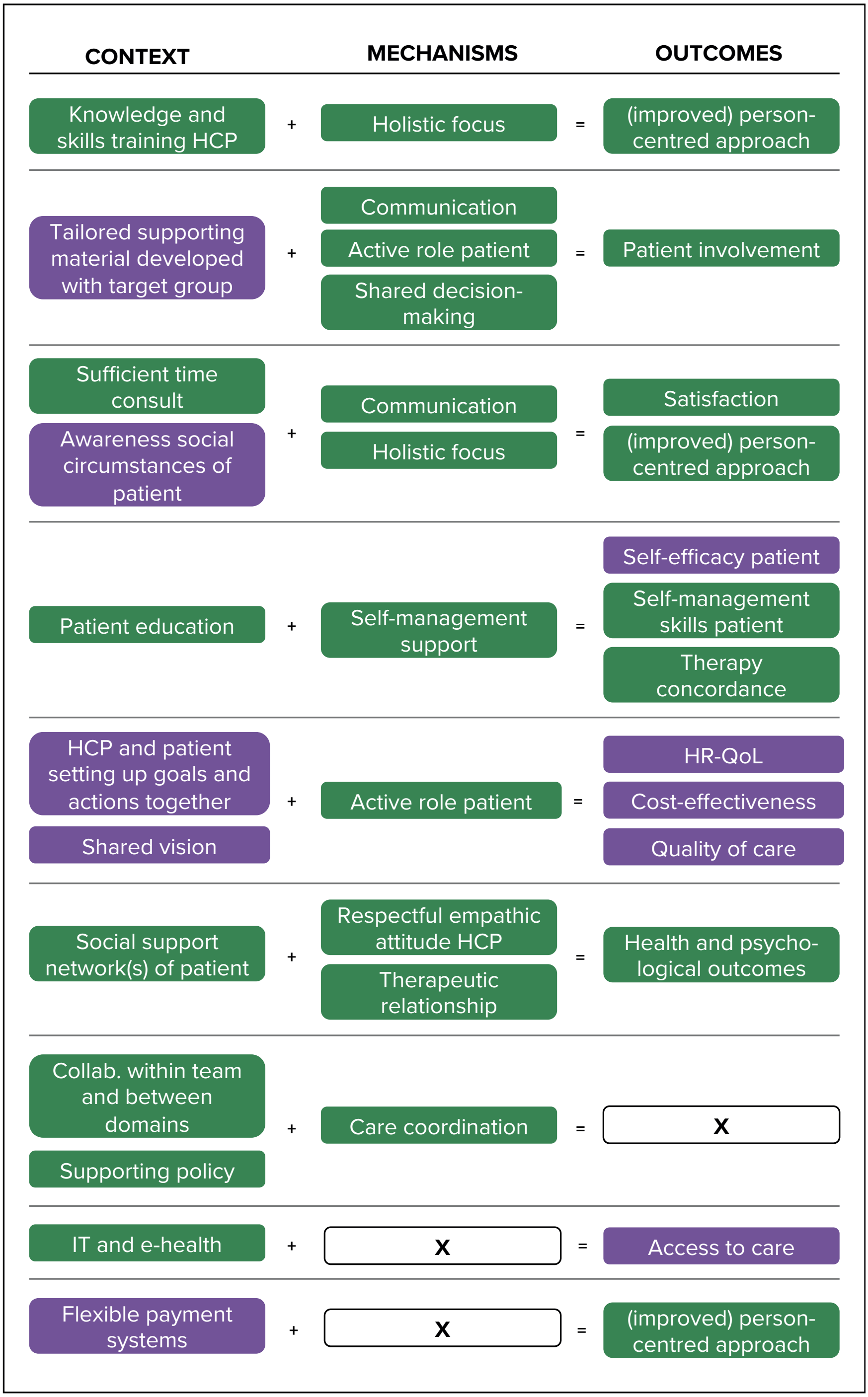
Additional items

In addition to the items identified in the literature, the participants stated several other items, such as caregivers having more pleasure in their job as an outcome. To enhance (the focus on) PCC in primary care for low health literacy skills groups, the expertise of professionals who are familiar with working and treating these groups from diverse backgrounds could be used (i.e., peer education). Another item mentioned was that when involving patients in their care process, the responsibilities of the patient and HCP need to be clearly defined.

Refined programme theory

Based on the results of the FGDs, the middle-range PT derived from the international RRR has been refined for the Dutch setting (Figure 5.4). In this refined PT the context items (C), mechanisms (M), and outcomes (O) that have been added, are underlined. The non-underlined items were already included in the middle-range PT.

The refined PT demonstrated that to provide a better intensity of support to the patient (O) and optimally align care to the patient (O), it is necessary that HCPs are equipped with the knowledge and skills and are trained and educated (C) to have a holistic focus (M) taking into account the diversity aspect (C), instead of a biomedical, disease-oriented approach (C). Communication (M) tailored to the needs and health literacy skills of the patient plays an important role, just as tailor-made supporting material (C) being available for patients. By developing these together with the target group (C), it is more likely these will match the target group and contribute to realising a more active role of the patient (and their families) in the care process (M, O), and in the shared decision-making process (M). To communicate effectively (M), HCPs should be provided with sufficient time and space (C), also to become aware of the patient's (social) circumstances (C), discuss the wishes and preferences of patients (M), and work in a culturally competent way (C). As a result, a higher satisfaction of patient, informal caregivers and/or HCP(s) (O) can be achieved and the PCC treatment approach (O) can be improved. If several HCPs are involved in the care process, good collaboration within the team (C) and between different domains (C) is desirable to ensure good care coordination (M). These elements can be stimulated by including them in the policy of (care) organisations, wherein attention is also paid to people with low health literacy skills (C). HCPs having an open, respectful, and empathic attitude (M) plays an important role in establishing a strong therapeutic relationship (M). Patient's social support networks (C) also help to improve the patients' (psychological) health (O). In addition, better integration between ICT systems (C), offering e-health options and access to documents, recorded consultations (C), play a key role in a more accessible care (O). Flexible payment models (C) could facilitate PCC in primary care (O). Next to providing patient education (C), HCPs should provide self-management support to patients (M), stimulating patient's self-management skills (O), self-efficacy (O) and therapy concordance (O). When goals and action plans are set up together during personalised care planning (C), HCPs and patients have a shared vision (C), the patient has more confidence to ask questions (C) about the treatment (possibilities), and has more insight into the importance of his/her treatment (M), this may lead to improved HRQoL (O). On the long-term, higher cost-effectiveness of healthcare (O) and a higher quality of care (O) can be accomplished.



CONTEXT		MECHANISMS		OUTCOMES
🟩 Knowledge and skills training HCP	+	🟩 Holistic focus	=	🟩 (improved) person-centred approach
🟪 Tailored supporting material developed with target group	+	🟩 Communication 🟩 Active role patient 🟩 Shared decision-making	=	🟩 Patient involvement
🟩 Sufficient time consult 🟪 Awareness social circumstances of patient	+	🟩 Communication 🟩 Holistic focus	=	🟩 Satisfaction 🟩 (improved) person-centred approach
🟩 Patient education	+	🟩 Self-management support	=	🟪 Self-efficacy patient 🟩 Self-management skills patient 🟩 Therapy concordance
🟪 HCP and patient setting up goals and actions together 🟪 Shared vision	+	🟩 Active role patient	=	🟪 HR-QoL 🟪 Cost-effectiveness 🟪 Quality of care
🟩 Social support network(s) of patient	+	🟩 Respectful empathic attitude HCP 🟩 Therapeutic relationship	=	🟩 Health and psycho-logical outcomes
🟩 Collab. within team and between domains 🟩 Supporting policy	+	🟩 Care coordination	=	X
🟩 IT and e-health	+	X	=	🟪 Access to care
🟪 Flexible payment systems	+	X	=	🟩 (improved) person-centred approach

HCP: healthcare professional, Collab.: collaboration, IT: information technology
Green boxes: items included in the previous middle-range PT.
Purple boxes: items added to refine PT

Figure 5.4 Refined PT by FGDs

DISCUSSION

Principal findings

In this study the middle-range PT from the international RRR was refined for PCC in primary care in the Netherlands by assessing the level of consensus on the relevance of items derived from the RRR by means of FGDs and a Delphi-panel.

Based on the FGDs, several items have been added to refine the PT. The context items that were added concern HCPs being aware of the patient's (social) circumstances, working in a culturally competent way, HCPs and patients having a shared vision and setting up goals and action plans together, patients having more confidence to ask questions, providing tailor-made supporting material, developing supporting material and tools together with the target group, a better integration between ICT systems, providing patient access to documents and recorded consultations, and flexible payment models being in place. No mechanisms were added. Outcomes that were added include better alignment of care to the patient, having accessible care, improving the patient's self-efficacy, improving HRQoL, higher cost-effectiveness of healthcare, and a higher quality of care. One item was excluded from the middle-range PT to refine the PT as not all FGDs found this item relevant for PCC in primary care in the Dutch setting, namely improved health system outcomes (outcome).

This study makes clear that sufficient attention needs to be paid to the complex interplay of the context items, mechanisms and outcomes concerning PCC in primary care in the Netherlands. Bypassing this complexity will most likely not lead to the desired effectiveness of PCC in primary care. The use of all items in their mutual coherence is necessary to truly realise PCC.

Strengths and limitations

One of the strengths of this study is the use of the combination of FGDs and the Delphi method. The participation of both – the often thought of as hard to reach - patients with low (health) literacy levels and primary care professionals increase the face validity of the results of this study. A possible limitation concerns the limited number of FGDs. It is suggested to conduct two to three FGDs to capture 80% of themes, and three to six groups for 90% of themes (49). However, data saturation seemed to be reached as in the second and fourth FGD no new items were mentioned than in the first and third FGD. Also, there were no specific inclusion criteria for participants of FGD 1 and 2. These participants were recruited through convenience sampling. A third limitation to be considered is that the group moderators of FGD 3 and 4 were not impartial to the study. Nevertheless, they only moderated the discussion and did not share their own opinions.

Comparison to previous studies

Consistent with our refined PT, studies have found that in order to deliver effective PCC the patient wishes, needs, and abilities need to be taken into account to align care to the patient (50, 51). Also, HCPs should stimulate patients to set and achieve their own treatment goals, and access to care should be optimised (51). The importance of providing tailored supporting materials, culturally competent working, and self-efficacy of the patient has also been reported (50, 52, 53). Individualised care plans, physical comfort at GP practice, and providing patients emotional support were also mentioned, but not found in our study (51).

Implications for practice and research

Given the complexity of the interplay of all items, it is recommended *for healthcare organisations* to develop and implement an all-encompassing approach and to divide the approach into phases, to make it manageable. During the first phase (initiation) HCPs need to acquire relevant knowledge and skills through education and training. Patients need to be aware of their role in their care process and that they have social support networks. In the second phase (decision & adoption) adjustments regarding the healthcare system, policy-making, financing issues, integration between ICT systems, and creating sufficient experimental space, time and resources are made concrete. In the third phase (execution) the focus is on the implementation of a good collaboration between HCPs, the provision of self-management support, patient education, shared decision-making, whereby information and communication should be simplified. In the fourth phase (monitoring & evaluation) it is necessary to gain insight into (unexpected) problems and challenges, to find out to what extent the intended results/effectiveness are being achieved and to meet the needs for resources. With respect to further research, it is recommended to assess how and to what extent the items have been collectively implemented and to evaluate how effective PCC is in practice, for whom, how and why. Also, items on which dissensus was found need to further examined why they were found irrelevant for the Dutch setting. Our understanding of PCC is likely to increase (faster) when applying realist research iteratively and in different settings.

CONCLUSION

This study shows that for PCC to be effective in primary care, the complex interplay of context, mechanisms, and outcomes deemed relevant to a setting must be met. Added items to refine the PT for the Dutch primary care setting indicated that to optimally align care to the patient, next to tailored communication, also tailored supporting material that is developed together with the target group is key. HCPs and patients need to have a shared vision and set up goals and action plans together. HCPs should stimulate patient's self-efficacy, need to be aware of the patient's (social) circumstances and work in a culturally sensitive way. Better integration between ICT-systems, flexible payment models, and patients access to documents, recorded consultations should be in place. On the long-term higher cost-effectiveness and a higher quality of healthcare can be realised when sufficient attention is paid to the interplay of relevant context items, mechanisms and outcomes.

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SUPPLEMENTARY FILE 5.1

Topic guide for FGD 1 and 2

1. **Communication/relationship with healthcare provider**
    - What do you like about your GP? How would you like your GP to act?
    - Do you think that your GP pays enough attention to you during the appointments/consultations, for example do you have the feeling that the doctor listens to you and responds to what you tell the doctor? If not, what could be better?
    - Do you think the doctor has enough time during the appointments? If not, do you think more time is needed? Why do you need more time?

2. **Empathy by healthcare provider/empathy in communication**
    - Do you think that during the appointments your GP 1) sympathizes/thinks along with you, 2) understands your problem or question?

3. **Good communication/understandable information material, and simplified information**
    - Does the GP adapt his communication sufficiently to you? Do you understand what your doctor means?
    - Do you like the conversation you have with your GP during the appointments?
    - Does the doctor use things like pictures or information on the computer to explain things?

4. **Building a confidential relationship/partnership between patient and healthcare provider**
    - Do you feel comfortable with your GP?
    - Can you tell everything to your GP? Do you feel safe with your GP?
    - Do you have self-confidence to ask all questions to the doctor?
    - Do you think the relationship/bond with your GP is important?
    - Do you trust your GP?

5. **Transparency**
    - Do you feel that your GP tells you everything about your problem/situation? That he/she is open?
    - Or sometimes that he/she doesn’t tell you everything? When did this happen?

6. **Awareness of patient’s background**
    - Does the GP know your background? Does he/she know that you are low-literate?
    - When you first visited the GP, were you told something about what the GP does?

- Was something told about how health care works in the Netherlands? For example, information about health insurance with basic package, supplementary package, and deductible? If so, what was said?

7. **Personalized care plan**
    - Do you prepare for an appointment with the doctor? And how do you do that? Do you write things down? Are you looking for things on the computer/the Internet?
    - Is during the appointments discussed what should be done/what the treatment entails and what the result should be (setting goals)? Was this written down?
    - And was this discussed (assessed) again at the end?
    - Did you need more information about how to make appointments?

8. **Motivation/stimulation of self-reliance/self-management (support)**
    - If you have to do something at home for your medical condition, such as regularly checking your blood sugar, does your GP feel that this is important?
    - Does your GP tell you what you should do yourself to cope with the disease? So, for example, a good explanation of what to do, why, how, when, and how often?
    - And does he/she tell you how long you should continue with this and why this is important?

9. **Shared-decision making**
    - Does the doctor tell you the different options/choices you have?
    - If decisions have to be made about, for example, a treatment, does the GP do this alone or do you do it together?

10. **Respecting preferences and wishes of patients and involvement family**
    - For example, if you wanted or would prefer a certain treatment, will your GP listen?
    - If you had a particular wish because of culture or religion, did your GP approve?

11. **Regular visits**
    - Do you regularly visit the doctor? How often is that? Do you like it better if you visit more often? Do you trust your GP more?

12. **Use of tools and technology**
    - Are other things or tools being used to help you with your medical condition? To help you understand your medical conditions or treatment? For example, a special phone number that you can use if you have any questions? Or something on the computer?

13. **Physical, geographical, financial, social, and cultural accessibility to care**
    - Are you have pain when you go to the doctor? (physical)
    - Is it easy to get to the doctor? Walking, cycling, or by car? (geographical)
    - Do you ever think about the costs if you have to go to the doctor? Or not because you think the costs will be high? (financial)
    - Are there any social or cultural aspects that play a role when visiting the doctor?

14. **Involvement of patients in the development of new instruments/including patient experiences in setting up care**
    - When something new is developed, for example a booklet, a folder (or a new model/instrument), are you asked what is important?
    - And is it asked what would be helpful when developing new tools/instruments/booklets?

15. **Higher patient satisfaction (outcome)**
    - If the GP gives you more attention and asks for more personal things, are you more satisfied with the appointment?

16. **Better health outcomes (outcome)**
    - Has your health improved if your GP pays more attention and asks for personal things? So, for example, better sugar values?

SUPPLEMENTARY FILE 5.2

Delphi questionnaire for FGD 3 and 4

Title

Person-centred care in primary care: relevance of context, mechanisms and outcomes

Introduction

This questionnaire is part of the study 'Evaluation of person-centred care in primary care'. The research is financed by the National Health Care Institute (ZIN) and carried out by Pharos and Panaxea.

The study focuses on the question 'for whom, how and why does PCC in primary care (not) work and under what circumstances? The core of PCC is that the care provider does not focus on the complaint or medical condition, but on the person presenting the complaint. The treatment does not focus on the health problem, but on the way in which the patient views life and deals with the problem himself. PCC refers to care that is tailored to the characteristics, the environment and the needs of each patient. Diversity, or differences between patients may exist in age, gender, socio-economic status, education, migration background, and presence of disease(s). Diversity between patients can also be reflected in differences in personal preferences and care needs.

The study consists of three phases. In the first phase of the study, a literature study was conducted, in which information was collected about how and in what circumstances PCC results in outcomes. These findings from the literature review are categorised using three constructs: (1) context, (2) mechanisms and (3) outcomes.

- Context refers to the wider external conditions necessary for PCC and the mechanisms to result in outcomes;
- Mechanisms are the processes/triggers that arise when PCC results in outcomes under the right conditions;
- Outcomes are the results that arise from the interplay of PCC and the mechanisms in a certain context.

To get insight into the degree of relevance of the context items, mechanisms and outcomes identified in the literature, the input of stakeholders is required (phase 2). Therefore, we kindly request you to assess the context items, mechanisms and outcomes of PCC for their relevance in primary care in the Netherlands. Your assessment scores will be included in the survey anonymously.

Questionnaire

The questionnaire starts with some general questions. Then, we will ask you to indicate the degree of relevance of context items, mechanisms and outcomes for PCC in primary health care in the Netherlands. The survey ends with a few open questions, with room for any additional items. We kindly request you to answer all questions.

General questions

- What is your gender? [Male/Female]
- What is your age?
- What is your highest level of education achieved? [none, high school, bachelor's degree, master's degree, PhD]
- What is your current position?
- How many years have you been working in this position?
- How many years of experience do you have with person-centred care?

Context items, mechanisms, and outcomes

In the next section, rate the relevance of each item by checking the box that best fits your answer. There are no right or wrong answers.

[Options: Highly irrelevant, Irrelevant, Fairly irrelevant, Somewhat irrelevant, Neither irrelevant nor relevant, Somewhat relevant, Fairly relevant, Relevant, Highly relevant]

Context

1. Setting up a personalised care planning
2. Preparation of consultation by patient
3. HCPs setting goals, making action plans, coordinating, supporting and assessing care process of patients
4. Training/educating young HCPs during medical education on important aspects of person-centred care
5. HCPs having the right skills (e.g., regarding communication, shared decision-making, providing culturally sensitive care)
6. HCPs having the right knowledge about the epidemiology and the treatment effects in different ethnic groups
7. Having better patient access to documents, recorded consultations (notes, etc.)
8. Improving the accessibility of healthcare organisations
9. Supporting better integration between ICT systems
10. Efficient use of information technology (IT)
11. Applying IT- and e-health initiatives
12. Foresee in the required capacity (time, staff, resources)
13. Having sufficient male and female HCPs per practice
14. Offering (more) space and resources to HCPs to experiment
15. Patients having social support (networks)

16. Having structural attention for low health skills/person-centred care in the policy of the organization
17. Strengthening the quality of care through supportive health policy
18. Aligning healthcare purchasing to local needs/policy
19. Providing patient education
20. HCPs stimulating patient empowerment
21. Having a good collaboration between HCPs/strong team
22. Actively involving patients and patient experiences when designing care (processes)
23. Involving patients in the development of new instruments (tools, step-by-step plan, booklets)
24. Patients having a high/low socioeconomic status
25. Providing better administrative support for HCPs
26. HCPs having a shared vision
27. Using evidence-based guidelines
28. Shifting the focus from a disease- and complaint-oriented approach
29. Foreseeing in sufficient time for patients during consultation
30. Flexible payment systems

Mechanisms

31. HCPs providing effective communication
32. Simplifying treatment strategies and information for patients
33. Investing in understandable information material
34. Encouraging patients to ask questions to HCP(s)/patients having the confidence to ask questions
35. Involving family and informal caregivers in the care process
36. Patients having an active role in their care process
37. Stimulating patient's self-efficacy
38. HCPs promoting involvement, support and reinforcement of patients
39. Providing self-management support
40. Focus on care coordination
41. Establishing a therapeutic relationship
42. Achieving effective collaboration between patient and HCP(s)
43. HCPs having an open and empathic attitude
44. HCPs respecting the wishes and preferences of patients
45. HCPs applying shared decision-making together with patients
46. Have a holistic focus
47. HCPs who are aware of the patient's social circumstances
48. HCPs working in a culturally competent way
49. Stimulating self-monitoring by patient

Outcomes

50. Higher therapy adherence
51. Improved patient-centred treatment/approach
52. Improved intensity of support provided
53. Improved health-related quality of life (HRQoL)
54. Improved self-management skills of patients
55. Higher satisfaction of patient, informal caregiver and/or HCP(s)
56. Improved health outcomes
57. Improved health system outcomes (reduced use of healthcare system, less referrals, less follow up examinations, reduced emergency department visits, reduced hospital (re)admissions)
58. Increased patient involvement
59. Higher cost-effectiveness of healthcare
60. Higher quality of care
61. More accessible care
62. Improved relationship between patient and HCP(s)
63. Improved psychological health outcomes

Open questions

- Do you have additional items to the aforementioned context items, mechanisms, and/or outcomes based on your own experience(s)?
- Do you have general feedback or comments about the questionnaire?

Closing

This is the end of the questionnaire. Thank you for your participation!
If you have any questions, please contact Ms Anam Ahmed (researcher at Panaxea) at anam.ahmed@panaxea.eu

SUPPLEMENTARY FILE 5.3

Results Delphi round 1

Items	Median (IQR)	Consensus in 1-3 range (%)	Consensus in 4-6 range (%)	Consensus in 7-9 range (%)	Overall consensus
Context					
Setting up a personalised care planning	7 (3)	0	27	73	*Equivocal*
Preparation of consultation by patient	7 (2)	9	27	64	*Equivocal*
HCPs setting goals, making action plans, coordinating, supporting and assessing care process of patients	8 (0)	0	9	91	Relevant
Training/educating young HCPs during medical education on important aspects of person-centred care	9 (1)	0	0	100	Relevant
HCPs having the right skills (e.g., regarding communication, shared decision-making, providing culturally sensitive care)	9 (1)	0	0	100	Relevant
HCPs having the right knowledge about the epidemiology and the treatment effects in different ethnic groups	8 (0)	0	0	100	Relevant
Having better patient access to documents, recorded consultations (notes, etc.)	7 (1)	0	9	91	Relevant
Improving the accessibility of healthcare organisations	9 (1)	0	9	91	Relevant
Supporting better integration between ICT systems	8 (3)	0	36	64	*Equivocal*
Efficient use of information technology (IT)	7 (2)	0	27	73	*Equivocal*
Applying IT- and e-health initiatives	7 (2)	0	45	55	*Equivocal*
Foresee in the required capacity (time, staff, resources)	8 (2)	0	0	100	Relevant
Having sufficient male and female HCPs per practice	6 (2)	0	64	36	*Equivocal*
Offering (more) space and resources to HCPs to experiment	7 (2)	0	36	64	*Equivocal*
Patients having social support (networks)	8 (2)	0	18	82	Relevant
Having structural attention for low health skills/person-centred care in the policy of the organization	8 (2)	0	0	100	Relevant

Results Delphi round 1 (continued)

Items	Median (IQR)	Consensus in 1-3 range (%)	Consensus in 4-6 range (%)	Consensus in 7-9 range (%)	Overall consensus
Context (cont.)					
Strengthening the quality of care through supportive health policy	8 (1)	9	9	82	Relevant
Aligning healthcare purchasing to local needs/policy	8 (1)	9	9	82	Relevant
Providing patient education	8 (1)	0	18	82	Relevant
HCPs stimulating patient empowerment	5 (4)	18	55	27	*Equivocal*
Having a good collaboration between HCPs/strong team	8 (1)	0	9	91	Relevant
Actively involving patients and patient experiences when designing care (processes)	9 (1)	0	0	100	Relevant
Involving patients in the development of new instruments (tools, step-by-step plan, booklets)	8 (1)	0	18	82	Relevant
Patients having a high/low socioeconomic status	7 (5)	27	18	55	*Equivocal*
Providing better administrative support for HCPs	7 (3)	0	45	55	*Equivocal*
HCPs having a shared vision	7 (2)	0	45	55	*Equivocal*
Using evidence-based guidelines	7 (1)	0	18	82	Relevant
Shifting the focus from a disease- and complaint-oriented approach	8 (2)	0	18	82	Relevant
Foreseeing in sufficient time for patients during consultation	9 (2)	0	18	82	Relevant
Flexible payment systems	7 (2)	0	27	73	*Equivocal*
Mechanisms					
HCPs providing effective communication	9 (1)	0	0	100	Relevant
Simplifying treatment strategies and information for patients	8 (2)	0	0	100	Relevant
Investing in understandable information material	8 (1)	0	9	91	Relevant

Results Delphi round 1 (continued)

Items	Median (IQR)	Consensus in 1-3 range (%)	Consensus in 4-6 range (%)	Consensus in 7-9 range (%)	Overall consensus
Mechanisms (cont.)					
Encouraging patients to ask questions to HCP(s)/patients having the confidence to ask questions	8 (1)	0	9	91	Relevant
Involving family and informal caregivers in the care process	7 (1)	0	18	82	Relevant
Patients having an active role in their care process	8 (1)	0	0	100	Relevant
Stimulating patient’s self-efficacy	7 (2)	0	18	82	Relevant
HCPs promoting involvement, support and reinforcement of patients	8 (2)	0	27	73	*Equivocal*
Providing self-management support	8 (1)	0	9	91	Relevant
Focus on care coordination	8 (2)	0	9	91	Relevant
Establishing a therapeutic relationship	9 (1)	0	0	100	Relevant
Achieving effective collaboration between patient and HCP(s)	8 (2)	0	9	91	Relevant
HCPs having an open and empathic attitude	8 (1)	0	9	91	Relevant
HCPs respecting the wishes and preferences of patients	8 (1)	0	0	100	Relevant
HCPs applying shared decision-making together with patients	8 (1)	0	9	91	Relevant
Have a holistic focus	8 (2)	0	18	82	Relevant
HCPs who are aware of the patient’s social circumstances	9 (1)	0	9	91	Relevant
HCPs working in a culturally competent way	7 (1)	0	9	91	Relevant
Stimulating self-monitoring by patient	6 (3)	0	64	36	*Equivocal*

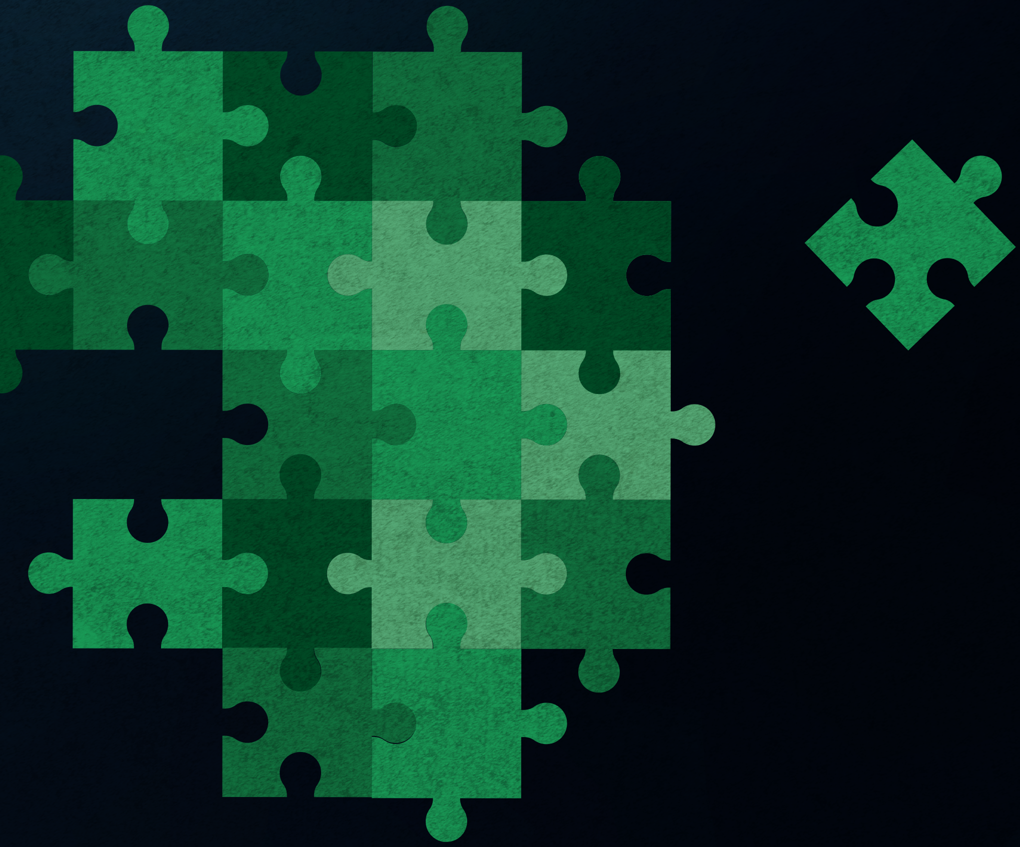
Results Delphi round 1 (continued)

Items	Median (IQR)	Consensus in 1-3 range (%)	Consensus in 4-6 range (%)	Consensus in 7-9 range (%)	Overall consensus
Outcomes					
Higher therapy adherence	8 (2)	0	0	100	Relevant
Improved patient-centred treatment/approach	9 (1)	0	9	91	Relevant
Improved intensity of support provided	8 (2)	0	36	64	*Equivocal*
Improved health-related quality of life (HRQoL)	8 (1)	0	9	91	Relevant
Improved self-management skills of patients	7 (2)	9	18	73	*Equivocal*
Higher satisfaction of patient, informal caregiver and/or HCP(s)	8 (2)	0	9	91	Relevant
Improved health outcomes	8 (1)	0	9	91	Relevant
Improved health system outcomes (reduced use of healthcare system, less referrals, less follow-up examinations, reduced emergency department visits, reduced hospital (re)admissions)	7 (2)	0	27	73	*Equivocal*
Increased patient involvement	8 (1)	0	9	91	Relevant
Higher cost-effectiveness of healthcare	8 (1)	0	18	82	Relevant
Higher quality of care	8 (2)	0	0	100	Relevant
More accessible care	8 (1)	0	18	82	Relevant
Improved relationship between patient and HCP(s)	8 (2)	0	9	91	Relevant
Improved psychological health outcomes	8 (1)	0	9	91	Relevant

SUPPLEMENTARY FILE 5.4

Results Delphi round 2

Items	Median (IQR)	Consensus in 1-3 range (%)	Consensus in 4-6 range (%)	Consensus in 7-9 range (%)	Overall consensus
Context					
Setting up a personalised care planning	7 (1)	9	36	55	*Equivocal*
Preparation of consultation by patient	6 (2)	18	64	18	*Equivocal*
Supporting better integration between ICT systems	8 (1)	9	9	82	Relevant
Efficient use of information technology (IT)	6 (3)	9	45	45	*Equivocal*
Applying IT- and e-health initiatives	7 (2)	9	36	55	*Equivocal*
Having sufficient male and female HCPs per practice	5 (2)	18	55	27	*Equivocal*
Offering (more) space and resources to HCPs to experiment	8 (1)	0	9	91	Relevant
HCPs stimulating patient empowerment	5 (4)	27	45	27	*Equivocal*
Patients having a high/low socioeconomic status	5 (5)	27	27	45	*Equivocal*
Providing better administrative support for HCPs	7 (2)	18	18	64	*Equivocal*
HCPs having a shared vision	8 (1)	9	9	82	Relevant
Flexible payment systems	8 (2)	0	9	91	Relevant
Mechanisms					
HCPs promoting involvement, support and reinforcement of patients	8 (2)	0	9	91	Relevant
Stimulating self-monitoring by patient	6 (2)	9	55	36	*Equivocal*
Outcomes					
Improved intensity of support provided	8 (1)	0	0	100	Relevant
Improved self-management skills of patients	6 (2)	9	45	45	*Equivocal*
Improved health system outcomes (reduced use of healthcare system, less referrals, less follow-up examinations, reduced emergency department visits, reduced hospital (re)admissions)	5 (1)	18	64	18	*Equivocal*



CHAPTER 6

General discussion

BACKGROUND AND OBJECTIVE

Due to the increasing (complex) care needs, problems are expected to arise in the future, such as increasing pressure on care (1), shortages of health personnel (2), and an increase in healthcare costs (3). Current healthcare systems, largely focused on single diseases and acute problems, no longer fit to deliver health (and social) care for the entire population (4-9). Vulnerable groups in healthcare are those at a heightened risk of encountering poor health outcomes and limited access to healthcare services, such as older people, people with low health literacy skills and for people with a diverse ethnic and socioeconomic background (10-12).
IPCC is considered the most effective and appropriate care delivery model for maximizing health, function, and well-being across the life course especially for older people and people with multiple chronic conditions (13, 14). IPCC focuses on the total needs of client, in addition to the services provided by a network of HCPs and organisations (15, 16). Primary care has been shown to be the most efficient setting for delivering high-quality, cost-effective care and has a central role in the delivery of care within an integrated person-centred healthcare system (13). However, IPCC faces several challenges, including lack of coordination between care providers, insufficient training and education opportunities of HCPs, incompatible IT systems for information sharing, lack of sustainable financial resources, and inadequate person-centredness (17). There is a lack of primary care research focusing on IPCC for “hard-to-reach or underserved” groups such as migrants, ethnic minorities, individuals with low educational levels, or low health literacy (18-21). Consequently, their expectations and needs remain unclear, and it is evident that the current healthcare services are often not well-suited for their specific requirements (22-24). Scientific literature on the effectiveness of IPCC is inconclusive, partly due to the heterogeneity in outcomes (25-32).

To provide a more detailed understanding of the interrelatedness of relevant Items that influence the effectiveness of IPCC, the realist research approach is applied in this dissertation. The realist approach aims to highlight the impact of interactions between the contextual factors and the mechanisms on the programme outcomes (33-37). One of the main objectives of realist research is to develop a programme theory, a hypothesised description of how, why, and for whom the complex programme is expected to work in what circumstances (35, 36). The initial programme theory, middle-range programme theory, and refined programme theory represent different stages of developing and refining the understanding of how a programme works.

The overarching objective of this dissertation is to examine the relationships between the context in which IPCC for vulnerable groups in the Netherlands is applied, the mechanisms by which the complex programme (does not) work, and the outcomes resulting from this interaction by establishing a programme theory. To achieve the objective, this dissertation addresses the following sub-questions:

1. What context items, mechanisms and outcomes can be identified in international literature concerning integrated care programmes for community-dwelling frail older people?
2. What is the level of consensus among healthcare providers on the relevance of the context items, mechanisms, and outcomes of integrated care programmes for community-dwelling frail older people, as identified in international literature, for the 'Dutch setting'?
3. What works (or not), why, and in what circumstances concerning person-centred care in primary care for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background, according to international literature?
4. How relevant are the identified context items, mechanism, and outcomes of person-centred care in primary care, according to people with low health literacy skills and healthcare providers in the Netherlands?

The current chapter first summarizes the main findings of this dissertation and its relation to previous research and literature. This is followed by the methodological considerations, including the strengths and limitations of this study. Then recommendations are provided for future research and practice. Finally, this chapter ends with an overall conclusion.

MAIN FINDINGS

Integrated care programmes for community-dwelling frail older people

To identify context items (C), mechanisms (M) and outcomes (O) in the international literature concerning ICPs for community-dwelling frail older people, a rapid realist review was conducted (**Chapter 2, research question 1**). This resulted in a programme theory that demonstrated that ICPs need to approach older people as individuals rather than patients (M), with attention being paid to all aspects of their health on the physical, mental, and social domain (M). This holistic approach can lead to improved quality of life of older people (O). Health education for both older people and their caregivers (C) can improve their understanding of treatment and the care process (M), leading to tailor-made care plans and improved functionality of the older person (O), as well as reduced hospital readmission rates (O). Multidisciplinary core teams (M) consisting of HCPs with various areas of expertise (C) are essential to meet the complex and diverse care needs of older people (O). A clear division of roles and responsibilities, along with awareness of each other's expertise (C) are crucial for effective collaboration (M) and higher satisfaction of older people, caregivers, and HCPs (O). Training and education of HCPs in shared decision-making, empowerment of older people, interprofessional collaboration, and communication (C) can enhance their skills and knowledge (C) and improve the quality of healthcare (O). Through tailored communication (M), preventive home visits and extensive geriatric assessments, admission to a nursing home can be delayed (O) and healthcare utilization can be reduced (O), but this requires organizational alignment (C) and sufficient financial resources (C). For older people admitted to a hospital, an extensive discharge plan, developed by a core team (C) with an expert in discharge planning, in collaboration with the older person and caregivers (C), can promote collaboration between all disciplines involved (M). ICT-systems (C) can also support collaboration and communication (M) among involved HCPs, by sharing information through health-related social networks that allow interactions between older people and HCPs, provide electronic access to guidelines and protocols, and send reminders for older people and HCPs. On the long term, this may be result in lower healthcare costs (O).

This programme theory was then examined in relation to the WHO-IPCHS framework (**Chapter 2**), This showed that the strategies 'creating an enabling environment' (strategy 2) and 'strengthening governance and accountability' (strategy 5) are currently being prioritized in the provision of integrated care for older people. This finding implies that, while progress has been made in integrated care for older people, further development is required since not all five interconnected strategies outlined in the WHO-IPCHS framework are equally prevalent in existing ICPs.

For the second research question, the programme theory of the international RRR was tested and refined by means of a Delphi study with HCPs (**Chapter 3, research question 2**). This demonstrated that successful ICPs rely on well-designed implementation processes (C) that prioritize continuity of care (C). This is particularly crucial due to the growing number of older people (C) and the limited availability of hospital beds (C). Both national and local governments have a significant role to play (C) in promoting the adoption of ICPs, whether through funding and policy promotion or by providing clear guidelines on legislation and regulations related to ICPs (C). HCPs offering self-management support to older people and empowering them to take an active role in their own care have a positive impact the self-management skills (O), mental health (O) and perceived health of older individuals (O). In addition, optimizing the management and monitoring of care activities (M) by establishing a clear portfolio of the older person (C) and ensuring continuous feedback to HCPs (M) may help. Building trust between older people and HCPs (M), integration of case management within ICPs (C) and alignment of health and social care systems (C) may contribute to achieving effective outcomes. Besides improved care processes (O), ICPs cause an increase in end-of-life discussions (O) and a reduction in burden on informal caregiver(s) (O).

Integrated person-centred care for people with a diverse ethnic and socioeconomic background and low health literacy skills

To answer the third research question, a realist review was conducted which resulted in a middle-range programme theory (**Chapter 4, research question 3**). In line with the initial programme theory, the middle-range programme theory established that effective communication tailored to the unique needs and health literacy skills of individuals (M) influences their involvement in the care process (M) and empowers them to actively participate (O) in shared decision-making (M). To ensure such effective communication and cultivate other essential skills, HCPs need to undergo (comprehensive) training (C), embracing a person-centred care approach (M, O) that transcends a mere biomedical, disease-oriented perspective (C). HCPs should be provided with ample time (C) to engage in meaningful discussions regarding the person's wishes and preferences (M). This may lead to higher satisfaction of individuals and HCPs (O) and higher treatment concordance by the person (O). In complex care seamless collaboration of the multiple involved HCPs within teams (C) and across different domains (C) is vital to ensure optimal care coordination (M) and improved health system outcomes (O). Supporting policies (C) play an important role in reinforcing the significance of person-centred care. The initial programme theory was further developed by the findings of the review. It became evident that the respectful attitude of HCPs (M) plays is of crucial importance in establishing a strong therapeutic relationship (M), reinforcing the importance of nurturing a positive and empathetic care environment. By providing education to individuals (C), self-management support (M) and by collaboratively developing personalized care plans (C), HCPs can effectively enhance a person's self-management skills (O). The presence of social support networks (C) may improve the individual's overall health and well-being (O). Furthermore, ensuring sufficient capacity (C), offering access to appropriate and preferred care (C), and leveraging IT and e-health initiatives (C) play a pivotal role in embedding person-centred care practices within primary care settings. Items that were not observed in the realist review, but were emphasised in the initial programme theory were the need to embrace diversity in person-centred care, integrate person-centred care more prominently in medical studies, and establish comprehensive structures and payment models that facilitate person-centred care within primary care settings.

To refine the middle-range programme theory from the international RRR, focus group discussions (FGDs) were held to assess the level of consensus on the relevance of items derived from the RRR for the 'Dutch setting' (**Chapter 5, research question 4**). The findings from the FGDs resulted in the addition of several items to refine the middle-range programme theory from the RRR. The refined programme theory of IPCC unveils that to provide better support to individuals and align care to their needs (O) it is important to develop tailor-made supporting materials in collaboration with the target group (C). Additionally, HCPs should be aware of the person's social circumstances (C) and approach them culturally competent (C) to improve the care experience. Efficient integration of ICT systems (C) In combination with easy access to documents and (audio) recorded consultations (C) plays a pivotal role in accessibility of care (O). Furthermore, the implementation of flexible payment models (C) appears to be a precondition for the implementation of ICPs. If HCPs and individuals cultivate a shared vision (C), individuals feel more confident in asking questions (C) and actively participate in their care journey. HCPs play a crucial role in fostering self-efficacy (O), empowering individuals to take an active role in their own care and improve their health-related quality of life (HRQoL) (O). Over the long term, higher cost-effectiveness of healthcare and higher quality of care (O) can be achieved. One item that was observed In the middle-range programme theory, but was not considered relevant by participants of the FGDs for IPCC In the 'Dutch setting', was ' improved health system outcomes (O)

Key items across programme theories

Several key items are mentioned by both programme theories regarding IPCC for vulnerable groups. The benefit of examining multiple programme theories in this dissertation is that it can provide a more comprehensive and nuanced understanding of how IPCC works for vulnerable groups and in what circumstances. Both programme theories underscore the significance of tailoring care to address the unique needs and preferences of individuals (O). HCPs should strive to deliver holistic care (M) that encompasses the physical, mental, and social aspects of health, recognizing the diversity among individuals (C). The need for comprehensive training of HCPs (C) is emphasized in both programme theories. Equipping professionals with effective communication skills (M) and interprofessional collaboration competencies (M) enables them to deliver high-quality care (O). The recognition of collaboration within multidisciplinary teams and across different domains (C) also emerges as a common theme. The programme theories highlight the essential role of teamwork in achieving optimal care coordination (M), resulting in improved satisfaction of individuals (O). By fostering a clear division in roles and responsibilities (C), as well as promoting awareness of each other's expertise (C), HCPs can effectively collaborate (M) to address complex and diverse care needs. Effective tailored communication (M) serves as a cornerstone in both programme theories. By involving individuals in their care process (M) and empowering individuals (M) shared decision-making (M) can be facilitated. Both programme theories acknowledge the transformative potential of ICT-systems (C). By integrating technology into healthcare practices, accessibility of care (C, O) is enhanced, facilitating seamless communication among HCPs, individuals, and caregivers. Through information sharing (C), health-related social networks (C), and electronic access to guidelines and protocols (C), individuals are empowered to actively engage in their care journey (O). The programme theories underscore the role of education to people (C) and active involvement in their care process (M). By providing self-management support to people (M) and encouraging them to ask questions (C) their self-efficacy can be enhanced (O). Shared goal setting (C), personalized care planning (C), and a shared vision (C) can improve their overall health and well-being (O).

DISCUSSION OF MAIN FINDINGS

In the realm of IPCC, understanding the principles and initiatives that effectively work in practice and why they work presents a significant challenge.

Theoretical Frameworks for Integrated Person-Centred Care

Numerous frameworks and models have been developed to support the implementation of IPCC (38). Notable examples include the Chronic Care Model (39), The Rainbow Model of Integrated Care (40), The WHO-IPCHS framework (41), the PC-IC model (42), and The SELFIE framework (43). These frameworks provide a structured approach to designing, delivering, and/or evaluating integrated care interventions, considering various components and factors crucial to their success. While these frameworks have made valuable contributions, there has been limited success in their widespread adoption and their ability to address the complexity inherent in IPCC remains limited (6, 13, 44). Although they acknowledge the existence of complexity, their approaches often fall short in articulating or disentangling the complex dynamics and the interrelationships between the multitude of factors involved. The study of complexity in health services and systems requires a paradigm shift in research quality standards. Developing a systems mindset is vital for navigating the complexities of IPCC (45). Researchers must engage in profound conceptualization, knowledge generation, and pragmatic adaptation to changing contexts (46). Complexity science provides an analytical lens that recognizes the dynamic interrelationships within a system, urging researchers to move away from closed system assumptions and embrace the unpredictability and adaptability of real-world healthcare settings. Recognizing the changing interrelationships within the system and being adaptable to unexpected changes are essential elements (45). By embracing complexity and employing collaborative and reflexive approaches, HCPs and researchers together can negotiate good compromises, foster creative thinking, and strive for continuous improvement.

Theory-Based Research

Insufficient reporting of programme characteristics and implementation contexts hinders synthesis and transferability to similar circumstances (30, 47). Furthermore, amidst ongoing debates on achieving seamless care and struggles to explain heterogeneous outcomes, the need for theoretical guidance becomes essential (48, 49). To unravel the intricate workings of complex programmes such as IPCC, an increasing reliance is being placed on theory-based research (50). Theory-based approach employ explicit theories of change to draw conclusions about the contribution of programmes to observed results and examines collections of assumptions and hypotheses, forming a logical framework for empirical testing (51, 52). Theory-based research can play a pivotal role in enhancing our understanding of (the complexity of) IPCC. Theory-based evaluation encompasses two vital components: conceptual and empirical. Conceptually, it entails articulating a policy or programme theory that underlies the intervention. From an empirical standpoint, its objective is to test this theory and Investigate the causal relationship between policies or programmes and their intended or observed outcomes (52). Theory-based research may empower researchers, care providers, policy makers, programme managers and other stakeholders to make informed decisions and foster the ongoing development of effective integrated care practices (52).

Realist approaches offer powerful principles for building and testing programme theories. Unlike traditional approaches that focus solely on observable outcome patterns or subjective interpretations, realist approaches recognize that the realities of policies or programmes cannot be reduced to these simplistic explanations. By delving beyond surface-level observations, realist research uncovers the underlying mechanisms, contextual factors, and interactions that shape the outcomes of integrated care interventions (53). Integrated care is multifaceted and intricate making it a suitable subject for realist research approaches. Realist research approaches offer a means to generate stronger theoretical contributions in the field of integrated care. By going beyond simple cause-and-effect relationships, realist approaches shed light on the underlying theories and mechanisms that drive the success of integrated care initiatives (54, 55). Integrated care, often misconceived as a mere linkage of existing services, requires a more comprehensive understanding of the interaction of various factors. Numerous studies have examined individual components of integrated care in isolation (56-60). However, integrated care encompasses a coherent set of methods and models that foster connectivity, alignment, and collaboration within and between care sectors (61). This dissertation aims to emphasize the significance of coherence of items in achieving effective IPCC. Moreover, it seeks to demonstrate the value of a theory-based approach when evaluating complex programmes holistically, rather than perceiving them as independent interventions.

Findings in relation to previous research

A report of the Dutch Council of Public Health & Society highlights continuity and a holistic view as key primary care values (62). Continuity entails ongoing contact between patients and caregivers, fostering trust and understanding, while a holistic view integrates context knowledge with physical, psychological, and social factors (62-65). The report also mentions a coherence or overview of the diverse problems and stakeholders involved in an individual's care. Given the breadth of requests received by primary care providers, cultivating close relationships with other care providers and society becomes crucial for collaboration and referrals. Overview of the diverse problems also pertains to understanding the various problems a person encounters, ensuring well-connected care chains, smooth transitions, and clarity for the patient

(63). The findings of this dissertation also align with the strategies proposed in the WHO's report on strengthening the potential of primary healthcare (66). To contribute to the transformation and increased resourcing of primary healthcare, the model of care needs to be contextualized and tailored to diversity of population needs across communities. Also, in response to the interconnected (complex) health and social needs of vulnerable groups, integrated multidisciplinary primary healthcare teams and a networked approach hold great potential. To meet the challenges and complexities of multidisciplinary primary healthcare, the training of HCPs must be re-evaluated. It is important to incorporate both clinical and non-clinical competencies including the person's needs, continuity, coordination of care, teamwork and interpersonal communication. Governance arrangements at the national and subnational levels play a crucial role in successful primary healthcare. Adopting user-friendly integrated data systems, enabling remote consultations, supporting multidisciplinary teamwork through interprofessional health records, facilitating population health risk assessment, and providing self-diagnosis and management tools can support primary care to become more accessible, efficient, and person-centred. The WHO report also suggests the creation of stronger financial incentives to encourage the provision of services at the primary level (66). By aligning financial rewards with care delivery, primary healthcare can be further supported and resourced. Mukumbang (2022) identified mechanisms of community integrated healthcare services at different levels (i.e., system, provider, user level), including shared vision and goals, shared learning and empowerment, and trust and perceived support perceived interpersonal trust, user-empowerment, perceived accessibility to required services and self-efficacy (67). Similarly, a study examining driving factors of successful implementation of integrated care across eight European countries reveals that cultivating a multidisciplinary team culture with mutual recognition of roles, securing long-term funding, implementing innovative payment systems to overcome fragmented financing of healthcare and social services, and employing ICT to enhance collaboration and communication, are significant mechanisms (68). A theoretical logic model of integration in healthcare outlines various forms of integration and contextual factors that influence integration and its desired outcomes, such as health outcomes, clinical cost, experience of the person, and provider satisfaction (69). Organizational features, including governance structures and financial management, play significant roles, while interpersonal and clinical forms focus on people and processes like teamwork and shared care plans. Contextual factors encompass both external and internal organizational factors, including financial arrangements (69). A report by the National Academy of Medicine emphasizes the need for IPCC as a catalyst for long-term, transformational change (13). It advocates for care coordination by responsible providers and interdisciplinary teams, collaborative relationships with social service providers, comprehensive and shared health records, that include a care plan based on the person's goals, preferences, and values.

Integrated person-centred care in practice in the Netherlands

Countries around the world are actively exploring innovative models to enhance care integration. Studies have explored how hey were developed, implemented, sustained, and their impact on the broader healthcare landscape. Notable examples from the Netherlands, Denmark, Germany, Italy, and Scotland have demonstrated evidence of advancements in various aspects of service delivery and patient outcomes (70, 71).

In 2015, the Dutch government implemented long-term care (LTC) reforms to ensure the sustainability of LTC services (72). These reforms aimed to improve coordination between LTC, health, and social care sectors by involving health insurers and municipalities in procurement. General practitioners (GPs) acknowledged the attainability of the reform's ideals, including promoting self-reliance, and observed positive outcomes, such as increased engagement among HCPs and improved integration of medical and social care through social support teams (73). However, challenges persisted, such as coordination issues, inadequate funding for team meetings, and fragmented home care, largely due to insufficient consideration of the local context during implementation (73). GPs play a crucial role in multidisciplinary teams for vulnerable groups, demonstrating their ability to see the bigger picture (74). Key activities for a successful GP role include networking, team building, and integrating care elements. GPs act as spokespersons for HCPs, advocating for comprehensive care and leading the formation of multidisciplinary teams. In collaboration with nurses, GPs ensure holistic and person-centred care for patients by integrating the actions of the team (74). GPs acknowledge the importance of integrated multidisciplinary care for socially vulnerable populations. GPs perceive their role as coordinators and connectors, although the specific interpretation of this role varies among practitioners. However, GPs face obstacles in achieving integrated care, such as a lack of time for patient contact and collaboration, as well as difficulties in communicating with low-literacy individuals and migrants (75).

IPCC has become a prominent focus in the Dutch healthcare system, particularly in relation to vulnerable populations. Numerous initiatives have been developed and implemented to promote integrated care practices, reflecting a growing emphasis on providing comprehensive and person-centred healthcare in the Netherlands.
An example of such an initiative is 'Ketenzorg Ontketend' ('Optima Forma'), which merges existing single disease ICPs, such as those for diabetes mellitus type 2, chronic obstructive pulmonary disease (COPD), and cardiovascular disease into a comprehensive ICP for individuals with chronic conditions and multimorbidity (76). The goal of this initiative is to provide person-centred chronic care that considers the overall context of the person (76).
In 2022, the Integral Care Agreement (Integraal Zorgakkoord, IZA) was published in the Netherlands (77). The IZA aims to ensure good, accessible, and affordable care for the future. In line with this objective, the initiative 'Meer Tijd Voor De Patient' ('More Time

For The Patient', MTVDP) has been introduced. The concept behind MTVDP is that longer consultation times enable faster and more accurate identification of patients' core care needs, leading to improved follow-up care organization. It also leads to a reduced number of referrals to secondary care, limited medication and diagnostics, and improvement of the quality of care. MTVDP has been implemented and tested in over 100 practices over the past five years, demonstrating its potential benefits (78). It has been agreed in the IZA that from 2024 health insurers will facilitate GP practices and regional GP organisations that focus on the initiative MTVDP (78-80). The successful implementation of MTVDP relies on several key factors, which include fostering cooperation with local hospitals and social care, ensuring staff support and adapting patient care accordingly, securing adequate funding for adjustments, and appointing a project coordinator from a relevant organization (81, 82).

The so-called 'PlusPraktijk' builds upon the MTVDP pilot and focuses on collaborative efforts to enhance innovative GP care (83). One notable aspect is the adoption of a distinct communication approach by one of the participating practices, involving the use of open-ended questions during consultations. Through this approach, physicians have achieved a reduction in referrals (84).

Another initiative that has an integrated approach is ' Krachtige Basiszorg' ('Robust Primary Care') (85). 'Krachtige Basiszorg' in an initiative aimed at people with high health risks facing challenges in multiple areas of life. It encourages collaboration among healthcare, social welfare, and prevention professionals to improve health outcomes, quality of care, job satisfaction, and cost-effectiveness. Two key elements contribute to its success: structural cooperation between professionals and social care, supported by regular consultations and work agreements, and allocating more time to people while considering holistic health aspects using the 4D model (85-87).

When reflecting on 10 years of integration policies of the Netherlands, both progress and challenges are witnessed. It becomes evident that while system reforms and legislation have contributed to positive changes, they alone cannot unravel the web of challenges within health, social, and long-term care. The complexities inherent in these domains persist as obstacles to seamless integration across sectors and governmental layers (88).

METHODOLOGICAL CONSIDERATIONS

Realist research

Realist research is gaining popularity as it offers a more comprehensive understanding of complex programmes beyond simple assessments of effectiveness. However, the application of realist research is still limited, possibly due to a lack of awareness or training in mixed methods and difficulties in accessing and analysing relevant data (89). Realist research involves the active involvement of stakeholders and takes a holistic perspective to identify unintended consequences, recognizing that interventions do not operate in isolation but are part of a larger system of factors that can influence outcomes (90, 91). It requires a deep understanding of context and theory, which can pose challenges for researchers and practitioners lacking expertise in these areas. The approach can be time-consuming requiring significant resources to collect and analyse data, consultations with stakeholders, and iterative theory building and testing, which may limit its feasibility for some research projects (92). Realist research differs from traditional systematic reviews in its flexible and iterative nature, allowing for modifications to the research design based on emerging insights and data. This flexibility is seen as a strength, enabling innovation and optimizing outcomes (93). Realist research should be considered a “way of thinking”, rather than a methodological guidebook, that can improve knowledge translation and facilitate decision making (36, 94, 95). While guidance and reporting standards for realist research are provided, determining inclusion based on relevance and rigor rather than rigid inclusion criteria can be both liberating and challenging, requiring subjective judgment (94, 96-101). Realist research may also include useful data from methodologically weak studies, which would not be included in a traditional systematic review (102). Data extraction in realist research is theory-driven and tailored to each study, rather than following a standard form (103). The goal is to collect data that provides conceptual richness and contextual thickness, offering detailed descriptions of programme conditions and underlying thoughts and assumptions (100, 104). However, the emphasis on context limits the generalizability of findings and makes it challenging to apply results from one realist study to other settings or populations (96). Realist research can be challenging and demanding, requiring a balance between systematic and transparent approaches and creative and intuitive thinking (105). The iterative nature of the process can lead to uncertainty, and the quality of available data may restrict the study’s scope, especially regarding context and mechanisms (106). However, as realist approaches are increasingly applied for evaluating complex healthcare interventions, they are also increasingly used to explore the functioning of integrated care, its effectiveness (or lack thereof), and the specific contexts and patient populations in which it thrives (30, 107-113).

Mixed methods research

Mixed methods research (MMR) is increasingly used in health services research (HSR) and integrates qualitative and quantitative approaches, allowing researchers to capitalize on the strengths of each method while compensating for their weaknesses (114). MMR has also emerged as a powerful approach for studying integrated care (115-120). By combining diverse data sources, such as Delph-study and FGDs in this dissertation, researchers can obtain a comprehensive and nuanced understanding of the research topic (121-123). Data triangulation is a key component to combine quantitative and qualitative data in a single study (114, 124, 125). It entails the use of multiple data sources, methods, and perspectives to corroborate and validate the research findings (126). The triangulation of data from these different sources contributes to the validation of findings, ensuring consistency and reliability in the results (114). Data triangulation plays a crucial role in enhancing the trustworthiness of research findings. Trustworthiness can be defined as the degree to which the investigative process establishes the credibility, transferability, and confirmability of the study's findings, ensuring the reliability of its conclusions and facilitating the replication of the processes and results (127). By cross-validating and corroborating data from different sources and perspectives, triangulation reduces the potential for bias and increases confidence in the outcomes of the study (128, 129). Despite the growing body of literature on MMR in HSR, studies often lack detailed descriptions of the methodological approach and procedures for triangulating quantitative and qualitative data (130-133). It is important for researchers to provide transparent and thorough explanations of their methods to enhance the trustworthiness of their findings.

Limitations

Limitations of this dissertation should be acknowledged and discussed. Firstly, it is important to recognize that the engagement of participants in both the Delphi panel (Chapter 3) and the FGDs (Chapter 5) may have introduced a bias towards individuals with excessive interest in the topic IPCC. Consequently, the perspectives shared by these participants might not fully represent the views of 'average' HCPs with less passion for IPCC. Another limitation related to the number of FGDs conducted in Chapter 5, raising questions about data saturation. A total of two FGDs were held per target population, while it is recommended to conduct two to three FGDs to capture 80% of the themes and three to six groups for 90% of the themes (134). Additionally, the inclusion criteria for participants in FGDs 1 and 2, including individuals with low health literacy skills, were not clearly specified. The recruitment process relied on convenience sampling, which may have introduced selection bias and limited the diversity of perspectives represented in the discussions. Furthermore, it is important to note that the scope of this dissertation is limited to theoretical exploration and does not include an investigation of the actual implementation of person-centred integrated care in practice. Consequently, the extent to which a person-centred integrated approach is present in real-world healthcare settings and the conditions necessary for its success remain unexplored.

RECOMMENDATIONS

Research

The studies included in this dissertation have yielded several recommendations for future research. Firstly, to develop more comprehensive and robust programme theories, additional realist research is needed that focuses on the theoretical underpinning of the interrelatedness of factors (C, M, O). Current traditional literature contains limited information on the interaction of items, as the emphasis is placed on outcomes, rather than why and how these outcomes were achieved (96, 103, 135). This dissertation provides a valuable contribution towards achieving the desired outcomes by identifying an optimal combination of context items, mechanisms, interventions, and actors, as IPCC varies across settings. Additionally, more data on the health and healthcare use of vulnerable groups and the relationships of relevant factors are necessary, as these groups are underrepresented in research. Secondly, setting-specific validation of items needs to take place by involving stakeholders (e.g., people with care needs, informal caregivers, HCPs). Thirdly, the items on which no consensus was found need to be further investigated to understand why they were found irrelevant and the reasons behind it. This may help to explore whether IPCC in the Netherlands is conceptually different from elsewhere (or not) and why. It is also important to investigate to what extent the items considered relevant to the 'Dutch setting' have already been (collectively) implemented, applied, and reached the intended outcomes within their context and the effectiveness of IPCC, to validate the programme theories. These recommendations will enhance our understanding of how IPCC is applied in different settings and its effectiveness and support in improving IPCC for vulnerable groups like frail elderly, ethnic minorities, or people with low (health) literacy skills in the Netherlands.

Practice

Next to recommendations for research, the studies in this dissertation lead to several recommendations for practice. IPCC for vulnerable groups can be improved at different levels of the system, including micro level (individual care), meso level (organizational level), and macro level (policy level). Recommendations for each level are provided in the remainder of this paragraph. Within realist research, understanding complex programmes requires the consideration of all components together, rather than in isolation. This approach acknowledges that programmes are not made up of separate, distinct elements, but rather that these elements interact in complex ways. When making recommendations for practice and policy based on realist research, it is important to focus on the complex programme as a whole, rather than on individual components. This means that recommendations must consider how all the elements work together, and how they interact with the broader context in which the programme is implemented.

Micro level

At the micro level, HCPs need to prioritize (continuous) education and training in empathic and person-centred culturally sensitive care, effective communication, adopt a holistic approach, and apply self-reflection. They should be aware of available resources to access knowledge and expertise on differences in morbidity and treatment related to gender, health skills, or ethnicity. Building relationships with partners in primary and secondary care and social care is important for seamless coordination of health and social services. HCPs should get to know other providers during their training to stimulate interprofessional collaboration at a very early stage. Also, empathic, comprehensible communication with simulation patients should be practiced from the start, whereby people with limited health literacy skills and people with a migration background need to play the role of simulation patients (136-138). People and communities should look for possibilities and solutions to improve their care experience and become more proactive about their own goals, interests, and support needs to improve their own involvement in the care process. They can do this, for example, by preparing for consultations with the HCP, asking multiple questions about the care process, taking family or friends to the consultation for support, booking a double appointment with the HCP, and searching for relevant information on the internet.

Meso level

At the meso level, organizations need to formulate a broad and shared ambition and work towards this ambition integrally in policy, commissioning, and implementation. Collaboration with relevant partners in secondary care, social care, and/or public health can facilitate more and better connections. For example, (local) prevention agreements can be accompanied by bundled budgets for all relevant domains, including social, work, and health. Involvement of people in the design and organization of practice and care is essential to establish an overarching and shared vision of IPCC that includes the underlying aims and ambitions of individuals and their caregivers to ensure better alignment of care. To provide a tailor-made approach for vulnerable groups, stakeholders need to differentiate in terms of target populations. Registering and sharing knowledge about the relevant background information of a person, for example, by registering this information in the GP information system with International Classification of Primary Care (ICPC) codes, can improve care for vulnerable groups. Stimulating and facilitating training and education of HCPs in the field of person-centred, culturally competent care, and comprehensible communication is an important component. This can help to promote a more inclusive and welcoming healthcare environment for all people. Ambitions to reduce health inequalities should ideally be financed for a long period of time. This task is of a structural nature and requires time to achieve the desired results.

To promote regional and local collaboration and as part of the ‘Juiste Zorg op de Juiste Plek’ (‘Right Care at the Right Place’) initiative, a Dutch movement aimed at providing high-quality and meaningful care individuals with medical conditions, the initiative ‘regiobeelden’ (‘regional overviews’) was established. These ‘regional overviews’ overviews offer a reliable depiction of current and future healthcare needs of the population, which subsequently inform the development of ‘regioaanpak’ (‘regional approach’). Research on regional collaboration reveals ‘regional overviews’ and ‘regional approaches’ can significantly contribute to successful collaborations, provided that everyone embraces and fulfils their role and is able to do so. The key question here is whether the ‘regional overviews can strike a balance between capturing the needs of individuals and enabling healthcare organizations to respond effectively (139).

Macro level

On a macro level, recommendations relate to those who direct policy, financing, and organization of care, such as the Ministry of Health, Welfare and Sports, the National Health Care Institute and health insurers as well as associations of care professionals and patients. The importance of integrated PCC care with a focus on diversity should be promoted and concretized in policy. This can be achieved by, among other things, stimulating the development of integrated multidisciplinary care standards instead of disease-specific standards, developing and implementing quality indicators for person-centredness, comprehensible communication and accessibility of care, especially for people with limited health skills. Requirements should also be set regarding guideline development and the training of HCPs. Furthermore, breaking down barriers between the financing of secondary and primary care and between healthcare and the social domain can promote integrated cross-domain care. This can be achieved by developing policies that support the integration of healthcare services and social services, ensuring that all individuals receive high-quality, coordinated care regardless of where they access the system. Important developments that have taken place in the Netherlands with initiatives such as the ‘Passende Zorg’ (‘Appropriate Care’) programme by the National Health Care Institute and the Integral Care Agreement (“Integraal Zorgakkoord”). These initiatives acknowledge the significance of delivering integrated care that caters to the needs and conditions of diverse patient populations and strive to ensure that high-quality, accessible, and affordable care.

FINAL CONCLUSION

IPCC for vulnerable groups is complex and multifaceted and cannot be reduced to simple cause-and-effect relationships. The effectiveness of complex programmes, such as IPCC, varies and depends on specific contexts and mechanisms in different settings. The findings of this dissertation provide deeper insights into interrelatedness of items that influence effectiveness of IPCC. The findings emphasize the significance of understanding the relationships between context, mechanisms, and outcomes, recognizing that they form a larger interconnected system rather than acting independently. By comprehensively considering the interconnectivity of factors, such as social, cultural, and organizational elements, the impact of a programme can be better grasped. The realist approach enhances our understanding of the complex nature of programmes and promotes the development of programmes that are responsive to the diverse needs and contexts of individuals and communities. Furthermore, this knowledge can inform the design and implementation of future person-centred programmes, leading to more effective and tailored approaches that improve health outcomes.

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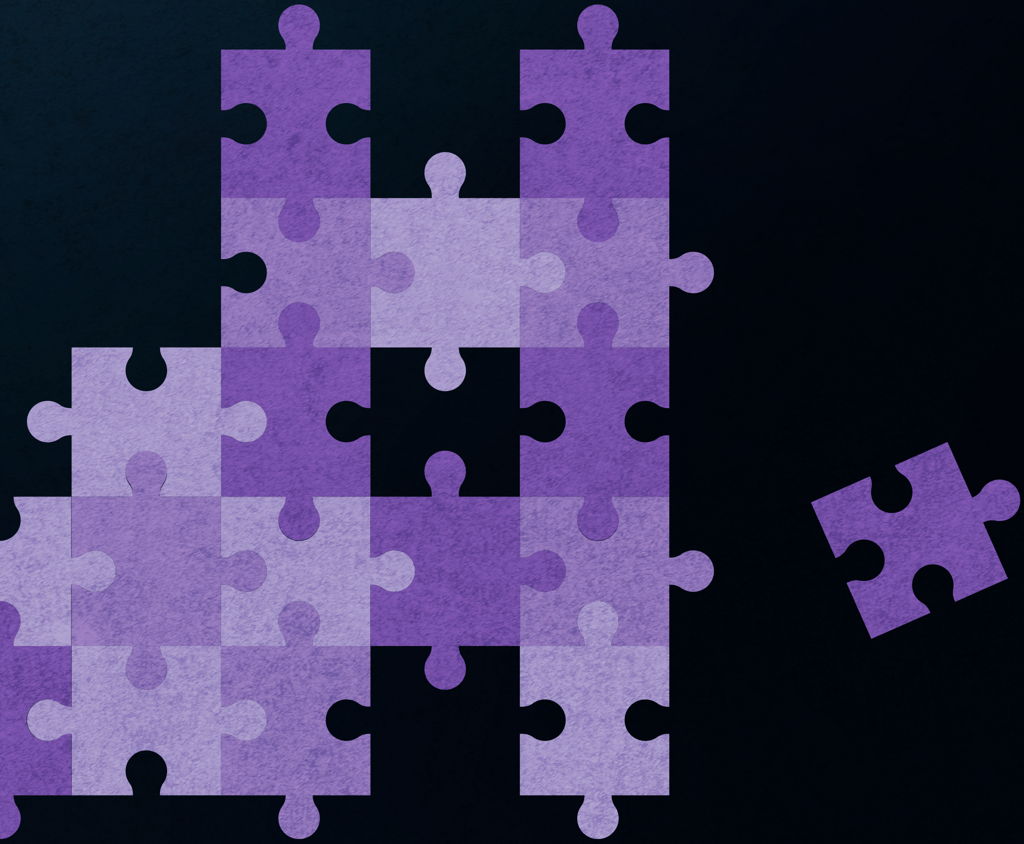

CHAPTER 7

Appendices

SUMMARY

Introduction

Due to the increasing (complex) care needs, current healthcare systems, still largely focused on single diseases and acute problems, are confronted by various problems, such as increasing pressure on care, shortages of health personnel, and increasing healthcare costs. They no longer fit to deliver health (and social) care for the entire population. In healthcare, vulnerable groups are those at a heightened risk of encountering poor health outcomes and limited access to healthcare services, such as older people, people with low health literacy skills and for people with a diverse ethnic and socioeconomic background.

Integrated person-centred care (IPCC) is considered the optimal care delivery model for maximizing health and well-being, particularly for older individuals and those with multiple chronic conditions. IPCC focuses on the total needs of client, in addition to the services provided by a network of healthcare providers (HCPs) and organisations. Primary care is acknowledged as the most efficient and cost-effective setting for delivering high-quality care and plays a central role in the delivery of care within an integrated, person-centred healthcare system. However, IPCC faces several challenges, including lack of coordination among care providers, insufficient training for HCPs, incompatible information (and communication) technology (I(C)T) systems, lack of sustainable financial resources, and inadequate person-centredness. Moreover, scientific literature on the effectiveness of IPCC is inconclusive, partly due to the heterogeneity in outcomes. Also, research on IPGZ in primary care for vulnerable groups is lacking, resulting in unknown expectations and needs, and unsuitable healthcare services.

To provide a more detailed understanding of the interrelatedness of relevant items that influence the effectiveness of IPCC, the ‘realist research’ approach is used in this dissertation. Realist research aims to develop a programme theory that explains how, why, and for whom a complex programme is expected to work in what circumstances. The initial programme theory, middle-range programme theory, and refined programme theory represent different stages of developing and refining the understanding of how a program works.

Objective

The overarching objective of this dissertation is to examine the relationships between the context in which IPCC for vulnerable groups in the Netherlands is applied, the mechanisms by which the complex programme (does not) work, and the outcomes resulting from this interaction, by establishing a programme theory. To achieve the objective, this dissertation addresses the following sub-questions:

1. What context items, mechanisms and outcomes can be identified in international literature concerning integrated care programmes for community-dwelling frail older people?

2. What is the level of consensus among healthcare providers on the relevance of the context items, mechanisms, and outcomes of integrated care programmes for community-dwelling frail older people, as identified in international literature, for the ‘Dutch setting’?
3. What works (or not), why, and in what circumstances concerning person-centred care in primary care for people with low health literacy skills and for people with a diverse ethnic and socioeconomic background according to international literature?
4. How relevant are the identified context items, mechanism, and outcomes of person-centred care in primary care, according to people with low health literacy skills and healthcare providers in the Netherlands?

Main findings

Integrated care programmes for community-dwelling frail older people

To identify context items (C), mechanisms (M) and outcomes (O) in the international literature concerning integrated care programmes (ICPs) for community-dwelling frail older people, a rapid realist review (RRR) was conducted (**Chapter 2, research question 1**). This resulted in a programme theory that demonstrated that ICPs need to approach older people as individuals rather than patients (M), with attention being paid to all aspects of their health on the physical, mental, and social domain (M). This holistic approach can lead to improved quality of life of older people (O). Health education can help both older people and their caregivers (C) gain a better understanding of the treatment and the care process (M), leading to tailor-made care plans and improved functioning of the older person (O), as well as reduced hospital readmissions (O). Multidisciplinary core teams (M) consisting of HCPs with various areas of expertise (C) are essential to meet the complex and diverse care needs of older people (O). A clear division of roles and responsibilities, along with awareness of each other’s expertise (C) are crucial for effective collaboration (M) and higher satisfaction of older people, caregivers, and HCPs (O). Training of HCPs in shared decision-making, empowerment of older people, interprofessional collaboration, and communication (C) can enhance their skills and knowledge (C) and improve the quality of healthcare (O). Through tailored communication (M), preventive home visits, and extensive geriatric assessments, admission to a nursing home can be delayed (O) and healthcare utilization can be reduced (O), but this requires organizational alignment (C) and sufficient financial resources (C). For older people admitted to a hospital, an extensive discharge plan, developed by a core team (C) with an expert in discharge planning, in collaboration with the older person and caregivers (C), can promote collaboration between all disciplines involved (M). ICT-systems (C) can also support collaboration and communication (M) among involved HCPs, by sharing information through health-related social networks that allow interactions between older people and HCPs, provide electronic access to guidelines and protocols, and send reminders for older people and HCPs. On the long term, this may be result in lower healthcare costs (O).

This program theory was then examined in relation to the framework of the World Health Organisation (WHO) for integrated person-centred health services (IPCHS) (**Chapter 2**). This showed that the strategies 'creating an enabling environment' (strategy 2) and 'strengthening governance and accountability' (strategy 5) are currently being prioritized in the provision of integrated care for older people. This finding implies that while progress has been made in integrated care for older people, further development is required, as not all five interconnected strategies outlined in the WHO-IPCHS framework are equally prevalent in existing ICPs.

For the second research question, the programme theory of the international RRR was tested and refined by means of a Delphi study with HCPs (**Chapter 3, research question 2**). This demonstrated that successful ICPs rely on well-designed implementation processes (C) that prioritize continuity of care (C). This is particularly crucial due to the growing number of older people (C) and the limited availability of hospital beds (C). Both national and local governments have a significant role to play (C) in promoting the adoption of ICPs, whether through funding and policy promotion or by providing clear guidelines on legislation and regulations related to ICPs (C). HCPs offering self-management support to older people and empowering them to take an active role in their own care have a positive impact the self-management skills (O), mental health (O) and perceived health of older individuals (O). In addition, optimizing the management and monitoring of care activities (M) by establishing a clear portfolio of the older person (C) and ensuring continuous feedback to HCPs (M) may help. Building trust between older people and HCPs (M), integration of case management within ICPs (C) and alignment of health and social care systems (C) may contribute to achieving effective outcomes. Besides improved care processes (O), ICPs cause an increase in end-of-life discussions (O) and a reduction in burden on informal caregiver(s) (O).

Integrated person-centred care for people with a diverse ethnic and socioeconomic background and low health literacy skills

To answer the third research question, a realist review was conducted which resulted in a middle-range programme theory (**Chapter 4, research question 3**). In line with the initial programme theory, the middle-range programme theory established that effective communication tailored to the unique needs and health literacy skills of individuals (M) influences their involvement in the care process (M) and empowers them to actively participate (O) in shared decision-making (M). To ensure such effective communication and cultivate other essential skills, HCPs need to undergo (comprehensive) training (C), embracing a person-centred care approach (M, O) that transcends a mere biomedical, disease-oriented perspective (C). HCPs should be provided with ample time (C) to engage in meaningful discussions regarding the person's wishes and preferences (M). This may lead to higher satisfaction of individuals and HCPs (O) and higher treatment concordance by the person (O). In complex care seamless collaboration of the multiple involved HCPs within teams (C) and across different domains (C) is vital to ensure optimal care coordination (M) and improved health system outcomes (O). Supporting policies (C) play an important role in reinforcing the significance of person-centred care. The initial programme theory was further developed by the findings of the review. It became evident that the respectful attitude of HCPs (M) plays is of crucial importance in establishing a strong therapeutic relationship (M), reinforcing the importance of nurturing a positive and empathetic care environment. By providing education to individuals (C), self-management support (M) and by collaboratively developing personalized care plans (C), HCPs can effectively enhance a person's self-management skills (O). The presence of social support networks (C) may improve the individual's overall health and well-being (O). Furthermore, ensuring sufficient capacity (C), offering access to appropriate and preferred care (C), and leveraging IT and e-health initiatives (C) play a pivotal role in embedding person-centred care practices within primary care settings. Items that were not observed in the realist review, but were emphasised in the initial programme theory were the need to embrace diversity in person-centred care, integrate person-centred care more prominently in medical studies, and establish comprehensive structures and payment models that facilitate person-centred care within primary care settings.

To refine the middle-range programme theory from the international RRR, focus group discussions (FGDs) were held to assess the level of consensus on the relevance of items derived from the RRR for the 'Dutch setting' (**Chapter 5, research question 4**). The findings from the FGDs resulted in the addition of several items to refine the middle-range program theory from the RRR. The refined programme theory of IPCC unveils that to provide better support to individuals and align care to their needs (O) it is important to develop tailor-made supporting materials in collaboration with the target group (C). Additionally, HCPs should be aware of the person's social circumstances (C) and approach them culturally competent (C) to improve the care experience. Efficient integration of ICT systems (C) In combination with easy access to documents and (audio) recorded consultations (C) plays a pivotal role in accessibility of care (O). Furthermore, the implementation of flexible payment models (C) appears to be a precondition for the implementation of ICPs. If HCPs and individuals cultivate a shared vision (C), individuals feel more confident in asking questions (C) and actively participate in their care journey. HCPs play a crucial role in fostering self-efficacy (O), empowering individuals to take an active role in their own care and improve their health-related quality of life (HRQoL) (O). Over the long term, higher cost-effectiveness of healthcare and higher quality of care (O) can be achieved. One item that was observed In the middle-range programme theory, but was not considered relevant by participants of the FGDs for IPCC In the 'Dutch setting', was ' improved health system outcomes (O).

Key items across programme theories

Several key items are mentioned by both programme theories regarding IPCC for vulnerable groups. The benefit of examining multiple program theories in this dissertation is that it can provide a more comprehensive and nuanced understanding of how IPCC works for vulnerable groups and in what circumstances. Both program theories underscore the significance of tailoring care to address the unique needs and preferences of individuals (O). HCPs should strive to deliver holistic care (M) that encompasses the physical, mental, and social aspects of health, recognizing the diversity among individuals (C). The need for comprehensive training of HCPs (C) is emphasized in both programme theories. Equipping professionals with effective communication skills (M) and interprofessional collaboration competencies (M) enables them to deliver high-quality care (O). The recognition of collaboration within multidisciplinary teams and across different domains (C) also emerges as a common theme. The program theories highlight the essential role of teamwork in achieving optimal care coordination (M), resulting in improved satisfaction of individuals (O). By fostering a clear division in roles and responsibilities (C), as well as promoting awareness of each other's expertise (C), HCPs can effectively collaborate (M) to address complex and diverse care needs. Effective tailored communication (M) serves as a cornerstone in both program theories. By involving individuals in their care process (M) and empowering individuals (M) shared decision-making (M) can be facilitated. Both program theories acknowledge the transformative potential of ICT-systems (C). By integrating technology into healthcare practices, accessibility of care (C, O) is enhanced, facilitating seamless communication among HCPs, individuals, and caregivers. Through information sharing (C), health-related social networks (C), and electronic access to guidelines and protocols (C), individuals are empowered to actively engage in their care journey (O). The program theories underscore the role of education to people (C) and active involvement in their care process (M). By providing self-management support to people (M) and encouraging them to ask questions (C) their self-efficacy can be enhanced (O). Shared goal setting (C), personalized care planning (C), and a shared vision (C) can improve their overall health and well-being (O).

Recommendations

Research

Recommendations for future research based on this dissertation include additional realist research focusing on the theoretical underpinning of the interrelatedness of items (C. M, O) to develop more robust program theories. This dissertation provides a valuable contribution towards achieving the desired outcomes by identifying an optimal combination of context items, mechanisms, interventions, and actors, as IPCC varies across settings. In addition, there is a need for more data on the health of and healthcare use by underrepresented vulnerable groups and their relationships with relevant items. It is also recommended to involve stakeholders (e.g., people with care needs, informal caregivers, HCPs) for setting-specific validation of items. Moreover, the items on which no consensus was found need to be further investigated to understand why they were found irrelevant and the reasons behind it. This may help to explore whether IPCC in the Netherlands is conceptually different from elsewhere or not and why. It is also recommended to investigate to what extent the items considered relevant to the 'Dutch setting' have already been (collectively) implemented, applied, and reached the intended outcomes within their context and the effectiveness of IPCC, to validate the programme theories.

Practice

This dissertation also leads to recommendations for practice at various levels of the system (i.e., micro, meso, macro level).

At the micro level (individual care), HCPs should prioritize training in empathic and person-centred (culturally sensitive) care, effective communication, holistic approach, and self-reflection. They should be aware of available resources to access knowledge and expertise on differences in morbidity and treatment related to gender, health skills, or ethnicity. Building relationships with primary, secondary, and social care partners is crucial for coordinated services. Interprofessional collaboration should be encouraged early in training. Practicing empathic communication with simulation patients, including those with limited health literacy or migration background, is recommended. Individuals and communities can improve their care experience by being proactive, preparing for consultations, asking questions, bringing support, booking longer appointments, and seeking relevant information online.

Organizations at the meso level should have a shared ambition and work integrally towards it in policy, commissioning, and implementation of IPCC. Collaboration with relevant partners can enhance connections, such as through bundled budgets and prevention agreements. Involvement of individuals is crucial for designing person-centred care aligned with their aims and ambitions. Tailored approaches for vulnerable groups and sharing background information of individuals can improve care. Ambitions to reduce health inequalities should ideally be financed for a long period of time. To promote regional and local collaboration, as part of the "Right Care at the Right Place" movement, "regional overviews" ('regiobeelden') and regional approaches ('regioaanpakken') can be set up.

On a macro level, recommendations relate to those who direct policy, financing, and organization of care, such as the Ministry of Health, Welfare and Sports, the National Health Care Institute and health insurers as well as associations of care providers, older people, and other vulnerable groups. It is crucial to promote and implement IPCC with a focus on diversity in policy. This includes developing multidisciplinary care standards, quality indicators for person-centredness, and accessible care. Guidelines and healthcare provider training should align with these principles. Breaking down financial barriers between secondary and primary care and healthcare and the social domain is essential for integrated, cross-domain care. Initiatives like the Appropriate Care programme ('Passende zorg') and Integral Care Agreement ('Integraal Zorgakkoord') in the Netherlands highlight the importance of high-quality, accessible, and affordable care for diverse patient populations.

Conclusion

IPCC for vulnerable groups is complex and multifaceted and cannot be reduced to simple cause-and-effect relationships. The effectiveness of complex programs, such as IPCC, varies and depends on specific contexts and mechanisms in different settings. The findings of this dissertation provide deeper insights into interrelatedness of items that influence effectiveness of IPCC. The findings emphasize the significance of understanding the relationships between context, mechanisms, and outcomes, recognizing that they form a larger interconnected system rather than acting independently. The realist approach enhances our understanding of the complex nature of programs, promotes the development of responsive programs for diverse need, and informs the design and implementation of future person-centred programs, leading to more effective and tailored approaches that improve health outcomes.

SAMENVATTING

Introductie

Vanwege de toenemende (complexe) zorgbehoeften worden huidige gezondheidszorgsystemen, die nog grotendeels gericht zijn op enkelvoudige ziekten en acute problemen, geconfronteerd met verschillende uitdagingen, zoals toenemende druk op de zorg, tekorten aan zorgpersoneel en stijgende zorgkosten. Ze zijn niet langer geschikt om gezondheids- en sociale zorg te bieden voor de gehele bevolking. In de gezondheidszorg worden kwetsbare groepen gekenmerkt door een verhoogd risico op slechte gezondheidsresultaten en beperkte toegang tot gezondheidsdiensten, zoals ouderen, mensen met beperkte gezondheidsvaardigheden en mensen met een diverse etnische en sociaaleconomische achtergrond.

Integrale persoonsgerichte zorg (IPGZ) wordt beschouwd als het optimale zorgmodel om gezondheid en welzijn te maximaliseren, vooral voor oudere personen en mensen met meerdere chronische aandoeningen. IPGZ richt zich op de totale zorgbehoeften van de patiënt, naast de diensten die worden geleverd door individuele zorgverleners of organisaties. De zogenaamde eerste lijn wordt erkend als de meest efficiënte en kosteneffectieve setting voor het leveren van hoogwaardige zorg en speelt een centrale rol in het leveren van zorg binnen een integraal persoonsgericht gezondheidszorgsysteem. IPGZ kent verschillende uitdagingen, waaronder het gebrek aan coördinatie tussen zorgverleners, onvoldoende training voor zorgverleners, niet op elkaar aansluitende informatie (- en communicatie) technologie (I(C)T)-systemen, gebrek aan duurzame financiële middelen en ontoereikende persoonsgerichtheid. Bovendien is de bestaande wetenschappelijke literatuur over de effectiviteit van IPGZ niet eenduidig, mede door de heterogeniteit in uitkomsten. Ook is sprake van een gebrek aan onderzoek naar IPGZ in de eerstelijnszorg voor kwetsbare populaties, met als gevolg dat hun verwachtingen en behoeften onbekend zijn.

Om meer gedetailleerde inzichten te bieden in de onderlinge samenhang van relevante items die van invloed zijn op de effectiviteit van IPGZ, is in dit proefschrift de ‘realist research’ benadering toegepast. Realist research streeft ernaar een programmatheorie te ontwikkelen die uitlegt hoe, waarom, voor wie en in welke omstandigheden een complexe programma naar verwachting werkt (of niet). De initiële programmatheorie, de ‘middle-range‘ theorie, en de verfijnde programmatheorie vertegenwoordigen verschillende stadia van het ontwikkelen en verfijnen van hoe een programma werkt.

Doelstelling

Het overkoepelende doel van dit proefschrift is inzicht krijgen in de relaties tussen de context waarin IPGZ voor kwetsbare groepen in Nederland wordt toegepast, de mechanismen waardoor het (niet) werkt, en de uitkomsten die voortvloeien uit deze interactie, door het opstellen van een programmatheorie. Om het beoogde doel te realiseren, richt dit proefschrift zich op de volgende onderzoeksvragen:

1. Welke context items, mechanismen en uitkomsten kunnen worden geïdentificeerd in internationale literatuur omtrent integrale zorgprogramma's voor kwetsbare thuiswonende ouderen?
2. Wat is de mate van consensus onder zorgverleners omtrent de relevantie van de context items, mechanismen en uitkomsten van integrale zorgprogramma's voor kwetsbare thuiswonende ouderen, zoals geïdentificeerd in de internationale literatuur, voor de 'Nederlandse setting'?
3. Wat werkt (of niet), waarom en onder welke omstandigheden voor mensen met beperkte gezondheidsvaardigheden en mensen met een diverse etnische en sociaaleconomische achtergrond, volgens de internationale literatuur met betrekking tot persoonsgerichte zorg in de eerste lijn?
4. Hoe relevant zijn de geïdentificeerde context items, mechanismen en uitkomsten van persoonsgerichte zorg in de eerste lijn, volgens mensen met beperkte gezondheids-vaardigheden en zorgverleners in Nederland?

Belangrijkste bevindingen

Integrale zorgprogramma's voor kwetsbare thuiswonende ouderen

Om context items (C), mechanismen (M) en uitkomsten (O) met betrekking tot integrale zorgprogramma's voor kwetsbare ouderen die zelfstandig wonen te identificeren in de internationale literatuur, is een 'rapid realist review' (RRR) uitgevoerd (**Hoofdstuk 2, onderzoeksvraag 1**). Hieruit volgde een programmatheorie die aantoonde dat integrale ouderenzorg zich dient te richten op het benaderen van ouderen als individuen in plaats van patiënten (M) met aandacht voor alle aspecten van hun gezondheid op fysiek, mentaal en sociaal gebied (M). Deze holistische benadering kan leiden tot een verbeterde kwaliteit van leven van ouderen (O). Gezondheidseducatie kan zowel ouderen als hun mantelzorgers (C) helpen om een beter begrip te krijgen van de behandeling en het zorgproces (M), wat kan leiden tot op maat gemaakte zorgplannen en daarmee verbeterd functioneren van de oudere persoon (O), evenals minder heropnames in ziekenhuizen (O). Multidisciplinaire kernteams (M), bestaande uit zorgverleners met verschillende expertises (C), zijn essentieel om te voldoen aan de complexe en diverse zorgbehoeften van ouderen (O). Duidelijke verdeling van rollen en verantwoordelijkheden, en bewustzijn van elkaars expertise (C) zijn cruciaal voor effectieve samenwerking (M) en betere tevredenheid van ouderen, verzorgers en zorgverleners (O). Training van zorgverleners op het gebied van gezamenlijke besluitvorming, empowerment van ouderen, interprofessionele samenwerking en communicatie (C) kunnen hun vaardigheden en kennis verbeteren (C) en de kwaliteit van de gezondheidszorg verbeteren (O). Door middel van communicatie op maat (M), preventieve huisbezoeken en uitgebreide geriatrische beoordelingen, kan opname in een verpleeghuis worden uitgesteld (O) en het gebruik van gezondheidszorg verminderen (O), maar dit vereist wel organisatorische afstemming (C) en voldoende financiële middelen (C). Voor ouderen, die zijn opgenomen in het ziekenhuis, kan een uitgebreid ontslagplan, ontwikkeld door een kernteam (C) met een expert in ontslagplanning, in samenwerking met de ouderen en mantelzorgers (C), de samenwerking tussen alle betrokken disciplines (M) bevorderen. ICT-systemen (C) kunnen ook samenwerking en communicatie (M) tussen betrokkenen bevorderen door het delen van informatie middels gezondheidsgerelateerde sociale netwerken waarin interactie mogelijk is tussen de oudere en zorgverlener, elektronische toegang bestaat tot richtlijnen en protocollen, en die herinneringen kan uitsturen voor zorgverleners en ouderen. Op de lange termijn resulteert dit in lagere kosten in de gezondheidszorg (O). Deze programmatheorie werd vervolgens tegen het licht van het framework van de Wereldgezondheidsorganisatie (WHO) voor integrale persoonsgerichte gezondheidsdiensten (IPCHS) gehouden **(Hoofdstuk 2).** Hieruit bleek dat de strategieën “het creëren van een faciliterende omgeving” (strategie 2) en “het versterken van governance en verantwoordingsplicht” (strategie 5) momenteel prioriteit krijgen in de verstrekking van integrale zorg voor ouderen. Deze bevinding impliceert dat hoewel vooruitgang is geboekt in integrale zorg voor ouderen, verdere ontwikkeling nodig is, aangezien niet alle vijf onderling verbonden strategieën die worden beschreven in het WHO-IPCHS-framework evenveel voorkomen in bestaande integrale zorgprogramma’s.

Voor de tweede onderzoeksvraag werd de programmatheorie van de internationale RRR getest en verfijnd door middel van een Delphi-studie met zorgverleners (**Hoofdstuk 3, onderzoeksvraag 2**). Hieruit kwam naar voren dat succesvolle integrale zorgprogramma’s afhankelijk zijn van goed ontworpen implementatie processen (C) die continuïteit van zorg (C) prioriteren. Dit is met name cruciaal gezien het groeiend aantal ouderen (C) en de beperkte beschikbaarheid van ziekenhuisbedden (C). Zowel nationale als lokale overheden spelen een belangrijke rol in het bevorderen van de adoptie van integrale ouderenzorg (C), of het nu gaat om financiering en beleidsbevordering of het bieden van duidelijke richtlijnen over wet- en regelgeving met betrekking tot integrale ouderenzorg (C). Zorgverleners die zelfmanagementondersteuning bieden aan ouderen en hen in staat stellen een actieve rol te spelen in hun eigen zorg, hebben een positieve invloed op de zelfmanagementvaardigheden (O), geestelijke gezondheid (O) en gezondheid van oudere personen (O). Bovendien kan het optimaliseren van het beheer en de monitoring van zorgactiviteiten (M) door het opstellen van een duidelijk portfolio van ouderen (C) en het waarborgen van voortdurende feedback aan zorgverleners (M) helpen. Het bevorderen van vertrouwen tussen ouderen en zorgverleners (M), integratie van casemanagement (C) en het afstemmen van gezondheids- en sociale zorgsystemen (C) kunnen bijdragen aan het bereiken van effectieve uitkomsten. Naast verbeterde zorgprocessen (O) leiden integrale zorgprogramma's tot een toename van gesprekken over het levenseinde (O) en een verminderde belasting voor mantelzorgers (O).

Integrale persoonsgerichte zorg voor mensen met een diverse etnische en sociaaleconomische achtergrond en beperkte gezondheidsvaardigheden

Om de derde onderzoeksvraag te beantwoorden, werd een 'realist review' uitgevoerd die resulteerde in een 'middle-range' programmatheorie (**Hoofdstuk 4, onderzoeksvraag 3**). In lijn met de initiële programmatheorie werd in de 'middle-range' programmatheorie vastgesteld dat effectieve communicatie, afgestemd op de unieke behoeften en gezondheidsvaardigheden van personen (M), van invloed is op hun betrokkenheid bij het zorgproces (M) en hen in staat stelt actief deel te nemen (O) aan gedeelde besluitvorming (M). Om dergelijke effectieve communicatie en andere essentiële vaardigheden te waarborgen, dienen zorgverleners (uitgebreide) training te ondergaan (C), waarbij ze een persoonsgerichte benadering omarmen (M, O) die verder gaat dan enkel een beperkt biomedisch, ziektegericht perspectief (C). Zorgverleners dienen voldoende tijd (C) te krijgen om te kunnen deelnemen aan betekenisvolle discussies over de wensen en voorkeuren van personen (M). Dit kan leiden tot een hogere tevredenheid van personen en zorgverleners (O) en toegenomen therapietrouw (O). In complexe zorg is naadloze samenwerking tussen de verschillende betrokken zorgverleners binnen teams (C) en over verschillende domeinen heen (C) essentieel om optimale zorgcoördinatie (M) en verbeterde uitkomsten van het gezondheidssysteem (O) te waarborgen. Ondersteunend beleid (C) speelt een belangrijke rol bij het versterken van het belang van persoonsgerichte zorg. De initiële programmatheorie werd verder aangepast door de bevindingen van de review. Daarbij kwam naar voren dat de respectvolle houding van zorgverleners (M) van cruciaal belang is bij het opbouwen van een sterke therapeutische relatie (M), wat het belang benadrukt van het creëren van een positieve en empathische zorgomgeving. Door het verlenen van educatie aan personen (C), ondersteuning bij zelfmanagement (M) en het gezamenlijk opstellen van gepersonaliseerde zorgplannen (C) kunnen zorgverleners effectief de zelfmanagementvaardigheden van personen verbeteren (O). De aanwezigheid van sociale ondersteuningsnetwerken (C) kan de algehele gezondheid en het welzijn van personen verbeteren (O). Bovendien spelen voldoende capaciteit (C), toegang tot passende en gewenste zorg (C) en het benutten van IT- en E-health-initiatieven (C) een essentiële rol bij het integreren van persoonsgerichte zorgpraktijken in de eerste lijn. Componenten die niet werden waargenomen in de realist review, maar werden benadrukt in de initiële programmatheorie, waren de noodzaak om diversiteit in persoonsgerichte zorg te omarmen, persoonsgerichte zorg prominenter in medische opleidingen te integreren en uitgebreide structuren en betaalmodellen te creëren die persoonsgerichte zorg in de eerstelijnszorg vergemakkelijken.

Om de ‘middle-range’ programmatheorie uit de internationale ‘realist review’ te verfijnen, werden focusgroep discussies (FGD’s) gehouden om het niveau van consensus te bepalen omtrent de relevantie van de items geïdentificeerd uit de realist review voor Nederland **(Hoofdstuk 5, onderzoeksvraag 4)**. De bevindingen uit de FGD’s resulteerden in het toevoegen van verschillende items om de programmatheorie te verfijnen. De verfijnde programmatheorie toonde aan dat het belangrijk is om op maat gemaakte ondersteunende materialen te ontwikkelen in samenwerking met de doelgroep (C) om betere ondersteuning aan personen te bieden en de zorg af te stemmen op hun behoeften (O). Bovendien dienen zorgverleners op de hoogte te zijn van de sociale omstandigheden van de persoon (C) en deze cultureel competent te benaderen (C), zodat de zorgervaring verbetert. Efficiënte integratie van ICT-systemen (C) in combinatie met makkelijke toegang tot documenten en het (audio) opnemen van consulten (C) spelen een cruciale rol bij de toegankelijkheid van zorg (O). Verder blijkt de implementatie van flexibele betaalmodellen (C) voorwaarde voor integrale zorgprogramma’s. Als zorgverleners en zorgvragers een gedeelde visie ontwikkelen (C), voelen personen zich zelfverzekerder om vragen te stellen (C) en actief deel te nemen aan hun zorgproces. Zorgverleners spelen een cruciale rol bij het bevorderen van zelfredzaamheid (O), waardoor individuen een actieve rol kunnen spelen in hun eigen zorg en hun gezondheidsgerelateerde kwaliteit van leven verbetert (O). Op de lange termijn kan er een hogere kosteneffectiviteit van de gezondheidszorg en een hogere kwaliteit van zorg worden bereikt (O). Eén item die in de ‘middle-range’ programmatheorie wel werd waargenomen, maar niet relevant werd geacht door de deelnemers van de FGD’s voor IPGZ in de Nederlandse setting, was ‘verbeterde uitkomsten van het gezondheidssysteem (O)’.

Belangrijke items in beide programmatheorieën

Verschillende kernpunten worden door beide programmatheorieën benoemd omtrent IPGZ voor kwetsbare groepen. Het voordeel van het onderzoeken van meerdere programmatheorieën in dit proefschrift is dat het een meer uitgebreid en genuanceerd begrip kan bieden van hoe IPGZ werkt voor kwetsbare groepen in welke omstandigheden. Beide programmatheorieën benadrukken het belang van zorg op maat om tegemoet te komen aan de unieke behoeften en voorkeuren van individuen (O). Zorgverleners dienen te streven naar holistische zorg (M) die de fysieke, mentale en sociale aspecten van gezondheid omvat en waarbij zij de diversiteit onder personen erkennen (C). De noodzaak van uitgebreide training en scholing van zorgverleners wordt in de programmatheorieën benadrukt (C). Het voorzien van professionals van effectieve communicatievaardigheden (M) en interprofessionele samenwerkingsvaardigheden (M) stelt hen in staat om hoogwaardige zorg te leveren (O). Samenwerking binnen multidisciplinaire teams en over verschillende domeinen (C) komt ook naar voren als een gemeenschappelijk thema. De programmatheorieën benadrukken de essentiële rol van samenwerking teneinde optimale zorgcoördinatie te realiseren (M), wat resulteert in verbeterde tevredenheid van personen (O). Door een duidelijke verdeling van rollen en verantwoordelijkheden aan te moedigen (C) en het bewustzijn van elkaars expertise te bevorderen (C), kunnen zorgverleners effectief samenwerken (M) om complexe en uiteenlopende zorgbehoeften aan te pakken. Effectieve communicatie op maat (M) dient als een fundament in beide programmatheorieën. Door personen te betrekken bij hun zorgproces (M) en hen te 'empoweren' (M), kan gezamenlijke besluitvorming (M) worden gefaciliteerd. Beide programmatheorieën erkennen het transformerende potentieel van ICT-systemen (C). Door technologie te integreren in de gezondheidszorg, wordt de toegankelijkheid van zorg (C, O) verbeterd, waardoor effectieve communicatie mogelijk is tussen zorgverleners, personen en verzorgers. Door het delen van informatie (C), gezondheidsgerelateerde sociale netwerken (C) en elektronische toegang tot richtlijnen en protocollen (C) worden personen in staat gesteld actief deel te nemen aan hun zorgtraject (O). De programmatheorieën benadrukken de rol van educatie aan (C) en actieve betrokkenheid van personen in hun zorgproces (M). Door individuen zelfmanagementondersteuning te bieden (M) en hen aan te moedigen vragen te stellen (C), kan hun zelfredzaamheid worden verbeterd (O). Gezamenlijk gedragen doelstellingen (C), gepersonaliseerde zorgplanning (C) en een gezamenlijke visie (C) kunnen de algehele gezondheid en het welzijn van personen verbeteren (O).

Aanbevelingen

Onderzoek

Aanbevelingen voor toekomstig onderzoek op basis van dit proefschrift omvatten aanvullend realist onderzoek dat zich richt op de theoretische onderbouwing van de onderlinge samenhang van items (C, M en O) om meer robuuste programmatheorieën over IPGZ te ontwikkelen. Dit proefschrift biedt een waardevolle voorzet voor het realiseren van de gewenste uitkomsten door het identificeren van een optimale combinatie van context items, mechanismen, interventies en actoren, aangezien IPGZ varieert tussen settings. Bovendien is sprake van een vraag naar meer data over de gezondheid van en het gebruik van zorg door ondervertegenwoordigde kwetsbare groepen en hun relaties met relevante items. Ook wordt aanbevolen om belanghebbenden (bijv. personen met zorgvraag, mantelzorgers, zorgverleners) te betrekken voor setting-specifieke validatie van items en om de redenen achter items zonder consensus te onderzoeken. Dit kan helpen om te onderzoeken hoe IPGZ in Nederland conceptueel verschilt van andere regio's/landen en waarom. Het wordt ook aanbevolen om te onderzoeken in hoeverre de als relevant beschouwde items voor de Nederlandse context al (gezamenlijk) zijn geïmplementeerd, toegepast en de beoogde resultaten binnen hun context hebben bereikt om de programmatheorieën te valideren.

Praktijk

Dit proefschrift leidt ook tot aanbevelingen voor de praktijk op verschillende niveaus van het systeem (micro, meso, macro niveau).

Op microniveau (individuele zorg) dienen zorgverleners prioriteit te geven aan training in het toepassen van empathische en persoonsgerichte (cultuursensitieve) zorg, effectieve communicatie, een holistische benadering en zelfreflectie. Ze dienen op de hoogte te zijn van de beschikbare bronnen om kennis en expertise op te doen over verschillen in morbiditeit en behandeling gerelateerd aan geslacht, gezondheidsvaardigheden of etniciteit. Het bouwen van relaties met partners in de eerste lijn, tweede lijn en sociale zorg is cruciaal voor gecoördineerde dienstverlening. Interprofessionele samenwerking zou al vroeg in de opleiding moeten worden gestimuleerd. Het oefenen van empathische communicatie met simulatiepatiënten, onder andere met beperkte gezondheidsvaardigheden of een migratieachtergrond, wordt aanbevolen. Personen en gemeenschappen kunnen hun zorgervaring verbeteren door proactief te zijn, zich voor te bereiden op consultaties, vragen te stellen, ondersteuning mee te nemen, langere afspraken te maken en relevante informatie online te zoeken.

Organisaties op mesoniveau dienen een gedeelde ambitie te hebben en integraal te werken aan beleid, opdrachtgeversschap en implementatie van IPGZ. Samenwerking met relevante partners kan de connecties verbeteren, bijvoorbeeld door gebundelde budgetten en preventieovereenkomsten. Participatie van kwetsbare groepen is essentieel voor het ontwerpen van persoonsgerichte zorg die aansluit bij hun doelen en ambities. Op maat gemaakte benaderingen voor kwetsbare groepen en het delen van achtergrondinformatie van personen kunnen de zorg verbeteren. Ambities om gezondheidsongelijkheden te verminderen, moeten idealiter voor een lange periode gefinancierd worden. Om regionale en lokale samenwerking te bevorderen, kunnen regiobeelden en regioaanpakken opgezet worden als onderdeel van de beweging ‘Juiste Zorg op de Juiste Plek’.

Op macroniveau hebben aanbevelingen betrekking op degenen die de regie voeren over beleid, financiering en organisatie van de zorg, zoals het ministerie van Volksgezondheid, Welzijn en Sport, Zorginstituut Nederland en zorgverzekeraars, maar ook verenigingen van zorgverleners, ouderen en andere kwetsbare groepen. Het is van cruciaal belang om IPGZ met aandacht voor diversiteit te bevorderen en te implementeren in het beleid. Dit omvat het ontwikkelen van multidisciplinaire zorgstandaarden, kwaliteitsindicatoren voor persoonsgerichtheid, en toegankelijke zorg. Richtlijnen en training van zorgverleners dienen in lijn te zijn met deze principes. Het doorbreken van financiële barrières tussen de eerste en tweede lijn en tussen zorg en het sociale domein is essentieel voor integrale zorg over domeinen heen. Initiatieven zoals het Passende Zorg en het Integraal Zorgakkoord in Nederland benadrukken het belang van hoogwaardige, toegankelijke en betaalbare zorg voor diverse patiëntenpopulaties.

Conclusie

IPGZ voor kwetsbare groepen is complex en veelzijdig en kan niet worden teruggebracht tot eenvoudige oorzaak-en-gevolgrelaties. De effectiviteit van complexe programma's, zoals IPGZ, varieert en is afhankelijk van specifieke contexten en mechanismen in de verschillende settings. De bevindingen van dit proefschrift bieden meer diepgaand inzichten in de onderlinge samenhang van items die van invloed zijn op de effectiviteit van IPGZ voor kwetsbare groepen. Dit proefschrift benadrukt het belang van het begrijpen van de relaties tussen context, mechanismen en uitkomsten, waarbij dient te worden erkend dat ze een groter onderling verbonden systeem vormen in plaats van onafhankelijk van elkaar werken. De realist benadering verbetert ons begrip van de complexe aard van programma's, bevordert de ontwikkeling van responsieve programma's voor diverse behoeften, en informeert het ontwerp en de implementatie van toekomstige persoonsgerichte programma's, wat leidt tot effectievere op maat gemaakte benaderingen die de gezondheidsresultaten verbeteren.

RESEARCH DATA MANAGEMENT

This page contains information on how research data were collected, stored, and protected during the course of this PhD.

Anam Ahmed was employed as an external PhD candidate at the Radboudumc. The thesis is primarily the product of studies conducted at Panaxea B.V. (Den Bosch, The Netherlands). Research conducted at Panaxea is performed according to the prevailing scientific standards and procedures relating to project management, data collection, archiving of data and confidentiality requirements. The standards and procedures on documenting, storing and archiving research data that apply to Panaxea research are described in the 'Guidelines for Research Data-Management – Data Management Policy PANAXEA (version January 2022)'. The data obtained during my PhD at the Radboud University medical center (Radboudumc) are archived according to the Findable, Accessible, Interoperable and Reusable (FAIR) principles.[1] All data obtained during this PhD were stored in the project folder at a secured server of Panaxea B.V. Research members work for a certain research project in a shared project folder that is accessible to the project members and backed up daily. This folder contained all relevant information, data and analyses. All data will be stored for a minimum 10 years after termination of the study. The data sets are only available from the corresponding author on reasonable request.

According to Article 1b of the Dutch Medical Research in Human Subjects Act, extensive formal approval was not needed for this study. However, all participants provided their (verbal) consent. Responses on surveys and transcripts of the focus group discussions were anonymised. The privacy of all study participants was assured by using unique individual subject codes. Details of the participants, necessary for the study, were stored separately from the other data during data collection.

Reference:

1. Wilkinson MD, Dumontier M, Aalbersberg IJ, et al. The FAIR Guiding Principles for scientific data management and stewardship. Sci Data 2016; 3: 160018.

LIST OF PUBLICATIONS

- Josephine Exley, Rebecca Glover, Martha McCarey, Sarah Reed, **Anam Ahmed**, Hubertus Vrijhoef, Tommaso Manacorda, Ketty Vaccaro, Francesco Longo, Ellen Stewart, Nicholas Mays and Ellen Nolte. Governing integrated health and social care: an analysis of experiences in three European countries. *International Journal of Integrated Care*. [*Under review].*

- Daria Shevtsova, **Anam Ahmed**, Iris Boot, Hubertus Vrijhoef. Trust in and acceptance of AI applications in medicine: a mixed methods study. *JMIR Human Factors*. *[Article in Press].*

- **Anam Ahmed**, Janne C Mewes, Isabelle Lepage-Nefkens, Hanno Tan, Hubertus JM Vrijhoef. Early modelling of the effects and healthcare costs of the Dutch citizen-rescuer system for out-of-hospital cardiac arrests. *PLoS One*, 2023;18(11): e0293965.

- **Anam Ahmed**, Maria ETC van den Muijsenbergh, Hubertus JM. Vrijhoef. Person-centred care in the Dutch primary care setting: refinement of middle-range theory by patients and professionals. *Plos One,* 2023;18(3):e0282802.

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- **Anam Ahmed**, Maria ETC van den Muijsenbergh, Hubertus JM. Vrijhoef. Consensus on integrated care for older people among Dutch experts: a Delphi study. *International Journal of Integrated Care.* 2021;21(4):30.

- **Anam Ahmed**, Maria ETC van den Muijsenbergh, Janne C Mewes, Walter P Wodchis, Hubertus JM Vrijhoef. Untangling the interrelatedness within integrated care programmes for community-dwelling frail older people: a rapid realist review. *BMJ Open*. 2021;11(4):e043280.

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chronic fatigue syndrome: a systematic review. *Journal of Health Psychology*. 2020;25(2):240-255.

- Janne C Mewes, **Anam Ahmed**, Hubertus JM Vrijhoef. How do integrated care programmes work for patients with cardiovascular disease, COPD, depression, diabetes, and multimorbidity? A rapid realist review. *International Journal of Care Coordination*. 2018;21(3):87-97.

PHD PORTFOLIO

Name PhD candidate: Anam Ahmed
Department: Primary and Community Care
Graduate School: Radboud Institute for Health Sciences
PhD period: March 2019 – February 2024
Promotor: Prof Dr. M.E.T.C. van den Muijsenbergh
Co-promotor: Dr. H.J.M. Vrijhoef

Training activities	Year	Hours
Courses		
Radboudumc – Introduction day	2019	6.0
RIHS - Introduction course for PhD candidates	2019	15.0
Radboudumc - Scientific integrity	2019	20.0
Centre for Participatory Strategies - Participatory Learning and Action Techniques	2019	45.0
RU - The Art of Presenting Science	2019	36.0
RU - Analytic Storytelling	2020	20.0
Dutch Federation of University Medical Centres - Basic Course on Regulations and Organisation for Clinical Investigators (BROK)	2020	42.0
RU - Qualitative Research Methods and Analysis	2020	84.0
RU - Grant Writing and Presenting for Funding Committees	2020	18.0
RU - The Art of Finishing Up	2021	10.0
RU - Effective Writing Strategies	2021	75.0
RU - Design and Illustration	2021	26.0
RU - Presenting and Poster Pitching	2022	51.0
Seminars (oral presentations)		
RIVM - Bijeenkomst Realist Intervisie Groep	2020	8.0
Eerstelijnsgeneeskunde (ELG) - Refereerbijeenkomst	2021	10.0
Sing Health - RR interest group	2023	8.0

Training activities	Year	Hours
Conferences (oral presentations)		
Symposium 'Persoonsgerichte, integrale eerstelijnszorg' (Radboudumc)	2018	8.0
CaRe Days 2021	2021	19.0
European Health Management Association (EHMA) Conference 2021	2021	29.0
World Organization of Family Doctors (WONCA) Conference 2021	2021	42.0
Care Days 2022	2022	20.0
International Conference on Integrated Care (ICIC) 2022	2022	31.0
European Forum for Primary Care (EFPC) 2022	2022	31.0
CaRe Days 2023	2023	20.0
Symposium 'Elk mens telt – inclusieve zorg, onderwijs en onderzoek' (Radboudumc)	2023	7.0
Health Services Research UK 2023	2023	24.0
European Forum for Primary Care (EFPC) 2023	2023	28.0
Other		
National Health Care Institute - interim and final project meetings with steering committee	2018 -2019	296.0
Total		**1,029.00**

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I am grateful to each and every person who has played a part, no matter how big or small, in my journey. Thank you from the bottom of my heart.

ABOUT THE AUTHOR

Anam Ahmed was born on May 20th, 1991 in Amsterdam, the Netherlands. After completing her pre-university education at the Hervormd Lyceum West in Amsterdam, Anam pursued her Bachelor's in Biomedical Sciences at VU University Amsterdam. She went on to expand her horizons and obtained a Master's degree in Science and Business Management from Utrecht University in 2014.

Driven by her ambition to create and facilitate bridges between health sciences and the practical field, Anam joined Panaxea as a research consultant. Panaxea is a research organization, which focuses on evaluating the benefits of healthcare innovations and facilitating informed decision-making in this domain. At Panaxea, Anam is specialized in health services research. During her time at Panaxea, Anam conducted two studies commissioned by the National Health Care Institute. These research studies served as the foundation for her doctoral research, which began in 2019 and ultimately led to the successful accomplishment of her PhD dissertation.

Currently, she works as a senior research consultant at Panaxea and aspires to make healthcare more accessible and person-oriented in the future.