Lotte Timmermans

Self-management support in primary care practice

2024

KU LEUVEN
ACADEMISCH CENTRUM HUISARTSGENEESKUNDE

Academie Voor De Eerste Lijn

Koning Boudewijnstichting
Samen werken aan een betere samenleving

Thuis in de eerste lijn
FONDS DR. DANIËL DE CONINCK

The development and implementation of self-management support in primary care practice

Lotte Timmermans

KU Leuven
Biomedical Sciences Group
Faculty of Medicine
Department of Public Health and Primary Care

KU LEUVEN

DOCTORAL SCHOOL
BIOMEDICAL SCIENCES

The development and implementation of self-management support in primary care practice

Lotte Timmermans

Supervisor:	Prof. Birgitte Schoenmakers
Co-supervisors:	Prof. Peter Decat Prof. Veerle Foulon Prof. Mieke Vermandere
Advisory person:	Prof. Ann Van Hecke
Chair public defence:	Prof. Ann Van den Bruel
Chair examining committee:	Prof. Koen Milisen
Jury members:	Prof. Theo van Achterberg Prof. Tine Van Regenmortel Prof. Thérèse Van Durme Prof. Mieke Rijken

Dissertation presented in partial fulfilment of
the requirements for the degree of Doctor in
Biomedical Sciences

March 2024

Cover: ® Lotte Timmermans, created using Canva AI photo generator

Table of contents

List of abbreviations

ACHG	Academic Centre for General Practice
ADC	Absorb-Do-Connect
APEASE	Acceptability, Practicability, Effectiveness, Affordability, Spill-over effects, and Equity
BCT	Behaviour Change Technique
BCW	Behaviour Change Wheel
CCM	Chronic Care Model
COM-B	Capability, Opportunity, Motivation-Behaviour
COREQ	Consolidated Criteria for Reporting Qualitative Research Guidelines
COVID-19	Coronavirus Disease 2019
CRISP	Consensus Reporting Items for Studies in Primary Care
EU	European Union
GDP	Gross Domestic Product
GP	General Practitioner
GOC	Goal-Oriented Care
HRQoL	Health-Related Quality of Life
IPC	Interprofessional Collaboration
JBI	Joanna Briggs Institute
LMS	Learning Management System
MEnToSS	More Encouragement Towards Self-management Support
MRC	Medical Research Council
NCDs	Non-Communicable Diseases
PCA	Primary Care Academy
PCC	Person-Centred Care
PCD	People living with chronic conditions and informal Caregiver Dyads
SF-36	36-Item Short Form Survey
SILCQ	Supporting, Involving, Listening, Coordinating and Questioning
SM	Self-Management
SMS	Self-Management Support
SDT	Self-Determination Theory
TDF	Theoretical Domains Framework
TPB	Theory of Planned Behaviour
UEQ-S	Short version of the User Experience Questionnaire
WHO	World Health Organization
WISE	Whole system informing self-management engagement
QoL	Quality of Life

General introduction

General introduction

Healthcare delivery is changing fundamentally. Transformations are being driven by the focus on person-centered approaches in which patients become active partners in healthcare(1). In this context there is an increasing emphasis on patient self-management(2). Despite the variety of self-management support interventions and the available evidence, practical implementation encounters significant obstacles. A paradigm shift is needed that focuses on the changing role of healthcare professionals and the need to adequately guide them to provide effective support for self-management. This transition is crucial to bridge the gap between existing knowledge and actual care practice, with the ultimate goal of improving patients' health and quality of life outcomes.

Healthcare transformations

Worldwide, nearly one in three adults is diagnosed with one or more chronic diseases(3). With increased life expectancy, attention to prevention of severe events and access to better treatments, this number will continue to rise(4,5). All of this is contributing to a larger focus on chronic care(6). In addition, healthcare systems are shifting from traditional disease-oriented systems to more holistic, person-centered approaches that place the individual at the centre of their healthcare journey(7). This profound transformation moves away from the conventional medical model and embraces biopsychosocial paradigms, focusing on the individual as a whole. The goal is to preserve patients' dignity and enable them to lead fulfilling lives despite their health challenges. This requires a holistic view of care, taking into account the physical, emotional and social aspects of the person behind the patient(8). Such a person-centered care approach is considered pivotal to improve patient satisfaction and treatment adherence(7). Person-centered care recognizes that patients are unique individuals, with different needs, values and preferences. It encourages them to actively participate in health decisions(9). To ensure that no one is left behind, community-based healthcare systems are being developed to actively involve each individual of the community in the care journey(10). Driven by patients' desire to gracefully age in the comfort of their homes, alongside with growing health consciousness and literacy(11), the goal is to reach out to a diversity of populations and create a healthcare system that encourages people in the community to actively participate in their care(12). Care professionals are no longer supposed to make decision *for* the patient, but together *with* the patient(13). It refers to the principles of shared-decision making to emphasize active patient participation, information sharing and respect for autonomy(14). It encourages healthcare professionals to include patients as equal partners in treatment decisions by

considering their values and preferences(15). In the midst of these changes, primary care and primary care professionals play a central role in the evolution of healthcare. Primary healthcare, as outlined by the World Health Organization (WHO), is a transformative approach to strengthening national health systems and ensuring community-based access to essential services(16). It encompasses a wide range of tailored health services across the lifespan and addresses the underlying determinants of health through community action. By empowering individuals, families and communities to take an active role in their health, primary care is emerging as a cornerstone in the evolving health landscape(17).

Self-management and self-management support

As a result of above-mentioned transformations, roles in healthcare are changing rapidly. Patients become more active players and there is a shifting of "power" from healthcare professionals to chronic patients(18). The concept of self-management has become very relevant.

Self-management is a form of self-regulation in which individuals take an active role in their care(19). It refers to patients controlling their own disease and health by using appropriate strategies, resulting in positive health and welfare outcomes(20). Several definitions have been described in literature. For the purpose of this manuscript, we follow the holistic definition established by Barlow (2002)(21). Self-management in chronic disease is defined as *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established"*(21).

Three different components can be identified, inspired by Corbin & Strauss (1988) and Lorig & Holman (2003)(22,23): medical management (coping with medical aspects), role or social management (coping with lifestyle adjustments) and emotional management (coping with emotional consequences). Engaging with these three components contributes to the development of effective self-management strategies(19). In understanding the concept of self-management, it is essential to discuss the complementary concept of self-management support, which enhances the practical application and effectiveness of empowering individuals in their healthcare journey(24). The correlation between patients' self-management and their support needs is represented in Table 1.

Self-management support is widely discussed in literature. Adams *et al.* (2004) offer a holistic definition that emphasizes the role of healthcare professionals, referring to self-management support as "*the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support*"(25). The goal is to provide patients with knowledge and skills needed to accurately manage their health conditions and adapt their lifestyle. (26). To engage in effective self-management, individuals need to feel empowered to take control of their health and wellbeing. Empowerment focuses on fostering self-efficacy and active participation in one's own care journey. It shifts the focus from a deficit-oriented approach to one that highlights strengths and potentials. In this context, empowerment serves as a theoretical foundation for understanding the mechanisms underlying effective self-management support interventions(27). Self-management support is a collaborative approach between healthcare professionals, patients and their informal network, and the healthcare systems in which patients are informed and empowered, thereby contributing to improved health and quality of life outcomes(28,29). Collaboration is essential to tailor care to the unique needs of individual patients and to increase the effectiveness of self-management support and its impact on patient outcomes. This collaborative approach is visually represented in Figure 1, inspired by the Co-Creating Health Model(30), which highlights the interconnected efforts of patients, health professionals and health systems. Together, they strive to promote self-management to achieve positive outcomes.

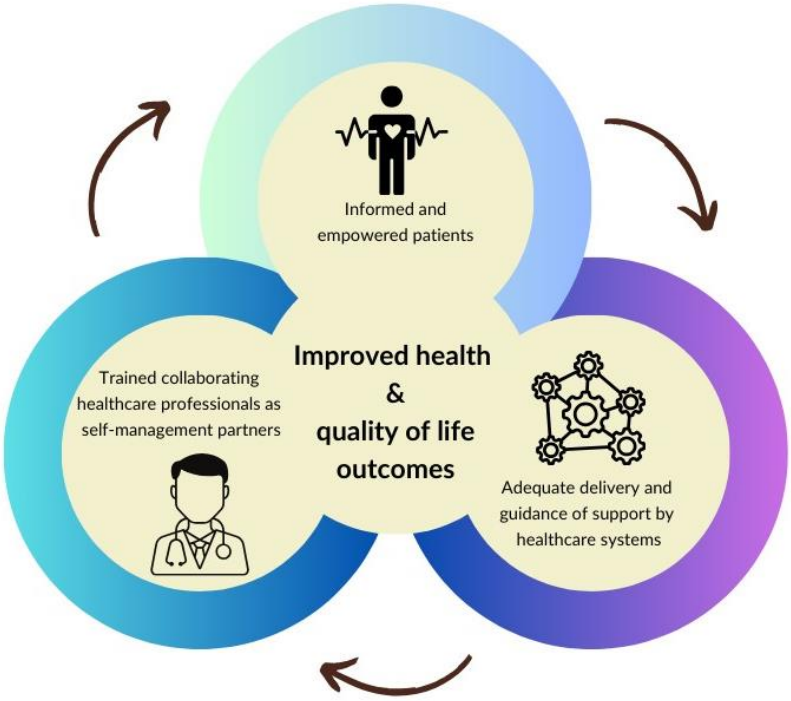


Figure 1: The collaborative approach of self-management support, inspired by the Co-Creating Health Model(30)

Table 1: Correlation between self-management and support needs(31)

Components of self-management **(Lorig & Holman, 2003)**(23)	**Self-management support needs** **(Dwarswaard et al., 2015)**(24)
Medical management	*Instrumental support* • *Knowledge: information and instruction* • *Internalizing knowledge* • *Adjusting daily life to the chronic condition*
Role or social management	*Relational support* • *Partnership* • *Sympathy*
Emotional management	*Psychosocial support* • *Recognition of emotional aspects of the chronic condition* • *Building self-confidence and empowerment*

Evidence and interventions

According to literature, effective self-management can have a positive impact on patient-related outcomes (including patients' activation and self-efficacy) and quality of life(32). In addition, a positive effect is reported on healthcare utilization (including workflow and efficiency, reduced long-term workload), cost of care, and clinical outcomes (including decreased mortality and morbidity)(33–36). These findings confirm the intrinsic value of self-management as a strategy that not only benefits the individual patient, but also brings broader benefits to the healthcare system as a whole. It is considered senseless to include numerical data in this context, given inherent limitations such as the heterogeneity of intervention studies, the emphasis on qualitative research, and the need for long-term research to make statements about effectiveness.

While focusing on self-management is crucial in the transforming landscape of healthcare, where person-centered care approaches are central, it is equally important to explore the mechanisms that help patients effectively manage their health conditions. In fact, chronic disease self-management is a complex collaborative effort between patients and their formal and informal healthcare networks, recognizing the diversity of self-management capabilities of

individuals(37). More specifically, self-management of chronic diseases requires six patient skills: action planning, decision making, patient–care professional collaboration, self-tailoring, problem solving, and resource utilization(23). These skills are acquired through a continuous lifelong learning process; they are not innate(19). Therefore, various interventions have been developed to guide patients in the self-management process, and an upward trend in the number and type of interventions has been observed in recent years. This increase can be attributed to a growing awareness and recognition of patient engagement in the care process(38). In 2015, the WHO explicitly articulated the need for evidence-based guidelines and programs to support patient self-management(39). Furthermore, the increase can also be attributed to patients' growing need for effective support to actually achieve self-management. Finally, the growing trend towards more interventions highlights the importance of researching and implementing innovative approaches. These developments are not only a response to changing dynamics of healthcare, but also reflect the evolutionary shift towards a patient-centered approach to healthcare, in which self-management is central.

Self-management support interventions come in different types and forms. Primarily, interventions focus on educating patients to achieve effective chronic disease self-management skills(40). Hence, further development and support of these skills are a prerequisite for achieving desired health and quality of life outcomes. A minority of interventions target individuals other than the patient in the health network, such as the informal caregivers or the healthcare professionals. According to international research, many of these self-management support interventions have shown promising results in practice(32). Specifically, several interventions have demonstrated the potential to increase patient engagement, improve self-management skills and contribute to improved health and welfare outcomes(41).

Challenges in implementation

Despite the evidence, the majority of interventions still encounter significant challenges, complicating the full implementation of self-management support in practice(42). One of the main challenges is the crucial requirement for healthcare professionals to act as companions of patients and actively support them in acquiring self-management skills(24,29). However, this essential companionship often clashes with a lack of knowledge among healthcare professionals on how to adequately fulfil this role. The traditional consultation model, rooted in a hierarchical approach in which the healthcare professional plays the lead role, often does not match the shift to self-management(43). The lack of clear guidelines, models and frameworks for this new form of collaboration complicates its implementation.

In addition, research reveals a number of other challenges. First, interventions are often focused on self-management support of one specific target group(44), making them inapplicable to a variety of chronic patients with diverse health needs(32). More specifically, they are either focused on one chronic condition, or they target only a specific group of patients. Secondly, interventions mainly address the patient, as the research subject or intervention participant(21). However, formal primary health- and welfare professionals and informal caregivers fulfill significant supportive roles(45). Neglecting or failing to involve them in self-management support programs may contribute to reduced effectiveness. Thirdly, the concept of self-management remains ambiguous, complex and without consensus(19,46). This causes various interpretations and misconceptions among healthcare professionals who, in most cases, are responsible for implementing the developed interventions. However, clarity and understanding are crucial for accessibility. As a result, it can be challenging to present self-management support interventions in practice. Fourthly, both patients and professionals struggle to access developed tools and support needed to effectively manage chronic conditions. Finally, self-management support interventions seem to fall short, also in the Belgian context. Although the significance is emphasized in several reports(47), evidence for the effectiveness in chronically ill patients is unclear (48). This complicates the impact of interventions within the national and international healthcare environment.

To overcome these challenges, there is a need for a clearer understanding of the roles of both the healthcare professional and the patient in the self-management process. A shift towards a more cooperative and collaborative process between patient and healthcare professional is essential. In this regard, conducting research to establish new models, develop support tools and foster a culture of shared responsibility are crucial steps to facilitate the transition to effective self-management support.

Knowledge-to-practice gap consequences

Within current healthcare practice, there is a clear gap between theory and practice of self-management support(42). Although research demonstrates the positive benefits of engaging patients in self-management, several challenges and barriers remain in the way of further development and implementation in primary care practice. This gap results in a critical lack of person-centered care in which the patient plays up an active role. This negatively impacts health and quality of life. At the same time, this gap places an enormous burden on the healthcare system and its healthcare professionals. Patients who experience inadequate self-management support translate into reduced quality of care, poorer healthcare outcomes, increased

healthcare utilization, greater costs and increased pressure on healthcare professionals. The result is a disbalanced healthcare system with staff stretched to their limits, facing the overwhelming challenge of meeting the increasing demands of patient care.

Thesis outline and objectives

To bridge the gap between theory and practice, namely to increase the uptake of self-management support in practice, this thesis project aims to provide comprehensive insights into effective self-management support. The aim is to gain practical knowledge by conducting both quantitative and qualitative research with all stakeholders (patients, informal and formal caregivers, representatives of patient organizations, policy makers, etc.). The focus is on developing a holistic model of self-management support, emphasizing the collaborative approach. In addition, the thesis project aims to contribute to the translation of this model into usable strategies. The ultimate goal is to empower healthcare professionals and promote a seamless integration of self-management support principles into everyday healthcare practice. The focus is on primary care because this usually serves as the initial gateway to the health system(17). Moreover, for chronic patients, primary care plays a crucial role in ensuring continuity of care.

The overall research question is defined as:

"How can we guide healthcare professionals to support people with moderate complex care needs to achieve adequate self-management?"

In order to answer this research question and to meet the objectives, the research is organized into three integral parts, comprising seven chapters (Figure 2).

Part I. Providing clarity on the plethora of self-management support interventions and their impact on patient outcomes

- *Chapter 1. Characteristics of self-management support interventions and their impact on Quality of Life in adults with chronic diseases: An umbrella review of systematic reviews*

Part II. Mapping patients' and professionals' experiences of primary care and self-management support

- *Chapter 2. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study*
- *Chapter 3. Self-management support in Flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach*
- *Chapter 4. Self-management support in primary care practice: a qualitative focus group study of care professionals' experiences*

Part III. Developing a theory-informed, contextually appropriate self-management support intervention

- *Chapter 5. Co-creation of an intervention to facilitate self-management support in primary care practice: online nominal group technique*
- *Chapter 6. Facilitating self-management support using the behaviour change wheel to address healthcare professionals' behaviour*
- *Chapter 7. Transforming healthcare: A pilot study to improve primary healthcare professionals' self-management support behaviour through blended learning*

Figure 2: Thesis outline - visual representation

Part I. Providing clarity on the plethora of self-management support interventions and their impact on patient outcomes

This part of the PhD dissertation aims to provide an overview by performing an umbrella review of systematic literature reviews.

Chapter 1. Characteristics of self-management support interventions and their impact on Quality of Life in adults with chronic diseases: An umbrella review of systematic reviews

In this first research chapter, we mapped the literature on self-management support interventions. The goals was to create an overview of existing interventions and their impact on the patient reported outcome Quality of Life(49).

Part II. Mapping patients' and professionals' experiences of primary care and self-management support

This second part aims to gain insights into the concept of self-management support in Flemish primary care practice. Firstly, the perspectives and insights of patients and their informal caregivers have been explored. Based on their input, we developed a conceptual self-management support model. Finally, we completed the picture of self-management support in the "healthcare ecosystem" by exploring perspectives and experiences of healthcare professionals. This sequential exploration is intended not only to enrich the theoretical model, but also to facilitate the practical implementation of self-management support (interventions) guided by the collective experience of all care stakeholders.

Part II consists of the following three chapters:

Chapter 2. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study.

Within this chapter, we explored how patients and their informal caregivers experience primary healthcare in Flanders. Dyadic interviews were conducted in order to gain a more comprehensive understanding(50).

Chapter 3. Self-management support in Flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach.

In this subsequent chapter, we carefully analyzed the dyadic interviews on the topic of self-management support. This study aimed to create a conceptual model of self-management support, intended to serve as a starting point in the development of future support interventions(51).

Chapter 4. Self-management support in primary care practice: a qualitative focus group study of care professionals' experiences.

In this fourth chapter, we aimed to understand healthcare professionals' experiences with self-management support and learn from these experiences about the characteristics, support strategies and barriers/facilitators of self-management support(52).

Part III. Developing a theory-informed, contextually appropriate self-management support intervention

In this third and last part, we move from theory to practice. Based on participatory research, we created a contextually appropriate self-management support intervention tailored for primary care in Flanders. To achieve this, we organized nominal brainstorming sessions in which we actively involved patients, their informal caregivers, healthcare professionals and representatives of health- and welfare organizations. These sessions generated insights, leading us to the next chapter: a comprehensive analysis of healthcare professionals' behaviour shaped a behavioural self-management support intervention. In the final chapter, we piloted and evaluated this practical intervention in primary care.

Part III consists of the following three chapters:

Chapter 5. Co-creation of an intervention to facilitate self-management support in primary care practice: online nominal group technique.

Based on a co-creative process, we collect ideas for a self-management support intervention in Flanders by organizing online nominal group sessions. We question what specific actions can be organized to guide healthcare professionals in supporting self-management of chronic patients(53).

Chapter 6. Facilitating self-management support using the behaviour change wheel to address healthcare professionals' behaviour.

Following the online brainstorm sessions, in this chapter we discuss the development of a theory-informed, contextually appropriate self-management support intervention to address the self-management support needs of patients, informal and formal care professionals. At the core of this intervention lies an analysis of professionals' behaviour using a behavioral change wheel.

Chapter 7. Transforming healthcare: A pilot study to improve primary healthcare professionals' self-management support behaviour through blended learning.

In this final chapter, we explore the impact of our developed intervention, namely a blended learning program, on healthcare professionals' reaction, learning and behaviour towards self-management support in primary care. We do so by means of a pilot study in Flemish multidisciplinary healthcare centers.

Primary Care Academy

This research project is part of the Primary Care Academy (PCA). Through research and teaching, the PCA aims to strengthen and support primary care in Flanders. The Academy consists of a group of four universities, six colleges, the White and Yellow Cross and the Flemish Patient Platform who join forces to achieve interdisciplinary impact in primary healthcare. Three main research themes are addressed: interprofessional collaboration, goal-oriented care and self-management support. Funding for the PCA projects is provided by the Dr. Daniel De Coninck Fund, which is directed by the King Baudouin Foundation (Belgium).

Part I. Conducting a literature review of self-management support interventions and their impact on patient outcomes

Chapter 1

Characteristics of self-management support interventions and their impact on Quality of Life in adults with chronic diseases: An umbrella review of systematic reviews.

Published as:
Timmermans L, Golder E, Decat P, Foulon V, Van Hecke A, Schoenmakers B; Primary Care Academy. Characteristics of self-management support (SMS) interventions and their impact on Quality of Life (QoL) in adults with chronic diseases: An umbrella review of systematic reviews. Health Policy. 2023 Sep;135:104880. doi: 10.1016/j.healthpol.2023.104880. Epub 2023 Jul 25. PMID: 37536047.

Abstract

Objective

To provide an overview of types and characteristics of self-management support (SMS) interventions in adults with chronic disease and to assess the impact on the patient reported outcome Quality of Life (QoL).

Methods

An umbrella review of systematic reviews was conducted. We searched PubMed, Embase, Web of Science, CINAHL and the Cochrane Library from January 2016 to November 2020 for reviews on SMS interventions for chronic diseases, assessing the impact on the patient reported outcome QoL. Quality assessment was based on the JBI Critical Appraisal Checklist for Systematic reviews and Research Syntheses tool.

Results

28 reviews were included. The extensive literature review revealed a variety of SMS interventions. The most frequently cited target group for the interventions were individuals with diabetes. Interventions primarily took place in the home setting. Interventional components that were often incorporated were education, eHealth and mHealth technologies, and coaching techniques. Telephone communication was regularly reported as a type of intervention follow-up. The impact on QoL was mixed and no firm conclusions can be drawn. However, our review revealed a beneficial effect of education.

Conclusions and practical implications

Interventions including educational components seem promising for supporting self-management and showed a beneficial effect on QoL. More research is needed to explore where, by whom and how interventions are ideally delivered.

Keywords

Chronic conditions, Health policies, Self-management, QoL

Introduction

There is a growing number of people worldwide with complex and long-term care needs due to multiple chronic conditions, cognitive and functional disabilities, mental health issues and social vulnerability(1,2). Over 50 million people in Europe were living with more than one chronic disease in 2014(3). Chronic diseases, such as cardiovascular diseases, cancer, chronic respiratory diseases and diabetes, are the major causes of death across Europe.(4) According to the World Health Organization (WHO), they account for 77% of the total disease burden and 86% of all deaths(5). Chronic diseases also have a major financial impact, with an increase in health spending from 8.8% to 9.6% of the Gross Domestic Product (GDP) account between 2008 and 2017(6).

The demographic changes in global health have a significant impact on healthcare needs and the demand for long-term care. In 2015, the WHO proposed interventions focusing on empowerment and self-management (SM) to engage individuals in their own care as a strategy for integrated people-centered health services(7). Patient empowerment is expressed as a mechanism to actively play a role in the chronic care process(8). SM is considered as essential and inevitable because living with a chronic condition requires 'self-managing' the long-term health condition to a certain extent(9). SM in chronic diseases is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Barlow *et al.* 2002)(10). Empowerment and SMS are key elements of the Chronic Care Model (CCM)(11) , in which six fundamental areas are defined to set up a system that encourages high-quality chronic disease management(12). The support is defined as "the process of making and refining multi-level changes in healthcare systems (and the community) to facilitate patients' self-management" (Glasgow *et al.* 2003)(13). This approach includes intensive collaboration between patients, healthcare professionals and the healthcare system(14).

Literature shows a heterogeneity of SMS interventions(15,16). Unfortunately, many publications report on a wide variety of outcomes(17,18). This diversity results in both ambiguity and lack of focus. In addition, the reported interventions usually involve a specific target group rather than chronic disease in general(19,20). As a consequence, the results are not generalizable. However, focusing on multiple chronic conditions is of great value with the increasing issue of multimorbidity(21). Moreover, while the existing literature often examines SM as part of a larger picture(22), it is equally true that numerous systematic reviews break down the concept into various components, focusing on specific aspect. As a result, a comprehensive overview summarizing the breadth of SMS interventions is lacking. Finally, in

addition to the diversity in outcomes and target population, the heterogeneity of interventions prevents conclusions being made about the impact of SMS. Therefore, the effectiveness for new and existing SMS interventions remains unclear(23). Given the exponentially growing number of new SMS interventions since the WHO proposed their global strategy on integrated people-centered care(7) (2015), the specific focus of earlier published literature and the abundance of individual systematic reviews, there is a need for a systematic holistic overview of SMS interventions, which specifically target chronic conditions in general and assess the impact on a clearly delineated outcome measure. For this review, the patient reported outcome Quality of Life (QoL) was chosen since recent research suggests that measuring QoL is invaluable throughout the patient's journey and therefore essential in clinical decision making(24–26), especially since measuring QoL ensures that an outcome important to patients is taken into account(27). In the context of SMS as part of more integrated people-centered care, we believe this outcome gives valuable meaning to this review. This paper is designed to set the scene, to present current knowledge in a structured way and to highlight gaps in the field. This review is a starting point to familiarize with SMS and their applications in healthcare practice.

The research questions addressed are: *What types of SMS interventions in adults with chronic disease exist and what are their characteristics? Do these SMS interventions result in an improvement in the QoL?*

Methods

This umbrella review includes an extensive literature analysis of different SMS interventions for patients with chronic conditions. An umbrella review of systematic reviews summarizes evidence from various systematic reviews and meta-analyses into a single review. Findings are originated from original primary research data, which were summarized in the included systematic reviews. Carrying out an umbrella review gives the opportunity to gain a clear understanding of a broad topic area(28). The review process was guided by a modified Joanna Briggs Institute (JBI) methodology for Umbrella Review. The protocol was uploaded in PROSPERO for registration prior to conduction of the umbrella review (Registration ID - CRD42020216728).

Search strategy

Relevant reviews were identified by searching PubMed, Embase, Web of Science Core Collection, CINAHL and the Cochrane Database of Systematic Reviews for systematic reviews published from 1 January 2016 to 24 November 2020. The starting date was deliberately chosen since research has accelerated significantly since this time, due to health policies that

advocated internationally for SMS, and increasing interest on the concept(7,29). More specifically, in 2015, the WHO published their strategy for integrated people-centered care, which highlighted the importance of SMS in healthcare and prompted notable changes in care systems and policies. Therefore, to capture the subsequent advancements and emerging interventions in SMS, we set the starting date for the inclusion of reviews at 2016. This approach ensures that our review encompasses the relevant literature published after the WHO note, while also acknowledging the comprehensive overview provided by previous studies such as Flanagan *et al.* (2017)(22).

A predefined search string was composed with the help of a research librarian. In addition, a manual search of the reference lists of relevant articles was conducted to select any studies overlooked while using the default search strategy. The search strategy employed variations and Boolean connections (AND, OR) of the following terms: "Self-management" AND "Chronic conditions" AND "Systematic" (supplemental file 1). The search for chronic diseases in general was supplemented with a specific search to the four main types of noncommunicable diseases(30) (cardiovascular diseases, cancer, chronic respiratory diseases and diabetes) to improve the relevance of the obtained research data.

Inclusion- and exclusion criteria

We included systematic reviews (with and without meta-analysis) since January 2016 focusing on at least one SMS intervention for adults with a chronic condition. To ensure consistency of SMS interventions within this umbrella review, the intervention must have explicitly stated to support 'self-management' or to include supportive strategies for 'self-management'. We adopted an inclusive approach to capture the broad spectrum of SMS interventions by intentionally not imposing a rigid definition of SM. No restrictions were placed on the content of interventions or their support strategy. In addition, QoL was chosen as the outcome measure for analysis of impact. Reviews were included if they met the following selection criteria: (1) Systematic reviews (with and without meta-analysis) published in the English language. If a review had been updated, the latest updated new version was included; (2) Participants included adults, 18 years or older, suffering from at least one chronic disease. Chronic diseases were defined according to the World Health Organization (WHO) as long standing and slowly deteriorating diseases(31). Patients who survived cancer and did not undergo active treatment were excluded since SMS interventions for this group of chronic patients differ due to the complexity, multidimensional and dynamic nature of experiencing cancer(32); (3) Interventions should be clearly defined and aim to support SM. For this review, we consider SMS as a collaborative patient-centered approach, that encourages patient activation, education and

empowerment(33). No restrictions were placed on the format, setting or delivery methods of the SMS intervention (for example, group or individual, professional or peer led, …), although the intervention should be delivered primarily to the patient. Outcome measures needed to be clearly defined and include a patient reported QoL measure.

Reviews were excluded if: (1) The review only included a care intervention related to end-of life care in patients; (2) Authors did not specify the included population or findings related to adults are not reported separately; (3) Authors incorporated theoretical studies or text and opinion as their primary source of evidence; (4) Authors did not describe the search strategy, inclusion criteria, or quality assessment; (5) The reviews were integrative reviews, scoping reviews, critical reviews, rapid reviews unless the primary included studies were nevertheless critically evaluated; (6) The reviews were withdrawn/retracted publications; (7) The reviews were previous versions of systematic reviews that have been updated, to ensure the inclusion of the most current data and to avoid duplication.

Data abstraction

The retrieved records were imported into EndNote and duplicates were removed. Titles and abstracts were independently (LT and BS) screened in Rayyan database against the inclusion and exclusion criteria using a screening template (supplemental file 2). Discrepancies were resolved by discussion and if necessary, through the independent assessment of a third author (EG). The following textual data on review characteristics were collected: Study details (Author/Year, Study country, Main objective, Included interventions with details of description, delivery method (included interventions), theoretical background/content/format (included interventions), setting/context (included interventions), participants (included interventions), key stakeholders/family members/professionals involved (included interventions), frequency/intensity (included interventions), follow-up (included interventions); Search details (Main databases searched, Range of included studies, Number of (QoL) studies included, Types of studies included, Country of origin of included studies); Appraisal details (Appraisal instruments used, Appraisal rating); Analysis details (Type of review, Meta-analysis yes/no, Outcome(s) assessed, Results/Findings related to QoL, Included instruments for measuring QoL, Article's conclusion on effectiveness QoL) and Comments. The data collection of each review was guided by the customized JBI data extraction tool for Systematic Reviews and Research Syntheses (supplemental file 3).

Quality assessment

The JBI Critical Appraisal Checklist for Systematic reviews and Research Syntheses tool was used by two reviewers (LT and EG) for the assessment of the methodological quality of the included systematic reviews (supplemental file 4)(34). The appraisal checklist consisted of 11 questions labeled "YES", "NO" or "UNCLEAR". To ensure high quality of our umbrella analysis, a cut-off on the inclusion of reviews was applied. More specifically, reviews were excluded if less than seven quality questions were assigned a "YES" label.

Data analysis

Two authors (LT and EG) independently extracted and analyzed the data from the reviews. Due to heterogeneity in terms of methodological approaches and included measurement instruments, our evidence synthesis regarding the impact of SMS interventions on the patients' QoL consists of a narrative overview.

Results

Study selection

An electronic search in November 2020 by consulting PubMed, Embase, Web of Science Core Collection, CINAHL and the Cochrane Database of Systematic Reviews for reviews yielded a total of 3254 articles. After removing duplicates and screening titles and abstracts, 189 reviews remained. Further screening of the methodological sections identified 58 eligible reviews for full-text screening. This screening yielded a total of 29 articles that were critically appraised prior to the synthesis, resulting in the exclusion of one additional review. Ultimately, 28 systematic reviews were included in the umbrella review for the narrative synthesis. After manually searching the reference lists of relevant articles, no additional articles were found. A detailed study selection process is illustrated in figure 1.

Characteristics of included reviews

Of the 28 reviews included, 25 were general systematic reviews(18,20,35–57), two were Cochrane systematic reviews(58,59), and one was a systematic integrative review(60). The number of included studies per review ranged between 3 and 26 studies. No methodological approaches were applied to investigate overlap of included primary studies. All reviews included one or more RCTs. A meta-analysis of at least one predefined outcome was performed in 21 reviews(18,20,35,37–39,42–45,47–55,58,59). The articles were published between 2016 and 2020 with the majority published in 2020 (n = 8/28).

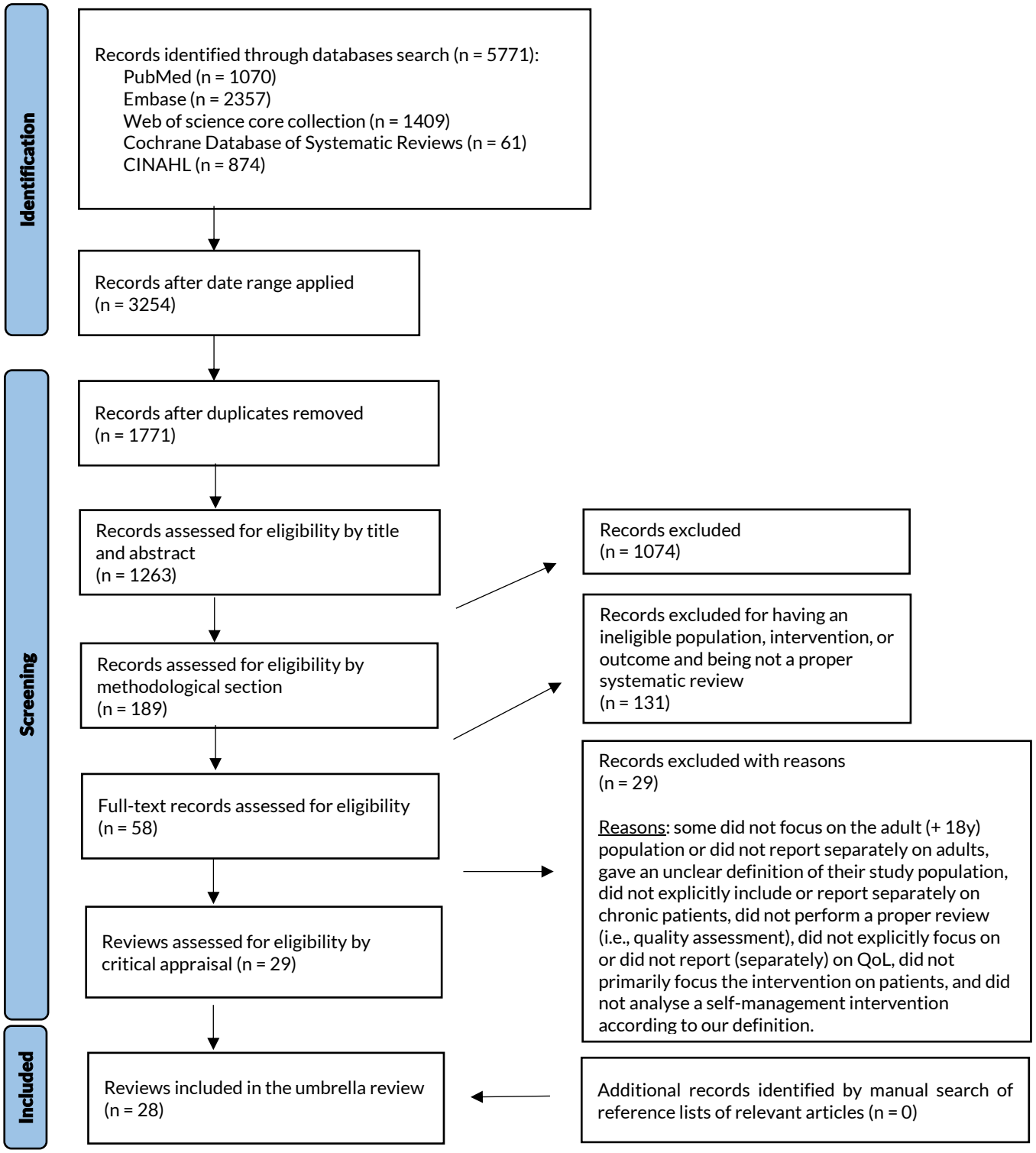


Figure 1. Umbrella review selection process (Page et al., 2020)(61)

The databases most frequently accessed were PubMed/Medline (n = 28/28), CINAHL (n = 25/28), Cochrane databases (n = 20/28), Embase (n = 19/28), PsycINFO (n = 12/28) and Web of Science (n = 11/28). The reported search dates of the included reviews ranged from 1995 to 2020. The reviews were conducted in Europe (UK, Belgium, , Italy, Ireland, Denmark), Asia (Taiwan, China, Singapore, Turkey, Japan), America (Canada, USA), Africa (Ethiopia) and Australia. The most frequently cited country of origin was the UK (n = 7/28). Full details of the characteristics of the included reviews can be found in supplemental file 5.

Methodological quality of included reviews

A total of 29 reviews were assessed for eligibility by critical appraisal using the JBI Critical Appraisal Checklist for Systematic reviews and Research Syntheses tool (supplemental file 4). However, one review did not meet the minimum quality criteria for inclusion after applying our cut-off score. The 28 remaining included reviews all set appropriate inclusion criteria for their predefined research question (Q2) and this question was explicitly stated in the methods section of 10 of the 28 reviews (Q1). Most of the included articles formulated the search strategy appropriately (Q3) and all included reviews consulted appropriate sources and resources for the inclusion of primary studies (Q4). These primary studies were appropriately critically appraised in all but one of the included reviews (Q5) and 24 of the 28 reviews did perform this appraisal by at least 2 independent reviewers (Q6). In addition, all included reviews used methods that appropriately combined the primary studies (Q8) and 25 of the 28 reviews also used methods to minimize errors in data extraction (Q7). Unfortunately, only nine of the 28 reviews reported on assessment of publication bias (Q9). Finally, 21 of the 28 included reviews gave recommendations for policy and/or practice that were supported by the reported data (Q10). In addition, only three of the 28 reviews gave appropriate directives for future research (Q11).

Critical appraisal of primary studies

The quality of the primary studies included in the systematic reviews was critically appraised using several instruments. Table 1 presents an overview of appraisal instruments cited in the included reviews. The choice of instrument depended significantly on the type of primary studies included. The majority was assessed by the (revised) Cochrane Collaboration Bias Appraisal tool (n = 22/28). Quality varied substantially among the primary studies and was not reported textually in one review(53) . Comparison of quality in relation to the appraisal instrument used is beyond the scope of this umbrella review. Blinding of the study population and investigators (performance bias) and blinding of the outcome assessors (detection bias) represented the highest risk of bias domains in most of the included studies.

The absence or unclear description of allocation concealment (selection bias) was also frequently mentioned as a quality limitation. The reported overall quality of evidence was very low to moderate/acceptable in most studies.

Table 1: Appraisal instruments cited in included reviews

Appraisal instrument	Number of reviews
Cochrane instruments	21
GRADE (Grading of Recommendations, Assessment, Development and Evaluations)	8
JBI (Joanna Briggs Institute) checklists	5
CASP (Critical Appraisal Skills Programme)	1
MCHRI (Monash Centre for Health Research and Implementation) template	1
Caldwell framework	1
Modified Jadad Scale	1
CEBM (Centre for Evidence-Based Medicine)	1
Effective Public Health Practice Project Quality assessment tool	1
PEDro scale	1

Characteristics of SMS interventions

The majority of included reviews analyzed a mix of different SMS interventions targeting different SM skills. Aspects of these mixed interventions were patient activation and health coaching (incl. information provision)(36–38,51), physical activity(36,38), support (incl. providing feedback) and counselling(42,49–51,56,58), occupational therapy to develop coping skills(54), problem identification/solving(49,58), decision-making(57), self-monitoring(42,49,50,59), reinforcing support tools(50,58), lifestyle adaptations(38,59), goal setting/developing action plans(49,58,59) and prevention(20,58). Two reviews exclusively examined coaching interventions(45,55). Interventions specifically targeting education were described in five separate reviews(18,39,41,43,44). These interventions mainly focused on facilitating knowledge, skills and abilities. One review specifically explored the teach-back method to support SM(41). Six reviews reported on eHealth technologies(40,42,47,50,52,59). The reported internet resources were computer, mobile phone, smartphone, tablet or other electronic equipment. Finally, one review(36) exclusively examined physical interventions.

Target group and setting

The included SMS interventions involved adults with a wide range of chronic conditions: COPD(18,38,39,42,45,51,59), metabolic diseases(52), stroke(46,54,58), chronic kidney disease(35,49,53,60), cancer(36,37,47,48,57), liver cirrhosis(20), diabetes(18,37,43,44,49,50,55), HIV(56), chronic respiratory disease(37) and cardiovascular disease(18,37,40). Three reviews included patients with multiple health conditions(18,41,49). The total number of participants recorded in a systematic review ranged from 299(20) to 10647(51).

Four reviews did not report their total sample size(37,52,53,55). The settings described for the included interventions were inpatient(18,20,41,44,45,47,49) and outpatient care(20,42,49,58), primary care(41,42,44,49,51), secondary care(42), community setting(42,58), specified primary care settings such as general practices(18), the physiotherapist(42), community pharmacies(41), education centers and churches(44), community health centers(18,44), home/non-healthcare residential setting (remote)(18,36,40,41,44,46,47,56–59) or combinations of the above(42). In two cases(50,52), the setting was not relevant to the intervention as it involved the use of the internet. In 13 systematic reviews, the settings were not or only partially reported in the findings section.

Delivery strategy and persons involved

The SMS interventions were delivered and/or supervised face-to-face(18,20,35,37,41,45,49,51,55,58), by phone contact(18,20,35,37,41,43,45–47,49,51,55,56,58), or by electronic assistance(36,40,42,47,49,50,52,55–57,59) (app, website, wearable technology, etc.), or combinations of the above. Three reviews indicated that audio-visual materials were employed to deliver the interventions(36,43,51). In addition, seven reviews cited the use of written materials(36,38,41,49,51,56,58). SMS interventions were delivered both individually(20,38,43,44,46,49,56–58,60) and in group settings(20,38,43,44,46,48,49,56–58,60). A single review described self-study as a delivery method(57). Three reviews did not report the delivery methods textually(39,53,54). The professionals carrying out the interventions, included in the systematic reviews, consisted of case managers(41,44), nurses(18,20,38,41,43,45,46,49,51,60), pharmacists(41,44,45), health coaches(45,55), general practitioners(39,49,51), nurse practitioners(51), medical assistants(51), psychologists(51), peers(49,51,56,58), laypersons from the community(20), social workers(20,49,60), trained healthcare professionals(58), specialists(39,49,60), research assistants(41), dieticians(41,43,44,49), community health workers(43,44), expert patients(43), educators(44), occupational therapists(46), physiotherapists(46), trainees(49) and

combinations of the above. Two reviews(50,57) did not specify the type of healthcare provider in the narrative overview and six other reviews(35–37,48,53,54) did not or only partially report the persons involved in intervention delivery of the original studies. In addition, five reviews did not describe any stakeholder or healthcare professional as the interventions consisted of e-health technologies(40,42,47,52,59) or self-study(57).

Theoretical background/rationale

Theoretical underpinnings for the SMS interventions were heterogenous. If reported, behavioural frameworks were mentioned most often (n = 6/28)(43,46,47,54,55,57). Other studies included in the systematic reviews indicated the use of the Self-Management Programme of Activity(45), Coping and Education (SPACE)(45), the Control Cognitions Theory(54), the Chronic Care Model(49,54), the Trans-theoretical Stages-of-Change(46), the concept of health literacy(49), the Stanford Model(49), the Expert Patient Programme(49), the Flinders Model(49)and psychosocial theories(46,54).

Intervention duration and follow-up

Duration of interventions included in the systematic reviews ranged between 2 weeks(42,43,52) and 3 years(56). In addition, follow-up time varied between 2 weeks(40) and 4 years(51). In four reviews(38,40,53,55) information about the duration of the included studies was absent, inconsistent or unclear, while 10 others(35,37,42–44,46–48,50,57) did not report follow-up time. Six reviews did not report duration or follow-up time in-text(18,36,39,41,54,60).

The effect of interventions on patient QoL

QoL measures were included as patient-reported psychological outcomes across all SMS interventions in the systematic reviews. The number of studies examining QoL included in a systematic review ranged from one(41,60) to 15(39). A median number of six studies per systematic review reported QoL outcomes. In addition to QoL, the included reviews assessed other outcomes such as behavioural outcomes, physiological and psychological outcomes, physical outcomes, healthcare outcomes and learning outcomes. Analysis of the impact on these other outcomes is beyond the scope of this umbrella review.

Instruments for measuring QoL

In total, the systematic reviews reported 41 different measurement tools to assess QoL. More than half of the included reviews focused on health-related quality of life - HRQoL (n = 21/28). The most frequently included measurement instruments, employed in the primary studies and reported in the reviews, were the 36-Item Short Form Survey (SF-36) (n = 12/28) and the

European Quality of Life-5 Dimensions instruments (EQ-5D) (n = 9/28). Table 2 presents an overview of general QoL measurement instruments cited in the included reviews that are not specific to any disease. In addition, QoL instruments for specific conditions were used to evaluate the included SMS interventions. These disease-specific instruments to measure QoL can be divided into the following categories: respiratory diseases-specific tools(38,39,42,45,51,59), stroke-specific tools (46,54,58), diabetes-specific tools(44,49,50,55), cancer-specific tools(20,36,47,48,57), kidney disease-specific tools(35), liver disease-specific tools(20), and heart failure-specific tools(41). Four systematic reviews did not mention their measurement instruments in the narrative overviews(37,52,56,60).

Table 2: General QoL measurement instruments cited in included reviews

Measurement instrument	Number of reviews
36-Item Short Form Survey (SF-36)	12
European Quality of Life-5 Dimensions instruments (EQ-5D)	9
12-Item Short Form Health Survey (SF-12)	4
Short Form 36 Physical Component Summary (SF-36 PCS)	1
Short Form 12 Physical Component Summary (SF-12 PCS)	1
Assessment of Quality of Life (AQoL)	1
Hospital Anxiety and Depression Scale (HADS)	1
Kessler Psychological Distress Scale (K10)	1
Health-related General Health Questionnaire-28 (GHQ-28)	1
World Health Organization Quality of Life Questionnaire (WHOQOL)	1
WHO-5 Well-Being questionnaire (WHO-5)	1
Long-Term Quality of Life Instrument (LTQL)	1
Functional Assessment of Chronic Illness Therapy – Fatigue (FACIT-F)	1
Healthy Days Measure Scale	1
WONCA scores	1

Impact on QoL outcomes

Nine reviews cited a positive impact of interventions on participants' QoL. Four of them demonstrated improvements related to educational interventions(39,50,56,60). Kuo *et al* (2018) described significant improvements through Internet empowerment-based interventions(52). Also, mobile and smartphone-based interventions were associated with positive outcomes(40,50). Furthermore, physical and patient- activating interventions improved QoL(36,37). Lin *et al* (2017) described a significant impact on HRQoL but the content of the interventions was not textually specified(35).

Eight other systematic reviews showed positive QoL trends for health coaching interventions(45), educational interventions(44), and interventions employing computer and mobile technologies(59). One review on group interventions found no significant differences, but subgroup analyses favored the interventions(48). Two other reviews described mixed positive results, depending on the measurement instrument used(38,46). Finally, two reviews described potential for SMS interventions to improve dimensions of QoL, particularly global HRQoL(57) in one review and mental components of QoL in another(53). Seven reviews found no (significant) benefit of their included interventions on patients' QoL. The content of these interventions varied: mixed SMS interventions(20), e-health interventions(47), health coaching interventions(55), community-based interventions(51), and occupational therapy interventions(54). Two reviews including heterogenous SMS interventions did also not observe significant improvements in QoL(49,58). Four reviews could not conclude on the impact on QoL because of inconsistency between the primary studies they reviewed(18,42,43) or a small sample size regarding QOL studies(41).

Discussion and conclusion

Discussion

Content, target group and setting of interventions

The umbrella review revealed a heterogeneity of SMS interventions, even within a specific type of intervention. This confirms the multifaceted complex nature of SMS and highlights that a comprehensive approach that recognizes that SM goes beyond a checklist of core skills is essential, allowing for more expanding descriptions of SM processes(62,63). Returning reported components in the included studies were education, eHealth and mHealth technologies, and coaching techniques. Unfortunately, in-depth information about their characteristics was often missing. Behavioral frameworks were frequently described to scientifically support interventions. However, these methodologies only facilitate SM partially(64). Therefore, it is essential to consult models representing holistic SMS before developing interventions(65). The most frequently cited target group for the interventions were individuals with diabetes. Only three reviews included patients with multiple health conditions. However, assessing the impact of interventions focusing on multiple health conditions is of great value given the increase in multimorbidity(21). The interventions primarily took place in the home setting/non-healthcare residential setting.

Delivery strategy, duration and follow-up

The support was mainly delivered face-to-face. In case of e- and m-Health, electronic assistance was provided. Telephone communication was regularly reported as a type of intervention follow-up. Information on this follow-up was often under-reported or limited. However, information on follow-up and drop-out of participants could provide valuable insights into the sustainability of SMS interventions. Therefore, it's valuable to include attrition as a secondary endpoint in interventions(66).

The duration was also regularly not or inconsistently reported in text but when provided, the interventions usually lasted no longer than one year. Interventions were delivered and/or supervised by a variety of individuals, with nurses being the most commonly reported. Remarkably, complex interventions were more likely to be conceptualized based on content, rather than on specific characteristics (i.e.; delivery, duration, follow-up).

Impact on QoL

A total of 41 different measurement instruments were reported. This highlights the need to develop standardized outcome measures related to QoL(22,67). The SF-36 tool was cited most, as it is representative of general QoL research in medicine and health sciences(68). Reviews describing positive outcomes included educational interventions, patient activation and health coaching interventions, physical interventions, and lifestyle components. These interventional components have also been reported as effective in more recent studies, not yet included in this umbrella review due to their recent publication date(69–71). However, it is important to note that the same recurring issues prevent drawing firm conclusions. One similar significant limitation is the lack of comprehensive and detailed information, reported in SMS studies(72). In addition, the implementation of theoretically effective components has many challenges, which in turn hinder the attainment of statistically significant effects(69). Recent studies therefore emphasize the need to draw more attention on understanding the implementation processes, as well as addressing difficulties and deficiencies during the implementation phase(73). In our review, most interventions associated with a positive impact on QoL included an educational component(39,50,56,60). However, consistent with previous research on the effect of SM education(74–76), further exploration should focus on whether education has added value on its own or only as a complement to other forms of SMS. In addition, if improvements on QoL were reported, they were often only seen on components of QoL(53). This can be explained from the perspective that QoL is a multi-faceted concept(77). In a more recent study, Song *et al.* (2021) investigated the impact of including different interventional components to facilitate SM(78). Their findings offer an insightful perspective on our own results, as blended interventions were

found to positively impact QoL. However, their study encountered the common challenge, namely the extensive heterogeneity in intervention approaches and outcome measures, hindering meaningful comparisons between findings(78).

Quality of the evidence

The methodological quality of the included systematic reviews varied. Inconsistency in data of the primary studies resulted in inconclusive systematic review findings, with consequently no firm conclusions in this umbrella review. Further, concerns can be expressed about the number of primary studies per systematic review. On average, fewer than seven primary studies were included per systematic review to make statements related to QoL. For example, Boudreault *et al*(20) (2020) concluded that there is no evidence for improvements in QoL based on the inclusion of only two primary QoL studies. Furthermore, it should be noted that the impact on QoL in the included reviews was often not thoroughly detailed. This lack of clarity raises concerns, as it was often not clear if the improvements were seen across all aspects of QoL or only in the HRQoL and its sub-scales. In addition, ambiguous or even incorrect reporting of findings should be mentioned as a recurring problem in the included systematic reviews. Yau *et al*(60) (2019) made no explicit statements but implied beneficial effect on HRQoL based on two included primary QoL studies. However, the results they presented did not clearly show which primary studies analyzed which outcomes. In addition, inconsistency between textual and tabular presentation of data was observed in some of the included reviews. Massimi *et al*(18) (2017) narratively underreported QoL relative to their tables and Areri *et al*(56) (2020) reported for fewer studies than included. Another example is the review of Aminuddina *et al*(50) (2019) , since the bias reported in the text (as an indicator of study quality) did not accurately reflect the bias reported in the table. These inconsistencies and ambiguities were the rationale for including only information from the articles' texts for this overarching umbrella review.

Limitations

Due to the large heterogeneity of the included SMS interventions, no firm conclusions can be drawn on effectiveness and results need to be interpreted with caution. However, this overarching review provides an extensive overview of existing SMS interventions. The limited reporting of intervention characteristics with respect to QoL resulted in it not being possible to disaggregate effects by intervention type. In addition, the included data was often of poor quality. Concerns should be expressed regarding the methodology of the primary studies. Also, meta-analysis was often not performed due to significant heterogeneity of data. This may however be seen as a limitation of the included reviews, rather than a limitation of our umbrella review. Furthermore, we did not analyze overlap between primary studies included in the

systematic reviews, which biased our findings of the umbrella review. Moreover, the inclusion process of the included systematic reviews was strongly influenced by the adopted definition of chronic disease(31) and our comprehensive approach towards the concept of self-management (support). This highlights the need for standardization of such concepts, prior to the performance of new healthcare research(79,80). This issue is also repeatedly highlighted in more recent literature research(63,71,72,78). Finally, since undertaking the literature search and analysis for this review, numerous additional systematic reviews reporting on QoL outcomes of SM interventions have been published. The time between conducting this umbrella review and its subsequent publication may have resulted in omitting some additional information relevant to this review. However, after consulting the latest research, we concluded that these findings are consistent with our conclusions. To reinforce this umbrella review and demonstrate the similarities, we have incorporated the most relevant new systematic reviews into the discussion section.

Conclusion

This review provides a clear overview of the types and characteristics of recent SMS interventions in adults with chronic disease. Heterogeneity in a variety of determinants (e.g., measurement instruments, definition of QoL and SM(S), QoL and QoL-related outcomes, interventional types and characteristics, target populations, delivery methods and settings) made it impossible to pool data and to provide clear evidence on the effectiveness related to QoL. Nonetheless, the analysis did yield several insights. In particular, education seems a promising component of SMS interventions and showed a beneficial effect on QoL. Where, by whom and how interventions are ideally delivered remains unclear. Comparative analyses and statements about effect are not appropriate until a standardized approach to defining and evaluating QoL is adopted.

Practical implications and suggestions for further research

We believe that SMS interventions have the potential to positively affect patients' QoL. Clinicians should ensure that future projects include effective components from existing or previous interventions. Incorporating educational components is highly recommended. In order to determine effective intervention characteristics, there a is need for standardization of terminology and measurement tools. Subsequently, efforts should be made for more high-quality research reporting data unambiguously and consistently.

References

1. Kuluski K, Ho JW, Hans PK, La Nelson M. Community care for people with complex care needs: Bridging the gap between health and social care. Int J Integr Care. 2017 Jul 21;17(4):2.
2. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. Lancet. 2012 Jul 7;380(9836):37–43.
3. Van Der Heide I, Melchiorre MG, Quattrini S, Boerma W. Innovating care for people with multiple chronic conditions in Europe An overview. 2015.
4. World Health Organization. Preventing Chronic Diseases: a Vital Investment [Internet]. World Health Organization. 2020 [cited 2020 Sep 8]. Available from: https://www.who.int/chp/chronic_disease_report/part1/en/index1.html
5. Alliance E chronic disease. Chronic disease & Policy - European chronic disease alliance [Internet]. 2020 [cited 2020 Aug 14]. Available from: https://alliancechronicdiseases.org/chronic-disease-policy/
6. Union O and E. Health at a Glance: Europe 2018 STATE OF HEALTH IN THE EU CYCLE [Internet]. 2018 [cited 2020 Aug 17]. 212 p. Available from: https://doi.org/10.1787/health_glance_eur-2018-en
7. WHO. WHO global strategy on integrated people-centred health services 2016-2026. 2015;
8. Markwart HI, Bomba F, Menrath I, Brenk-Franz K, Ernst G, Thyen U, et al. Assessing empowerment as multidimensional outcome of a patient education program for adolescents with chronic conditions: A latent difference score model. PLoS One. 2020;15(4):e0230659.
9. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7.
10. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
11. Knickman JR, Schroeder SA, Sandy LG, Gibson R. Chronic disease management: Social priorities in a changing health care market. Vol. 1, Disease Management and Clinical Outcomes. 1997. p. 2–4.
12. Institute for Healthcare Improvement: Changes to Improve Chronic Care [Internet]. 2019 [cited 2019 Dec 24]. Available from: http://www.ihi.org/resources/Pages/Changes/ChangestoImproveChronicCare.aspx
13. Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. Jt Comm J Qual Saf. 2003 Nov 1;29(11):563–74.
14. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract. 2001;4(6):256–62.
15. Panagioti M, Richardson G, Small N, Murray E, Rogers A, Kennedy A, et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: A systematic review and meta-analysis. BMC Health Serv Res. 2014 Dec 27;14(1):356.
16. Richardson J, Loyola-Sanchez A, Sinclair S, Harris J, Letts L, MacIntyre NJ, et al. Self-management interventions for chronic disease: A systematic scoping review. Clin Rehabil. 2014 Apr 30;28(11):1067–77.
17. Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. PLoS One. 2019;14(8):e0220116.
18. Massimi A, De Vito C, Brufola I, Corsaro A, Marzuillo C, Migliara G, et al. Are community-based nurse-led self-management support interventions effective in chronic patients? Results of a systematic review and meta-analysis. PLoS One. 2017;12(3):e0173617.
19. Lee JA, Choi M, Lee SA, Jiang N. Effective behavioral intervention strategies using mobile health applications for chronic disease management: a systematic review. BMC Med Inf Decis Mak. 2018;18(1):12.
20. Boudreault S, Chen J, Wu KY, Plüddemann A, Heneghan C. Self-management programmes for cirrhosis: A systematic review. J Clin Nurs (John Wiley Sons, Inc). 2020;29(19):3625–37.
21. Whitty CJM, MacEwen C, Goddard A, Alderson D, Marshall M, Calderwood C, et al. Rising to the challenge of multimorbidity. BMJ. 2020 Jan 6;368:I6964.
22. Flanagan S, Damery S, Combes G. The effectiveness of integrated care interventions in improving patient quality of life (QoL) for patients with chronic conditions. An overview of the systematic review evidence. Health Qual Life Outcomes. 2017 Sep;15(1):188.
23. Lawn S. Chronic physical illness: self-management and behavioural interventions. Vol. 9, International Journal of Integrated Care. Ubiquity Press, Ltd.; 2009. e07 p.
24. Buiting HM, Olthuis G. Importance of Quality-of-Life Measurement Throughout the Disease Course. JAMA Netw Open. 2020 Mar 2;3(3):e200388–e200388.
25. Shofany C. Quality of life among chronic disease patients. Nurs Care Open Access J. 2017 Dec 7;4(2):385–94.
26. Addington-Hall J, Kalra L. Measuring quality of life: Who should measure quality of life? Br Med J. 2001 Jun 6;322(7299):1417–20.
27. Boger EJ, Demain S, Latter S. Self-management: a systematic review of outcome measures adopted in self-management interventions for stroke. Disabil Rehabil. 2013 Aug;35(17):1415–28.

28. Aromataris E, Fernandez R, Godfrey CM, Holly C, Khalil H, Tungpunkom P. Summarizing systematic reviews: Methodological development, conduct and reporting of an umbrella review approach. Int J Evid Based Healthc. 2015;13(3):132–40.
29. Miller WR, Lasiter S, Bartlett Ellis R, Buelow JM. Chronic disease self-management: A hybrid conceptanalysis. Nurs Outlook. 2015 Mar 1;63(2):154–61.
30. World Health Organization. Noncommunicable diseases [Internet]. 2020 [cited 2020 Aug 17]. Available from: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases
31. Alliance E chronic disease. Chronic disease & Policy - European chronic disease alliance [Internet]. 2020 [cited 2020 Oct 12]. Available from: https://alliancechronicdiseases.org/chronic-disease-policy/
32. Howell D, Richardson A, May C, Calman L, Fazelzad R, Moradian S, et al. Implementation of self-management support in cancer care and normalization into routine practice: A systematic scoping literature review protocol. Syst Rev. 2019 Jan 31;8(1):37.
33. Jones MC, MacGillivray S, Kroll T, Psych D, Reza Zohoor A, Connaghan J. A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. J Nurs Healthc Chronic Illn. 2011 Sep 1;3(3):174–85.
34. Aromataris, E., Fernandez, R., Godfrey, C., Holly, C., Khalil, H. & Tungpunkom P. The Joanna Briggs Institute Reviewers' Manual 2014: Methodology for JBI Umbrella Reviews. Joanne Briggs Inst. 2014;1–34.
35. Lin M-Y, Liu MF, Hsu L-F, Tsai P-S. Effects of self-management on chronic kidney disease: A meta-analysis. Int J Nurs Stud. 2017;74:128–37.
36. Van Dijck S, Nelissen P, Verbelen H, Tjalma W, Gebruers N. The effects of physical self-management on quality of life in breast cancer patients: A systematic review. Breast. 2016;28:20–8.
37. Lin M-Y, Weng W-S, Apriliyasari RW, Van Truong P, Tsai P-S. Effects of Patient Activation Intervention on Chronic Diseases: A Meta-Analysis. J Nurs Res (Lippincott Williams Wilkins). 2020;28(5):e116–e116.
38. Helvaci A, Metin ZG. The effects of nurse-driven self-management programs on chronic obstructive pulmonary disease: A systematic review and meta-analysis. J Adv Nurs. 2020;76(11):2849–71.
39. Cannon D, Buys N, Sriram KB, Sharma S, Morris N, Sun J. The effects of chronic obstructive pulmonary disease self-management interventions on improvement of quality of life in COPD patients: A meta-analysis. Respir Med. 2016;121:81–90.
40. Coorey GM, Neubeck L, Mulley J, Redfern J. Effectiveness, acceptability and usefulness of mobile applications for cardiovascular disease self-management: Systematic review with meta-synthesis of quantitative and qualitative data. Eur J Prev Cardiol. 2018;25(5):505–21.
41. Ha Dinh TT, Bonner A, Clark R, Ramsbotham J, Hines S. The effectiveness of the teach-back method on adherence and self-management in health education for people with chronic disease: A systematic review. JBI Database Syst Rev Implement Reports. 2016;14(1):210–47.
42. Shaw G, Whelan ME, Armitage LC, Roberts N, Farmer AJ. Are COPD self-management mobile applications effective? A systematic review and meta-analysis. npj Prim Care Respir Med. 2020;30(1):11.
43. Tanaka R, Shibayama T, Sugimoto K, Hidaka K. Diabetes self-management education and support for adults with newly diagnosed type 2 diabetes mellitus: A systematic review and meta-analysis of randomized controlled trials. Diabetes Res Clin Pract. 2020;169:108480.
44. Cunningham AT, Crittendon DR, White N, Mills GD, Diaz V, LaNoue MD. The effect of diabetes self-management education on HbA1c and quality of life in African-Americans: a systematic review and meta-analysis. BMC Heal Serv Res. 2018;18(1):367.
45. Long H, Howells K, Peters S, Blakemore A. Does health coaching improve health-related quality of life and reduce hospital admissions in people with chronic obstructive pulmonary disease? A systematic review and meta-analysis. Br J Heal Psychol. 2019;24(3):515–46.
46. Kristine Stage Pedersen S, Lillelund Sørensen S, Holm Stabel H, Brunner I, Pallesen H. Effect of Self-Management Support for Elderly People Post-Stroke: A Systematic Review. Geriatr. 2020;5(2):38.
47. Xu AQ, Wang YP, Wu X. Effectiveness of e-health based self-management to improve cancer-related fatigue, self-efficacy and quality of life in cancer patients: Systematic review and meta-analysis. J Adv Nurs. 2019;75(12):3434–47.
48. Smith-Turchyn J, Morgan A, Richardson J. The Effectiveness of Group-based Self-management Programmes to Improve Physical and Psychological Outcomes in Patients with Cancer: a Systematic Review and Meta-analysis of Randomised Controlled Trials. Clin Oncol (R Coll Radiol). 2016;28(5):292–305.
49. Zimbudzi E, Lo C, Misso ML, Ranasinha S, Kerr PG, Teede HJ, et al. Effectiveness of self-management support interventions for people with comorbid diabetes and chronic kidney disease: A systematic review and meta-analysis. Syst Rev. 2018;7(1):84.
50. Aminuddin HB, Jiao N, Jiang Y, Hong J, Wang W. Effectiveness of smartphone-based self-management interventions on self-efficacy, self-care activities, health-related quality of life and clinical outcomes in patients with type 2 diabetes: A systematic review and meta-analysis. Int J Nurs Stud. 2019;116:103286.
51. Jolly K, Sidhu MS, Bates E, Majothi S, Sitch A, Bayliss S, et al. Systematic review of the effectiveness of community-based self-management interventions among primary care COPD patients. npj Prim Care Respir Med. 2018;28(1):44.
52. Kuo CC, Su YJ, Lin CC. A systematic review and meta-analysis: Effectiveness of internet empowerment-based self-management interventions on adults with metabolic diseases. J Adv Nurs. 2018;74(8):1787–802.

53. Lee M-C, Wu S-FV, Hsieh N-C, Tsai J-M. Self-Management Programs on eGFR, Depression, and Quality of Life among Patients with Chronic Kidney Disease: A Meta-Analysis. Asian Nurs Res (Korean Soc Nurs Sci). 2016;10(4):255–62.
54. Wray F, Clarke D, Forster A. Post-stroke self-management interventions: a systematic review of effectiveness and investigation of the inclusion of stroke survivors with aphasia. Disabil Rehabil. 2018;40(11):1237–51.
55. Pirbaglou M, Motamed M, Pludwinski S, Katz J, Ritvo P, Walker K. Personal Health Coaching as a Type 2 Diabetes Mellitus Self-Management Strategy: A Systematic Review and Meta-Analysis of Randomized Controlled Trials. Am J Heal Promot. 2018;32(7):1613–26.
56. Areri HA, Marshall A, Harvey G. Interventions to improve self-management of adults living with HIV on Antiretroviral Therapy: A systematic review. PLoS One. 2020;15(5):e0232709.
57. Cheng L, Kotronoulas G. How effective are self-management interventions in promoting health-related quality of life in people after primary treatment for breast cancer? A critical evidence synthesis. Eur J Oncol Nurs. 2020;47:101776.
58. Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. Cochrane Database Syst Rev. 2016;2016(8):CD010442.
59. McCabe C, McCann M, Brady AM. Computer and mobile technology interventions for self-management in chronic obstructive pulmonary disease. Cochrane Database Syst Rev. 2020;5(5):Cd011425.
60. Yau CLH, Chun JCP. The Effects of Self-Management Interventions on the Health Outcomes of Individuals With Chronic Kidney Disease After Critical Illness: An Integrative Review. Connect World Crit Care Nurs. 2019;13(3):126–44.
61. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. Vol. 372, The BMJ. British Medical Journal Publishing Group; 2021. p. n71.
62. Grady PA, Gough LL. Self-management: A comprehensive approach to management of chronic conditions. Am J Public Health. 2018 Dec 1;108(8):S430–6.
63. Tharani A, Van Hecke A, Ali TS, Duprez V. Factors influencing nurses' provision of self-management support for patients with chronic illnesses: A systematic mixed studies review. Int J Nurs Stud. 2021 Aug 1;120:103983.
64. Hannah Burd, Michael Hallsworth. Supporting self-management: A guide to enabling behaviour change for health and wellbeing using person- and community-centred approaches [Internet]. 2016 Sep [cited 2022 Dec 23]. Available from: https://www.nesta.org.uk/report/supporting-self-management-a-guide-to-enabling-behaviour-change-for-health-and-wellbeing-using-person-and-community-centred-approaches/
65. Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, et al. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022;23(1):1–13.
66. Meyerowitz-Katz G, Ravi S, Arnolda L, Feng X, Maberly G, Astell-Burt T. Rates of Attrition and Dropout in App-Based Interventions for Chronic Disease: Systematic Review and Meta-Analysis. J Med Internet Res. 2020 Sep 29;22(9):e20283.
67. Ware JE, Gandek B, Guyer R, Deng N. Standardizing disease-specific quality of life measures across multiple chronic conditions: Development and initial evaluation of the QOL Disease Impact Scale (QDIS®). Health Qual Life Outcomes. 2016 Jun 2;14(1):1–16.
68. Haraldstad K, Wahl A, Andenæs R, Andersen JR, Andersen MH, Beisland E, et al. A systematic review of quality of life research in medicine and health sciences. Qual Life Res. 2019 Oct 1;28(10):2641.
69. Liu S, Li J, Wan DY, Li R, Qu Z, Hu Y, et al. Effectiveness of eHealth Self-management Interventions in Patients With Heart Failure: Systematic Review and Meta-analysis. J Med Internet Res. 2022 Sep 1;24(9):e38697.
70. Shnaigat M, Downie S, Hosseinzadeh H. Effectiveness of patient activation interventions on chronic obstructive pulmonary disease self-management outcomes: A systematic review. Aust J Rural Health. 2022 Feb 1;30(1):8–21.
71. Davidson P, LaManna J, Davis J, Ojeda MM, Hyer S, Dickinson JK, et al. The Effects of Diabetes Self-Management Education on Quality of Life for Persons With Type 1 Diabetes: A Systematic Review of Randomized Controlled Trials. Sci diabetes self-management care. 2022 Apr 1;48(2):111.
72. Schrijver J, Lenferink A, Brusse-Keizer M, Zwerink M, Valk PDLPM van der, Palen J van der, et al. Self-management interventions for people with chronic obstructive pulmonary disease. Cochrane database Syst Rev. 2022;1(1):CD002990.
73. Feng C, Wang Y, Li S, Qu Z, Zheng S. Effect of self-management intervention on prognosis of patients with chronic heart failure: A meta-analysis. Nurs Open. 2023 Apr 1;10(4):2015–29.
74. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Vol. 26, Annals of Behavioral Medicine. Lawrence Erlbaum Associates Inc.; 2003. p. 1–7.
75. Otsu H, Moriyama M. Effectiveness of an educational self-management program for outpatients with chronic heart failure. Jpn J Nurs Sci. 2011 Dec;8(2):140–52.
76. Abbasi A, Najafi Ghezeljeh T, Ashghali Farahani M. Effect of the self-management education program on the quality of life in people with chronic heart failure: a randomized controlled trial. Electron physician. 2018 Jul 25;10(7):7028–37.

77. Teoli D, Bhardwaj A. Quality Of Life. In Treasure Island (FL); 2022.
78. Song X, Hallensleben C, Zhang W, Jiang Z, Shen H, Gobbens RJJ, et al. Blended Self-Management Interventions to Reduce Disease Burden in Patients With Chronic Obstructive Pulmonary Disease and Asthma: Systematic Review and Meta-analysis. J Med Internet Res. 2021 Mar 1;23(3):e24602.
79. Li J, Zhang L, Zhou J, Wang G, Zhang R, Liu J, et al. Development and validation of self-management scale for tuberculosis patients. BMC Infect Dis 2022 221. 2022 May 27;22(1):1–13.
80. Van De Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: A concept analysis. BMJ Open. 2019;9(7):e027775.

Appendix Chapter 1

Supplementary file 1: search strategy Medline

Pubmed search

("Self-Management"[Mesh] OR Self-Manag*[tiab] OR self-care-manag*[tiab]) AND ("Chronic Disease"[Mesh] OR Chronic-condition*[tiab] OR long-term-condition*[tiab] OR chronic-health-condition*[tiab] OR "chronic care"[tiab] OR "chronic health care"[tiab] OR "chronic healthcare"[tiab] OR "complex care"[tiab] OR chronic-illness*[tiab] OR Chronically-Ill[tiab] OR "Noncommunicable Diseases"[Mesh] OR Noncommunicable-Disease*[tiab] OR Non-communicable-Disease*[tiab] OR "Respiratory Tract Diseases"[Mesh] OR "Cardiovascular Diseases"[Mesh] OR Respiration-Disorder*[tiab] OR Cardiovascular-Disease*[tiab] OR "Diabetes Mellitus"[Mesh] OR “diabetes”[tiab] OR diabetic*[tiab] OR “asthma” [tiab] OR “hypertension” [tiab] OR “heart failure” OR “stroke”[tiab] OR heart-disease*[tiab] OR "Neoplasms"[Mesh] OR “cancer"[tiab] OR lung-disease*[tiab] OR chronic-obstructive-pulmonary-disease*[tiab] OR “COPD” [tiab] OR (chronic[tiab] AND disease[tiab]) OR “Comorbidity"[Mesh] OR comorbid*[tiab] OR multimorbid*[tiab] OR multi-morbid*[tiab]) AND (“systematic”[sb] OR "systematic literature review" OR "Meta-Analysis" [Publication Type] OR "Systematic Review" [Publication Type] OR “meta-analysis” [tiab] OR “systematic review” [tiab] OR cochrane database syst rev[ta])

Supplementary file 2: screening template

Review title	…	
Date of screening	../../….	
Inclusion criteria	*Systematic reviews or meta-analyses*	**Y/N**
	Participants are adults suffering from at least one chronic disease (WHO definition)	**Y/N**
	Self-management support intervention, assessing QoL as an outcome measure	**Y/N**
Exclusion criteria	*Care intervention related to end-of life care*	**Y/N**
	No specified study population or no separate reporting for adults	**Y/N**
	Included studies based on theoretical studies or text and opinion	**Y/N**
	No clear description of search strategy, inclusion criteria, and quality assessment	**Y/N**
	Review without systematic approach (integrative, scoping, rapid review, etc)	**Y/N**
	Withdrawn/retracted publication	**Y/N**
	New version of article exists	**Y/N**

Y= Yes; N=No; WHO=World Health Organization

Supplementary file 3: customized JBI data extraction tool for Systematic Reviews and Research Syntheses

ARTICLE **DATE**
Study details Author/year Study country Main objective Included interventions with details of description Delivery method Theoretical background/content/format Setting/context Participants Key stakeholders, family members and professionals involved Frequency/intensity Follow-up
Search details Main databases searched Range of included studies Number of (QoL) studies included Types of studies included Country of origin of included studies
Appraisal details Appraisal instruments used Appraisal rating
Analysis details Type of review Meta-analysis yes/no Outcome(s) assessed Results/Findings related to QoL Instruments for measuring QoL Article's conclusion on effectiveness QoL
Comments

Supplementary file 4: JBI Critical Appraisal Checklist for Systematic reviews and Research Syntheses

Author, year	Is the review question clearly and explicitly stated in the method section?	Were the inclusion criteria appropriate for the review question?	Was the search strategy appropriate?	Were the sources and resources used to search for studies adequate?	Were the criteria for appraising studies appropriate?	Was critical appraisal conducted by two or more reviewers independently?	Were there methods to minimize errors in data extraction?	Were the methods used to combine studies appropriate?	Was the likelihood of publication bias assessed?	Were recommendations for policy and/or practice supported by the reported data?	Were the specific directives for new research appropriate?
Long et al., 2019	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
Mikhael et al., 2020	No	Yes	Unclear	No	Yes	Unclear	No	Yes	No	No	No
Jolly et al., 2018	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Kuo et al., 2018	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Lee et al., 2016	No	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
Boudreault et al., 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Fryer et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wray et al., 2018	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Pirbaglou et al., 2018	No	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes
Areri et al., 2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Cheng et al., 2020	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	No	Yes	Yes
Lin et al., 2017	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Yau et al., 2019	No	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Van Dijck et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	No	No	Yes

Lin et al., 2020	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**
Helvaci et al., 2020	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Unclear**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Cannon et al., 2016	**Yes**	**Yes**	**Unclear**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Coorey et al., 2018	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Unclear**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Ha Dinh et al., 2016	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Aminuddina et al., 2019	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Massimi et al., 2017	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Shaw et al., 2020	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
McCabe et al., 2020	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Tanaka et al., 2020	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**
Cunningham et al., 2018	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Pedersen et al., 2020	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**No**	**Yes**
Xu et al., 2019	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Smith-Turchyn et al., 2016	**No**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**Yes**	**Yes**
Zimbudzi et al., 2018	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**No**	**No**	**Yes**

Supplementary file 5: characteristics of the included reviews

Available at https://pubmed.ncbi.nlm.nih.gov/37536047/

Part II. Mapping patients' and professionals' experiences of primary care and self-management support

Chapter 2

How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study.

Published as:
Boeykens D, Sirimsi MM, **Timmermans L**, Hartmann ML, Anthierens S, De Loof H, De Vliegher K, Foulon V, Huybrechts I, Lahousse L, Pype P, Schoenmakers B, Van Bogaert P, Van den Broeck K, Van Hecke A, Verhaeghe N, Vermandere M, Verté E, Van de Velde D, De Vriendt P; Primary Care Academy. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. J Clin Nurs. 2023 Feb;32(3-4):422-437. doi: 10.1111/jocn.16243. Epub 2022 Feb 17. PMID: 35178849.

Abstract

Aims and objectives

Gaining insight in how people living with chronic conditions experience primary healthcare within their informal network.

Background

The primary healthcare system is challenged by the increasing number of people living with chronic conditions. To strengthen chronic care management, literature and policy plans point to a person-centered approach of care (PCC). A first step to identify an appropriate strategy to implement PCC, is to gain more insight into the care experiences of these people and their informal caregivers.

Design

A phenomenological-hermeneutical philosophy is used. The study is in line with the Consolidated Criteria for Reporting Qualitative Research Guidelines (COREQ).

Method

In-depth, semi-structured interviews with people living with chronic conditions and informal caregiver dyads (PCDs) (n=16; 32 individuals) were conducted. An open-ended interview guide was used to elaborate on the PCDs' experiences regarding primary care. A purposive, maximal variation sampling was applied to recruit the participants.

Results

Based on sixteen PCDs' reflections, ten themes were identified presenting their experiences with primary care and described quality care as: 'listening and giving attention to what people with chronic conditions want, to what they strive for, and above all to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family, and friends.

Conclusion

To meet the PCDs' needs, self-management should be addressed in an interprofessional environment in which the PCD is an important partner. The findings may facilitate a shift to encourage PCDs in their strengths by enabling them to share their personal goals and by working towards meaningful activities in team collaboration.

Relevance to clinical practice

Three strategies – self-management support, goal-oriented care, and interprofessional collaboration - have been suggested to improve the PCDs primary care experiences. These strategies could guide nursing practice in using more and improve high- quality of nursing care.

Keywords
Chronic illness, Lived experiences, Nursing practice, Phenomenological-hermeneutical, Primary care, Qualitative study

What does this paper contribute to the wider global clinical community?

- Primary care providers and especially nurses play a crucial role in the lives of people with chronic conditions and their informal caregivers as they support them in performing essential activities (e.g., taking medication, showering, etc.). Our findings suggest the need to reconsider the roles and responsibilities of primary care providers to encourage and also support people living with chronic conditions in performing meaningful activities (e.g., gardening, knitting).
- Care for people with chronic conditions and their informal caregivers, should pay attention to their needs, what they strive for, and promote their autonomy in a context where they are supported by a team of formal caregivers, family, and friends. By addressing these elements, people with chronic conditions and their informal caregivers can experience high-quality of care.

Introduction

As a result of the increasing number of people with chronic conditions high quality and accessible primary health care is required to improve coordination and continuity of care(1). Moreover, a person-centered care (PCC) approach is needed since each individual has different experiences towards primary healthcare(2). The main objective of this study is to gain in-depth insight into the daily lives of people living with chronic conditions and their informal caregivers, support they need regarding primary care, and the organization of primary care.

Background

In Europe, more than 50 million people have multiple chronic conditions(3). In Belgium, this is estimated at one-third of the national population and is increasing each year(4). Chronic conditions, defined as conditions lasting at least one year and requiring ongoing medical attention and usually limiting daily living activities(5), are associated with higher mortality, reduced functional status, and increased rate of consultations in health care and medication use (1, 6).

In 2007, the World Health Organization (WHO) formulated a response to the increasing prevalence of chronic conditions by recommending a reorganization of current healthcare systems towards a PCC approach. This approach emphasizes the needs of people with chronic conditions to be informed about their conditions and empowered in promoting and protecting their own health(7). PCC is currently considered the key concept for primary health care settings. It not only includes the person during the care process, but also guides the care providers to respect choices and autonomy of people with chronic conditions(8, 9). Therefore, PCC requires that health providers have good knowledge of their needs and preferences(8). Scientific literature has shown the importance of being listened to, being appreciated, feeling safe, and independent(10, 11). Numerous studies have analyzed people's experiences of primary healthcare using various research methods in a variety of populations(12). This has led to a large heterogeneity and findings, many of which are context- and care-specific (e.g., end-of life care, self-management, treatment, involvement in shared-decision making, health outcome prioritization/ goal-setting, healthcare service delivery, and screening/ diagnostic testing)(13). To our knowledge, Kuluski et al. (2019) are the only research group who have performed qualitative research with people with multimorbidity and informal caregivers to capture their priorities more broadly, without focusing on specific issues(11).

In addition to the literature, the relevance of listening to people with chronic conditions is expressed in governmental plans, local, and worldwide. In Flanders (the Dutch speaking part of Belgium), the primary care system is currently undergoing a transition from acute to chronic care including a shift towards PCC based on the WHO global strategy(14). This shift is based on three pillars: 1) people must be empowered to participate in their care processes, 2) care delivery should be adapted to the needs of people with chronic conditions, and 3) informal caregivers are an essential pillar in the outpatient care processes, especially for vulnerable older persons(15,16). Informal caregivers should be considered as full partners in care and should have the possibility to provide input into the care process of their relatives(14). Including the perspectives of both the people with chronic conditions and their informal caregivers could contribute to integrated care systems that enable PCC(17).

Although, both the literature and governmental plans describe the importance of the PCC system, the translation into practice has not yet been realized(14). To succeed in this transition, an important prerequisite is to gain more in-depth insights into care experiences of people living with chronic conditions and their informal caregivers. This applies not only to the Flemish context, but also worldwide, as primary care is undergoing a shift from acute to chronic care(14). In this shift, nurses are being given a prominent role, as they seem to be key figures in the lives of people living with chronic conditions and their informal caregivers(18). In addition, nurses are getting more and more involved in primary care (e.g., home environments, general practices) to deal with the increasing number of people with chronic diseases and support them in living autonomously for as long as possible(19). Because Flanders is currently undertaking a reorganization of primary care, this context is a relevant opportunity to expand knowledge on how people with chronic conditions and their informal caregivers experience primary care. In addition, most available Flemish studies are performed in the hospital settings instead of primary care settings(20) and of the diversity of people and conditions is poorly addressed, since most studies focus on one specific disease or population(21). Therefore, our study aims to get a broad picture of primary care experiences of diverse populations of people living with chronic conditions in Flanders.

To support the shift towards PCC in Flanders, the Primary Care Academy (PCA), a consortium of four universities, six universities of applied sciences, patient representatives and White-Yellow Cross (Flemish home care organization), has been established. The PCA aims to strengthen the capacity of primary care by developing interventions, optimal roadmaps, and hands-on toolkits for primary care policies, practice, and education. The PCA adopted therefore the guidelines of the Medical Research Council (MRC)(22). The study reported here is a first step in the entire

project and aims to contribute to the identification of an appropriate theory to implement PCC in the Flemish primary care context(22). The phenomenon under investigation in this study is the daily life of people living with chronic conditions and their informal caregivers, what support they need from their primary care providers, and how primary care is organized. The corresponding research question is: *how do people living with chronic conditions and their informal caregivers experience primary healthcare in Flanders?*

Methods

Design

This study used a qualitative study design with a phenomenological-hermeneutical philosophy following Lindseth and Norberg(23). The combination of both epistemological backgrounds (phenomenology and hermeneutics) allowed us to examine the meaning of the experiences of people living with chronic conditions and their informal caregivers with primary care (phenomenology) as well as to interpret the transcripts describing this phenomenon (hermeneutics). In this study, the phenomenon under investigation is the daily life of people living with chronic conditions and their informal caregivers, what support they need from their primary care providers, and how primary care is organized. It responds to the ongoing transition from acute to chronic care, especially in primary care. This study complies with the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Supplementary File 1)(24).

Research team

This study is conducted by a team of researchers with different professionals backgrounds: occupational therapists (DB, F, Drs; DVdV, M, PhD & PDV, F, PhD), pharmacists (MMS, M, Drs & LT, F, Drs), registered nurse (MLH, F, PhD), and gerontologist (PDV). This ensures a diverse and broad perspective when analyzing the data of PCDs.

Participants and sampling method

In total 32 individuals, comprising 16 people with chronic conditions informal caregivers dyads (PCDs), consent to participate. The informal caregivers were proxies of the people with chronic conditions and provided voluntary support by helping them with essential or meaningful activities. To recruit these PCDs, a maximal variation, purposeful sampling was used. The sampling was based on the definition of people with complex care needs operationalized by Iglesias (2018)(25). Participants were included when they met the following main criteria: a) having a single severe chronic condition or multimorbidity, b) having the support of an informal caregiver, and c) getting support from three or more primary care and welfare providers (e.g.,

family doctor, pharmacists, social workers, etc.). Maximum variation was sought when the participants met one of the following additional criteria: d) taking four or more different medications related to their chronic conditions, or e) having a higher need of care, or f) having a low socio-economic situation, or g) lacking health literacy, or h) showing the need for more care according to at least one member of the primary care team. Inclusion criteria were selected to recruit people with chronic conditions that could serve as exemplars due to their chronicity and the frequent and ongoing interactions they have with a range of health professionals. Participants were excluded when they were: a) under the age of 18, b) legally incapable, c) incapable to reason about care (e.g., severe mental illness, cognitive impairment), d) incapable of being interviewed for 1 hour, e) unable to provide informed consent, and f) terminally ill. People with chronic conditions were recruited using flyers distributed via health and welfare organizations, and family doctors, the latter being the central contact point for the patients and researchers. Upon giving oral informed consent to the family doctor, people with chronic conditions indicated their main informal caregiver. All participants who were contacted were interviewed. Then, researchers contacted the person with chronic conditions or informal caregiver to introduce the study and schedule the interview. Written, informed consent was obtained before the start of the interview.

Data collection

A qualitative, semi-structured interview technique was chosen to explore the PCDs' point of view and their unique care experiences reflecting their care situation. Prior to constructing the interview guide, gaps in literature regarding primary care were identified. Thereafter, several brainstorm sessions were organized with the authors to develop this interview guide and to collect sufficient data about the care experiences, preferences, and needs of people with chronic conditions and their informal caregivers. Interviews were conducted with PCDs with the focus on the care experiences of people with chronic conditions. The informal caregiver was able to complete the answers or help to elaborate on the questions, which could possibly result in deeper insight in the care experiences, as described by Morgan et al. 2013(26). The semi-structured in-depth interviews started with the daily life and activities of the PCDs during the last week using the question: 'Tell me. What did your last week look like, and 'What did you do?'. These opening questions were followed by topics covering the care experiences of people with chronic conditions, support they receive from formal and informal caregivers, the way PCDs are involved in their care, and their care needs. By using eliciting probes, the PCDs were encouraged to elaborate and deepen their answers. The interviews were conducted between January 2020 and August 2020; physical interviews at home environments of the person with chronic

conditions, or by videocall due to COVID-19 measures imposed by the Flemish and national government. The interviews were conducted by the three principal researchers who were trained in qualitative research techniques (DB, MMS, LT). Data collection and analysis were done simultaneously to confirm or refute the preliminary findings until data saturation. This strategy allowed identification of specific gaps for which more information was needed and to tailor the focus of the interviews with the remaining PCDs. No member check was performed and transcripts were not returned to the participants. Before data collection and analysis, the researchers performed reflexive bracketing to decrease the influence of pre-conceived understanding. This approach reduced the risk of confirmation bias by the researchers and thus increased the neutrality(27).

Data analysis

The interviews were audio-recorded, transcribed verbatim, and combined with non-verbal observations such as emotions. No software program was used to manage the data and interviews were coded manually. Analysis according to the three-step method of Lindseth and Norberg (2004) was conducted: 1) naïve understanding, 2) structural analysis, and 3) comprehensive understanding. All steps were guided by an inductive logic. To describe the naïve understanding, the principal researchers (DB, MMS, LT) read the entire interviews and formulated an initial and personal understanding. These individual naïve understandings were discussed with the co-authors (MLH, DVdV, PDV) and gave rise to one overall naïve understanding. Subsequently, a structural analysis was conducted for which data were broken down into meaning units and condensations resulting in themes, as shown in Table 3. Meaning units were parts of transcript containing information about experiences towards primary care. The structural analysis was an iterative process containing three stages. First, one interview was analyzed together by the three principal researchers to gain common insights in the data. Second, five more interviews were analyzed simultaneously by two researchers to serve as validators for each other. These analyses resulted in a preliminary overview of the themes and were presented to the co-authors to serve as extra validation to increase credibility. Third, ten more interviews were conducted, analyzed individually, and integrated with the first analysis. Based on these three stages, preliminary themes were presented, discussed, and reformulated in final themes by all the authors. In the last stage of the structural analysis, the themes were presented to all senior researchers of the Primary Care Academy (PCA) and discussed until consensus was reached. Finally, the comprehensive understanding was developed to create an overarching reflection of the results related to the themes of the structural analysis. All the three steps were guided by an inductive logic.

Ethical considerations

Approval was obtained from the Ethical Committee of Antwerp University Hospital with the file number (B300201942302). The study was in accordance with the principles outlined in the Declaration of Helsinki. The participants received verbal and written information about the purpose and methods of the study. The informed consents were approved by the above-mentioned Ethical Committee. People with chronic conditions and their informal caregivers were informed that participation was voluntary, and that confidentiality would be ensured. All participants gave written informed consent in advance.

Results

A total of 16 PCDs, comprising 32 individuals (16 people with chronic conditions and 16 informal caregivers) were interviewed (characteristics presented in Table 1). No participants refused to be interviewed. People with chronic conditions had a mean age of 67.5 years; of which 11 were female, and 13 were retired. For informal caregivers the mean age was 66.8 years, and 11 of the 16 PCDs were living together.

Since this study is based on the shared input during the interviews from the PCDs, the results are presented as shared views and experiences. Therefore, the word 'PCDs' or 'participants' are used to emphasize that the results of both people living with chronic conditions and informal caregivers. When their views were different, this is explicitly indicated using the words 'people with chronic conditions' or 'informal caregivers'.

Naïve understanding

The interviews showed that the people with chronic conditions preferred to live at home and stay engaged in meaningful activities despite their chronic conditions. Their informal caregivers confirmed these preferences. The people living with chronic conditions expressed the needs for regular support for performing meaningful and essential activities from their informal and formal caregivers. In addition to the central (in)formal caregivers, the broader social environment, such as family members and friends, played a significant role in terms of practical support and for listening. Furthermore, the narratives showed that the independence of people with chronic conditions increased by reorganizing activities and adapting them to their current capabilities with or without the use of assistive devices. Elaborating on the competences and skills of the care professional, PCDs expected a sufficient level of professional expertise of them, encompassing both practical and emotional skills. In fact, PCDs longed for more personal contact and the feeling of being heard, through open communication with formal caregivers. This open communication seemed to be facilitated when PCDs were actively involved and experienced co-

determination in care-related decisions. PCDs also mentioned that (interprofessional) communication could connect different partners in their care to facilitate coordination. Finally, PCDs experienced major barriers that impede caregivers to deliver high quality of care as they face for example barriers regarding reimbursements.

Structural analysis

The structural analysis was based on condensing the meaning units and reorganizing into themes (see Table 2 for an excerpt from an analysis) and resulted in ten themes, which are presented in Table 3 and highlighted with illustrative quotations from different PCDs interviews. Each quote indicates whether the information was from a person living with chronic conditions (P) or informal caregiver (IC) and is added with the number as indicated in the table.

Table 1: Overview of the participants' characteristics

Characteristic	**Patients (N=16)**	**Informal caregivers (N=16)**
Sex, *N*		
Female	11	9
Male	5	7
Age in years (range)	67.5 (44-89)	66.8 (45-82)
Civil registration, *N*		
Single	4	1
Married	12	15
Relationship of informal caregiver with patient (CH = cohabiting)		
Partner		10 (CH = 10)
Parent		2 (CH=1)
Child		4
Employment		
Employed	0	1
Unemployed	0	1
Unemployed due to disability	3	3
Retired	13	11
Inclusion criteria (multiple criteria possible)		
Taking four or more types of medications	11	
Having a higher need for care	6	
Having a low socio-economic situation	3	
Lacking health literacy	3	
Showing the need for more care according to at least one member of the care team	2	

Table 2: Example of structural analysis of a meaning unit

Meaning unit	Condensation	Themes
"Yes, the homecare nurse is coming every week to help me shower, then she puts me in the shower."	Homecare nurse helps with showering.	Performance of essential activities supported by a team of (in)formal caregivers.
"… in the morning, I always have to wait for the homecare nurse. They come always at different times to help me dress. So, I always have to wait…"	Waiting for the homecare nurse who comes always at different times.	Care coordination as part of care continuity.
"We are knitting blankets for the children hospital… I am looking forward to Saturday… The hospital has asked to make blankets in the colors of the minions..."	Knitting blankets for the children hospital and looking forward to handing over them.	Meaningful activities to create a fulfilling life.

Table 3: Overview of the themes

1. Autonomy to be in charge of health and welfare decisions
2. Meaningful activities to create a fulfilling life
3. Performance of essential activities supported by a team of (in)formal caregivers
4. Supportive network to participate in society
5. Practical and psychosocial support to manage meaningful and essential activities
6. Balance between practical and emotional formal caregivers' skills
7. Patient-provider dialogue to achieve open communication
8. Involvement of patients to facilitate 'care decision-making'
9. Care coordination as part of care continuity
10. Barriers to provide good care

1. Autonomy to be in charge of health and welfare decisions

Autonomy was expressed as a main life goal for the patients and their informal caregivers. They experienced autonomy as the ability to engage in activities they can carry out themselves, the ability to make their own decisions, and the freedom to go wherever they want to go. The analysis showed that PCDs strived to remain in charge of their own lives. When they felt no longer autonomous, they experienced the fear to lose individuality and their uniqueness.

"I have always been someone who was independent, did everything myself, never asked for help. For me, it is a huge step to ask someone, my son or family, for help [e.g., help with dressing]. Just putting my walking aid downstairs for a moment is very difficult. I feel my independence slipping away, I find it annoying. I try to do all that by myself, but then I am so tired." (*Patient - P14*)

While the PCDs expressed their wish to stay autonomous for as long as possible, they also feared to be placed in a nursing home. To experience a feeling of prolonged autonomy and independent life, PCDs replied within the constraints of their own possibilities to stay home, for example through acquiring assistive devices to increase mobility.

"I am afraid of going to a nursing home. You will no longer be independent. Everything is arranged for you. Goh... As long as you live at home, you can do everything you want. Sometimes we [informal care giver to partner] say to each other: 'Let's hope she [patient] doesn't have to go to a nursing home." (*Informal caregiver - P4*)

2. Meaningful activities to create a fulfilling life

When PCDs were asked to define a good day, they mostly reflected upon their engagement in meaningful activities (e.g., from knitting blankets for the children's hospital to going to flea markets, etc.). These activities created fulfillment and purpose for both patients and their informal caregivers. The performance of meaningful activities confronted PCDs with the patient's deterioration since the extent of disabilities played an important role in how these activities were done. Therefore, patients and informal caregivers had to find mutual connection in their activities, and were challenged to rearrange their activities, or discover new ones.

"We are still rearranging [e.g., restructuring activities]. Now I have to cook in several times while I used to do once… I also do some woodwork for a few hours in the hobby room and do some gardening. We rearrange ourselves to the things I am still able to do." (Patient – P10)

It was mainly the informal caregivers who had a hard time maintaining his/ her meaningful activities because they had to spend a lot of time providing care. A variety of coping strategies were reported by the patients; some changed their lifestyles according to their abilities and stated that this did not affect their happiness. They were grateful and are 'taking the day as it comes' (Patient - P6). These PCDs showed a positive outlook and realistic vision on the future.

"I'm actually someone who always looks for the positive in the negative. For example, I say: 'now I have the chance to see the sun going down'. Instead of earlier, while I used to be working or helping at home. Now this is no longer possible." (Patient – P6)

Others experienced feelings of dejection, losing interest in activities and expressed that they *"had nothing to strive for anymore" (Patient - P5).* These patients longed nostalgically for old times and regretted that they were not able to perform the activities they used to perform earlier.

"My mood…is not to talk about. How do I have to call it... Close to depression. I fight against it. I said to myself 'there are people who are worse off'. Then I start thinking what could be worse... Right? It is not fun. I am... sad..." (Patient – P5)

3. Performance of essential activities supported by a team of (in)formal caregivers

In addition to meaningful activities, PCDs also expressed they had to perform essential activities to make it through the day. Essential activities included showering and dressing, but also, for example, going to the physiotherapist and pain clinic. Some patients were able to perform these essential activities autonomously, others needed support from their informal caregiver who was seen as indispensable to cope with their situation in various ways. Informal caregivers offered practical (e.g., household chores) as well as psychosocial support (e.g., offering a listening ear) but also tried to entertain the patients by taking them out and going on excursions together. For these reasons, informal caregivers were described as "key figures" (Patient - P2) for patients.

"Concerning showering. Since her fall, she [patient] never takes a shower by herself anymore and has to use a chair. And if she had to bend down to wash herself I [informal caregiver] stood behind her and held her like this [places her hands in her side]." (Informal caregiver – P2)

Although informal caregivers "*did their utmost" (Informal caregiver - P2)*, support from formal caregivers (e.g., physiotherapist, home nurse, general practitioner) remained inevitable. They offer not only medical support, but also give advice and education (e.g., how to increase mobility). Formal caregivers supported patients with essential activities (e.g., dressing). With some, PCDs had bonded over the years, resulting in a strong connection. According to the PCDs, the good formal caregivers aimed to assist PCDs to live their lives to the fullest and as autonomously as possible. With the help of formal caregivers in essential activities, patients could use their energy more efficiently to perform meaningful activities.

4. Practical and psychosocial support to manage meaningful and essential activities

An important role emerged for practical and psychosocial support. Practical support was often related to assistive devices (e.g., a walking aid, a wheelchair, handles in the bathroom, and a stair lift). For PCDs, those devices were considered essential in remaining independent in their daily activities. In some cases, greater adjustments, such as home-modifications, were essential to allow patients to continue living in their own houses. For this reason, modifications were positively received, but required financial resources or homeowners willing to make the necessary changes.

"The homeowner has installed a walk-in shower, so I don't have to climb [over the bathtub which was removed] over and we have also installed a sauna [for the pain]. I think that is fantastic...I go in there once or twice a week." (Patient – P11)

PCDs expressed that psychosocial support, for example finding distractions in shared leisure activities was equally important as practical support. Some PCDs found also support in talking with peers through which *"they found an equal (Patient - P4)"*. Peers listened based on their own expertise or were "*companions (P4)"* to undertake activities to forget about worries. In contrast, other PCDs found contact with peers conflictive, because they were faced with their own functional deterioration compared to the observed better functioning of these peers.

"I have a good contact with a fellow MS [Multiple Sclerosis] patient, who is worse off than me. Sometimes I invite her to come over and relax in the garden. We are both interested in culture. We exchange experiences, things we've been through [e.g., visit to a museum] …We don't talk about our disease." (Patient - P9)

Another aspect raised by the participants was digital tools for the treatment and control of chronic conditions that have changed a lot. The use of applications, Internet, and social media offered support. However, they often doubted the reliability of the outcomes. Therefore, this innovative support was experienced by the participants as novel, but not providing yet enough trust to consider reliable.

5. Supportive network to participate in society

The social environment of PCDs varied from family members and friends to neighbors. Yet others had limited social contacts and had to rely mainly on themselves. The way this social environment was organized determined the amount of support PCDs received.

"They all [family e.g., children] live nearby. Yes, otherwise I wouldn't be able to live here, if they would live further away [family is helping her with daily activities]. I would enjoy staying here until I die. In my small house…" (Patient – P4)

The proximity of family members, in which the PCDs put trust, resulted for them in a sense of stability and the possibility to live as autonomous as possible. However, the impact was strongly

dependent on the availability, the work-life balance, the financial situation, and the health condition of their family members.

> *"Because my sister has her own family, she must take care of her household and her work, she can't take care of me on her own. That's a bit disappointing… I've already discussed with my mother…when I will be alone later that I would like to have someone to support me in cooking..." (Patient – P7)*

The social environment had a positive impact on the patients' situations, but some PCDs also faced a decrease in social contacts as the patients' functional capabilities decreased. In addition, PCDs experienced a feeling of being excluded from society due to external reasons e.g., inaccessible public places, family and friends who do not have the opportunity to invite PCDs for a visit because their house is not accessible. These external factors hampered PCDs to spontaneously interact with others and to go wherever they want to go, reflecting a lack of autonomy. Also, not every PCD could rely on a supportive network and expressed to "*living on an island (Informal caregiver - P13)"* hampering the management of meaningful and essential activities.

6. Combination of emotional support and practical skills to fulfill patients' needs

Previous themes illustrated the need for PCDs to be supported by formal caregivers in essential activities. However, in addition to the need for practical information, PCDs required emotional support from formal caregivers. They expressed the need for balance between practical and emotional caregivers' skills. From the narrative analysis, practical skills could be described as having theoretical knowledge and skills to provide the appropriate and technical treatment, expressed by PCDs as *"formal caregivers have to do their job." (Patient - P15).* Whereas emotional skills gave PCDs the feeling of being heard and treated as a person 'who has an illness' instead of 'who is the illness'.

> *"The most important thing is to build a relationship of trust. This isn't possible if there is no understanding or empathy from the caregiver to the patient…Authenticity…That a caregiver also shows a piece of himself, also show that he is human. Professionalism and knowledge are also extremely important and that is where I set a high standard, the importance of education and continuing learning." (Informal caregiver – P12)*

When reflecting on the emotional support, PCDs expected their formal caregivers to ask adequate questions, have a level of increased empathy, be authentic as a person, and pay attention to the person as a whole. Formal caregivers should also be able to use intuition to "*intuit patients' needs" (Patient - P14)"*, to *"discover the unexpressed patients' needs (Patient - P14)"*, and to adapt their treatment approach to the patient's personality. When PCDs experienced a lack of empathy they tended to change to another formal caregiver.

7. Patient-provider dialogue to achieve open communication

"Communication goes both ways (Informal caregiver - P15)" reflects the need for a dialogue between patients and their formal caregivers. Patients experienced that they want to share their story; formal caregivers in turn must provide the right context for patients to share their concerns. For this, trust was of utmost importance. PCDs gained trust when time was offered, when there was a longstanding relationship with the formal caregiver, or when they gained a second opinion to confirm a previous diagnosis.

"It is not that familiar as in e.g., the rehabilitation center … You miss tenderness. In the rehab center they take time to talk about how you feel and what you want to do. I think that is important. They provide time and space to you share our problems." (Patient – P16)

Open communication was also improved when adequate information was offered, expressing honesty about the diagnosis, treatment options, treatment method, and medication regime. In the following quote, a patient reflected on a situation when she did not receive adequate information to share her own diagnosis with her family.

"How I was supposed to tell my husband and my children [just after receiving the diagnosis of MS]? The doctor said: 'there is Internet and a library Miss.' So, I started looking on the Internet." (Patient – P6)

In addition, the physical context in which the communication occurs must allow and facilitate open and personal communication (e.g., using a laptop to take notes was indicated as a main obstacle hampering a trustfulness open conversation).

8. Involvement to facilitate 'care decision-making'

Patients expressed the wish to be involved in their care processes, for example by participating in the search for the best treatment. Involvement gave patients a sense of safety that made them feel respected and gave assurance that the treatment was for their own good, which in turn increased the adherence. As a result, trust towards their informal caregiver and their decision-making was facilitated.

"I am someone who enters a discussion with the medical doctor about my health… with my family doctor and my neurologist. I want to hear the various options which I will go for." (Patient – P6)

Participants were convinced that active involvement in their care process created different prescribing by the caregiver.

"If I go to the family doctor, he asks whether we would try this medication, or we prefer something else. So yes, I'm involved in the decisions." (Patient – P3)

9. Care coordination as part of care continuity

Participants received support from a broad range of providers to handle their conditions. It was important for them that those formal caregivers worked together and communicate with each other. This means that care must be "*well-coordinated (Informal caregiver - P8)*". Coordination was also mentioned as essential to ensure care continuity. This included communication among (in)formal caregivers and patients. PCDs preferred interaction with the entire team that contributed to better care and a more personal approach. Also, care coordination was mentioned in the context of the follow-up of previous diagnostical tests. Nowadays, "*it is all in the computer (Informal caregiver - P2)*" and facilitated by electronic and shared patients' records.

> *"Caregivers must dare to broaden their view and look beyond their own discipline. They must open up to have contact with other caregivers, so they become one. In that case, the patient would be supported by a network of caregivers." (Patient – P12)*

Although participants expressed the need for coordinated care, they experienced a lack of coordination and communication among professionals from different organizations and levels. For example, they experienced too little communication from the hospital towards the family doctor when patients were discharged. Patients desired better follow-up, especially from their family doctor, who should be aware of recent events that patients experienced. The PCDs suggested a home visit from their family doctor immediately after being discharged from the hospital as a possible way to guarantee a better follow-up.

> *"And the family doctor comes on a home visit. He said to her: 'see you in 4 - 6 weeks'. How is this possible?!? She [patient] just left the hospital, with all her worries and he said, till 4-6 weeks! …. Someone should, after leaving the hospital with a severe disease or so, warn the family doctor. Now you have to call him [FD] yourself which can takes 2-3 weeks." (Informal caregiver - P3)*

In addition to better follow-up, PCDs needed structure and certainty from their formal caregivers. In the case of home nurses, patients preferred the same nurse on the same hour to help them with their morning routines. This contributed to personal contact and trust bonding between the patient and the home nurse because they were continuously building on a sustainable relationship.

10. Barriers to provide quality care

Administrative procedures (e.g., application for refunds) were expressed as the main barrier to quality care. For example, PCDs got bogged down in bureaucracy when they applied for reimbursements of assistive devices. The use of applications took too much time and effort and were often too complex to understand resulting in inconsistent information to make the right decisions.

"Why should I prove that I have disabilities? It was not my first application. They [insurance company] do not realize that my condition is progressive. It was only after the renovation of our bathroom that they [insurance company] asked for a proof of invalidity…I got negative response…Then I had to defend myself and all they asked was why I have chosen a specific system…Now I am already waiting for nine months for an electric wheelchair…It always take so long…" (Patient – P15)

The struggle with administrative procedures led to sadness and frustration on top of the negative feelings some PCDs already experienced as a result of having the chronic condition. PCDs also experienced difficulties in finding leisure activities, contact with peers, or finding advice for modifications to their house and transport. PCDs felt on their own in finding their way through procedures and expressed this as "*a full-time job (Informal caregiver - P15)*". If support was provided, PCDs could focus on activities that give purpose to life.

Comprehensive understanding

The naïve understanding and the identified themes from the structural analysis were re-read as a whole to see how they interrelated and to formulate a comprehensive understanding. By doing so, patterns between the themes and thus the lived experiences of people living with chronic conditions regarding there care situation were articulated. This allowed us to visualize the associations among the different themes, illustrated in Figure 1. When someone is diagnosed with a chronic disease, this illness does not stop the person from being an individual human and having needs and preferences. PCDs expressed that it is of paramount importance that health care providers are capable to go beyond the level of purely functional and essential activities (e.g., washing, bathing, and clothing) to the level of meaningful activities and encounters. Although essential activities were necessary to get through the day – and for some it can even mean the beginning of their day – it was very important to find meaning in several ways: meaning in activities one performs, meaning in one's relationships with family and friends, but also meaning in the relationship with one's caregivers, and finally meaning in life. The search for meaning determined how people with chronic conditions interacted and coped with their conditions; a constant balance between what was strictly necessary on the one hand and what gave satisfaction and meaning in life on the other. The latter led to a satisfying care process that emphasizes the diagnosis and treatment adding that extra level of being treated as a person. Reading the person and being able to ask the unasked question to discover the unexpressed needs of people with chronic conditions, determined a 'quality caregiver'. PCDs expected formal caregivers to change how they delivered care and required that they look beyond their professional perspective of logical care solutions and assumptions. They should acquire skills to intuit the needs of people with chronic conditions. This intuitive 'reading' made these people feeling seen, heard, and committed in their care process. Quality care was described by the PCDs

as listening and giving attention to what they want, to what they strive for, and above all to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family, and friends. These elements could be found in care that starts from personal and meaningful goals in which care was delivered based on the needs and preferences of people living with chronic conditions and informal caregivers, while supporting their self-management, as prioritized goals, and encouraging them to live their life regardless their chronic conditions. Citing the PCDs, this could only be reached in a strong interprofessional collaboration in which the team worked together – among each other and with the PCDs- to that what was important to them.

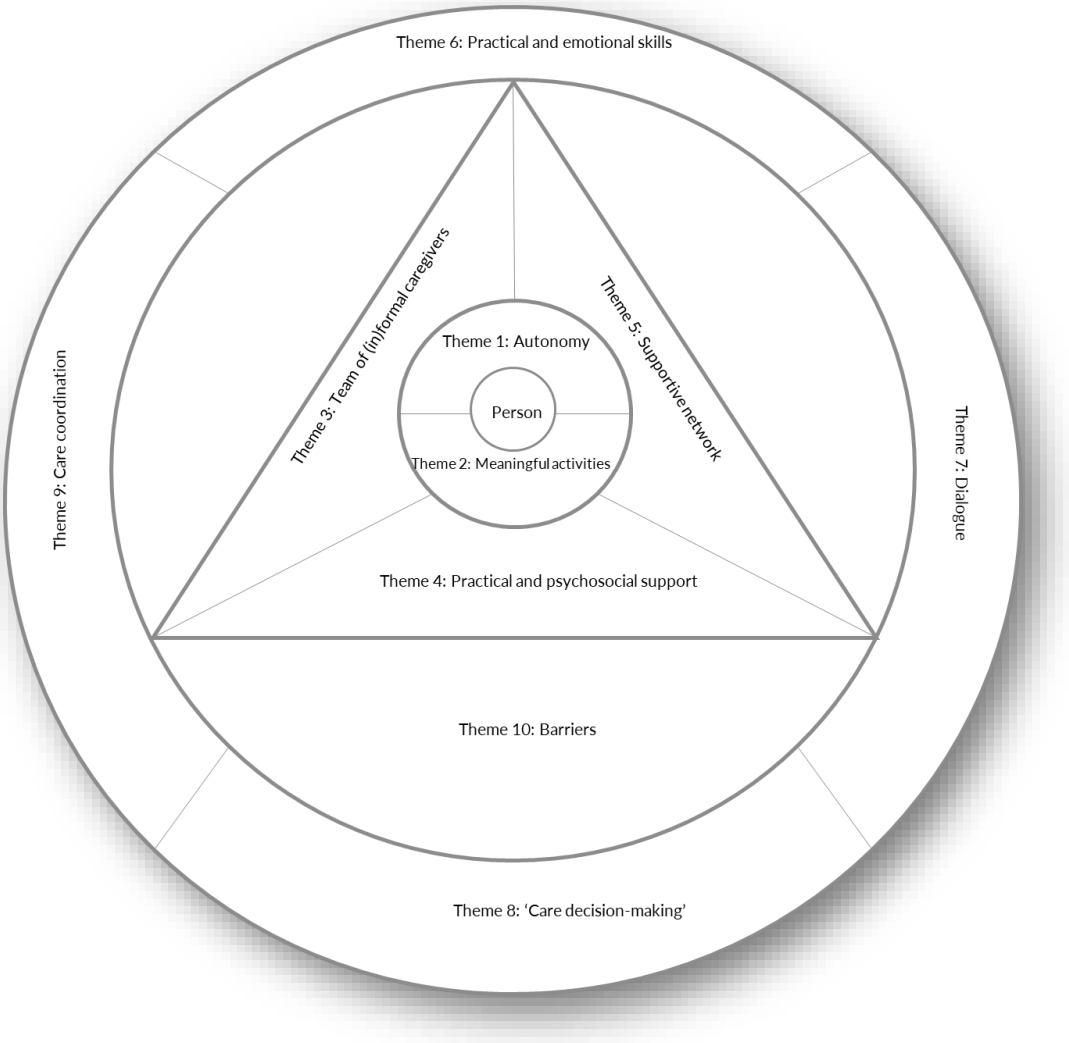


Figure 1: Schematic representation of the themes

Discussion

This study provides a broad picture about the daily life of people living with chronic conditions and their informal caregivers, what support they need from primary care providers, and how primary care is organized.

PCDs reflected on the importance of being autonomous, demonstrated by performing meaningful and essential activities. Therefore, PCDs needed support from a social environment of family and friends, formal caregivers, and in some cases assistive devices. Throughout these activities and relationships, their personal values should be mirrored. Consequently, PCDs expected to be treated as an equal partner that includes open communication. All this should take place in a context where collaboration among the PCDs and formal caregivers was facilitated. According to the PCDs, quality care was described as*: 'listening and giving attention to what the people with chronic conditions want, to what they strive for, and above all to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family, and friends'*.

These findings confirm other recent studies exploring the needs and preferences of people with chronic conditions. This is not surprising as the aim of this study was to start 'tabula rasa' and truly explore the experiences from the PCDs themselves. Common themes seem to be the need for person-centered open communication(28-30), involvement in the care process(29), a supportive network(31), and adequate multidisciplinary coordination(32). Despite similarities in results, these studies were slightly different since previous studies have focused on the experiences of people with chronic conditions and not of PCDs. However, informal caregivers should be considered as full partners in care and their presence could improve the research process for people with chronic conditions who lack communication skills(1, 33, 34). Based on our observations, the presence of informal caregivers allowed people with chronic conditions to elaborate more on their care experiences, because they felt supported, which allowed us to gain more insight. While most of the studies focused on specific components of care (e.g., collaboration, communication), we addressed the large majority of health and social needs of people with chronic conditions from a wide range of chronic conditions(35). This was done intentionally to recruit participants with diverse health profiles resulting in contrasting cases. As far as we know, only a few studies such as Lim et al. (2017) have included broad study populations and their needs. Lim et al. (2017) performed interviews with people suffering from multiple chronic conditions and defined six domains essential for well-being and health (principles, relationships, emotions, activities, abilities, and possessions). Their findings are similar to our ten themes and also emphasize the importance of activities (e.g., reading, gardening, and self-care) and having significant connections with others (e.g., family, friends, and the community)(36).

Our findings show that PCDs want to engage in meaningful activities, going beyond what they call the essential activities, to create fulfillment and purpose in life. Each "individual needs to have the opportunity to engage in activities that foster meaning and satisfaction, the so called 'occupational well-being'(37). Engaging in meaningful activities enables quality of life and - even more - impacts morbidity and mortality(38). In other words, it is important that the care process pay attention to meaningful activities and not only to essential activities(39). To create purpose in life, autonomy appeared to be an important requirement. More specifically, PCDs expressed the wish to stay autonomous by making shared decisions in which they take responsibility and experience freedom by choosing where they want to go. This shared decision-making throughout care delivery is one of the activities of a person-centered process of care and could be facilitated by nurses, among others(40). These findings also correspond to the multiple aspects of autonomy Basset and colleagues described such as having freedom of choice, taking responsibility, retaining independence in daily activities, and living independently(41). The feeling of autonomy could also be fostered by having agency over activities, and from a broader perspective over health and chronic conditions. This means that individuals should experience a sense of control over what, when, and how to engage in activities, including care activities(37, 42). PCDs found control in surrounding themselves by a broad supportive network, such as the formal caregivers and their social environment of family and friends. To keep up in their environments and to participate in society, they relied on practical support (e.g., assistive devices). In addition to using practical support, they received psychosocial support from peers who listened and made them feel safer and less lonely. These findings are in line with the literature which indicates that the presence of these networks has a positive influence on personal welfare status (e.g. loneliness)(43). Our research shows that psychosocial support is necessary to remain independent in daily living. PCDs tried to reorganize their lives and reinvent themselves by making use of their remaining capabilities, for example, by searching for activities they are still able to perform. People with chronic conditions adapt their activities to compensate their limitations and changed behaviors caused by their conditions(44). In our study, we found that PCDs also tried to maintain, change, or create new meaningful behaviors in activities and life roles. Based on this reasoning, PCDs could engage in role-management(45). This approach corresponds with the SOC-model (selection, optimization, and compensation) of Baltes(46), wherein ageing people carefully select activities they still can perform. Throughout these meaningful activities and relationships with formal caregivers, we found that it is important that the PCDs' personality and authenticity is mirrored. Therefore, personal values of people with chronic conditions should be highlighted in developing, sharing, and follow-up in the care plan(47). This can be achieved by approaching PCDs as equal partners in care, although this is

often hampered by a lack of time, among other factors, during visits with the caregiver(28, 32). Being treated as a whole person, is beneficial for people with chronic conditions. It can increase their satisfaction, enhance the relationship with their providers, and lead to better understanding and more knowledge regarding their own health(48). To be treated as a person, people with chronic conditions expressed the need for balance between practical and emotional caregivers' skills. To meet their needs and preferences providers should have a level of empathy and pay attention to the whole person(40). PCDs want to share their story with their formal caregivers. Gaining trust is a key achievement to perform communication between people with chronic conditions and providers. In addition, the ability to be able "to intuit their needs" and to recognize what they feel was indicated as an important skill, which can only be applied if an open communication between them and the provider is achieved. These findings correspond with findings from literature where communication skills and especially "empathy" are considered as the most important skills that caregivers should master to perform 'quality care(40).

Being in empathetic contexts allows people with chronic conditions to feel safer and to express their thoughts and problems that concern them(49). In addition, Franklin et al. (2019) showed that the caregivers' communication style is important to collaborate and negotiate on what people with chronic conditions prioritize(50). Formal caregivers are not exclusively communicating with the PCDs, but they constantly communicate with multiple other (in)formal caregivers. A recent editorial briefing by Kuluski explores these communication and relationships themes, identifying them as the core components of PCC(51). When reflecting on formal relationships, people with chronic conditions indicated that they receive support from a broad range of providers to handle their conditions. They want well-coordinated care, which is essential to ensure continuity of care. They also often experience a lack of coordination and communication among professionals working in primary care and hospitals. They require better follow-up after being discharged from the hospital(52). The importance of the care environment to deliver PCC was also described by McComarck (2004), who indicates that the environment has a major impact on the operationalization of PCC and has the greatest potential to limit or facilitate PCC(53). Interprofessional collaboration facilitates the integration of health workers and allows them to engage any individual whose skills can help achieve local health goals(54). To do so, health professionals need a shared vision and goals(55) and can be enhanced by using a PCC approach(16, 56).

Strengths and limitations

This study has several limitations. Firstly, by sampling mostly older and retired participants with certain functional limitations, our results could not be generalized to the entire population and cannot be transferred to other populations and contexts beyond this specific group we interviewed and met the inclusion criteria (e.g., working population or people with chronic conditions transitioning to the labor market). However, this sample could be considered as a clinical representative sample in the primary care context of Flanders, where most people with chronic conditions are elderly people(4). Notwithstanding it might be interesting to include more participants to capture the experiences of other ages, cultures, etc. Secondly, there are limitations with the data collection. Due to the covid-19 pandemic, we had to switch to video interviews which changed the context and created consequences (e.g. less non- verbal observations, lack of concentration)(57). Furthermore, the performance of PCDs interviews could have inhibited people with chronic conditions to share information that they would not want their informal caregiver to know. This limitation was addressed by giving people with chronic conditions the freedom to indicate their informal caregiver by which they felt most comfortable. The strategy of PCDs interviews also enabled us to improve the fluency of the interview for people with chronic conditions who lack communication skills. Through the open nature of the interview questions, PCDs were enabled to reflect not only on their care experiences, but also on their daily life with a chronic condition. Furthermore, interviews were conducted by the three first authors, all of whom are experienced in qualitative interviewing people with chronic conditions. No member check was performed and transcripts were not returned to the participants. However, data collection continued until saturation was reached; in the last interviews, no new information for the themes appeared(34, 58). It is common in qualitative research that the presence of a researcher influences the interpretation of the data. This risk of bias was minimized by triangulating researchers from different backgrounds (e.g., occupational therapists, pharmacists, nurses, gerontologists) and by conducting and analyzing interviews together in team of at least two researchers. This triangulation and intensive cooperation increased credibility and reduced the risk of bias to interpret the data based on pre-conceived understanding and personal opinions. Furthermore, the findings were debriefed in an iterative process, increasing the reflexivity and critical awareness for members of the consortium, which included a broad range of healthcare professionals. In the first stage, the three principal researchers (DB, MMS, LT) analyzed the interviews separately, afterwards they compared their findings. In a second stage, these preliminary results were presented and discussed with the co-authors (MLH, DVdV, PDV) until consensus was reached. In a third stage, the findings were presented to other senior researchers of the PCA consortium and then the

process began again if no consensus was reached. This stepwise approach decreased the risk of confirmation bias.

Relevance for clinical practice

Primary care providers and especially nurses play a crucial role in the PCDs' lives as they support performing essential activities (e.g., taking medication, showering, etc.). Our findings suggest reconsidering nurses´ roles and responsibilities to encourage and also support people living with chronic conditions in performing meaningful activities (e.g., gardening, knitting). From an academic point of view, the shift towards the support of people with chronic conditions while considering their strengths, listening to their goals, and collaboration with the entire team is already being made(59). To support among others nurses in further implementation of this shift into practice, possible strategies could include [1] a focus on self-management support to achieve an autonomous life(60), [2] care processes with a focus on personal and meaningful life goals of people with chronic conditions(61), and [3] interprofessional collaboration including the individual as a partner to ensure care continuity(62).

Conclusion

For people living with chronic conditions and their informal caregivers, it is important to be supported in their autonomy enabling them to engage in activities, both meaningful and essential. They should be supported in their self-management to deal with the consequences of chronic conditions. To meet these needs and to enable self-management at its fullest, care should be tailored to the individual with a focus on personal and meaningful life goals. Care should be organized in a context of interprofessional collaboration in which the person with chronic condition should be considered as an important partner and a whole person. This entails paying attention to what the person with chronic conditions want, to what they strive for, and to promote their autonomy in a context wherein they are supported by a team of formal caregivers, family and friends. Only then we are moving towards the translation of the basic PCC principles into practice.

References

1. Epping-Jordan, J.; Pruitt, S.; Bengoa, R.; Wagner, E. H. Improving the quality of health care for chronic conditions. BMJ Quality & Safety 2004, 13 (4), 299-305.
2. Bodenheimer, T.; Lorig, K.; Holman, H.; Grumbach, K. Patient self-management of chronic disease in primary care. Jama 2002, 288 (19), 2469-2475.
3. van der Heide, I.; Snoeijs, S.; Melchiorre, M. G.; Quattrini, S.; Boerma, W.; Schellevis, F.; Rijken, M. Innovating care for people with multiple chronic conditions in Europe. Brussels: ICARE4EU 2015.
4. J. Van der Heyden, D. N., F. Renard, A. Scohy, S. Demarest, S. Drieskens, L. Gisle. Belgisch gezondheidsonderzoek 2018; 2019/14.440/89; Sciensano, Brussel, België, 2018.
5. Hajat, C.; Stein, E. The global burden of multiple chronic conditions: A narrative review. Prev Med Rep 2018, 12, 284-293. DOI: 10.1016/j.pmedr.2018.10.008 From NLM.
6. Cassell, A.; Edwards, D.; Harshfield, A.; Rhodes, K.; Brimicombe, J.; Payne, R.; Griffin, S. The epidemiology of multimorbidity in primary care: a retrospective cohort study. British Journal of General Practice 2018, 68 (669), e245-e251. Niessen, L. W.; Squire, S. B. Universal health coverage and chronic conditions. Lancet Glob Health 2019, 7 (10), e1290-e1292. DOI: 10.1016/s2214- 109x(19)30366-3 From NLM.
7. World Health Organization. Regional Office for the Western, P. People-centred health care : a policy framework; Manila : WHO Regional Office for the Western Pacific, 2007.
8. Kogan, A. C.; Wilber, K.; Mosqueda, L. Person-Centered Care for Older Adults with Chronic Conditions and Functional Impairment: A Systematic Literature Review. J Am Geriatr Soc 2016, 64 (1), e1-7. DOI: 10.1111/jgs.13873 From NLM.
9. Smeets, R. G. M.; Kroese, M. E. A. L.; Ruwaard, D.; Hameleers, N.; Elissen, A. M. J. Person- centred and efficient care delivery for high-need, high-cost patients: primary care professionals' experiences. BMC Family Practice 2020, 21 (1), 106. DOI: 10.1186/s12875-020-01172-3.
10. Foo, K. M.; Sundram, M.; Legido-Quigley, H. Facilitators and barriers of managing patients with multiple chronic conditions in the community: a qualitative study. BMC Public Health 2020, 20 (1), 1-15.
11. Kuluski, K.; Peckham, A.; Gill, A.; Gagnon, D.; Wong-Cornall, C.; McKillop, A.; Parsons, J.; Sheridan, N. What is Important to Older People with Multimorbidity and Their Caregivers? Identifying Attributes of Person Centered Care from the User Perspective. Int J Integr Care 2019, 19 (3), 4. DOI: 10.5334/ijic.4655 From NLM.
12. Burt, J.; Campbell, J.; Abel, G.; Aboulghate, A.; Ahmed, F.; Asprey, A.; Barry, H.; Beckwith, J.; Benson, J.; Boiko, O.; et al. Programme Grants for Applied Research. In Improving patient experience in primary care: a multimethod programme of research on the measurement and improvement of patient experience, NIHR Journals Library
13. Gonzalez, A. G.; Schmucker, C.; Nothacker, J.; Motschall, E.; Nguyen, T. S.; Brueckle, M. S.; Blom, J.; van den Akker, M.; Röttger, K.; Wegwarth, O.; et al. Health-related preferences of older patients with multimorbidity: an evidence map. BMJ Open 2019, 9 (12), e034485. DOI: 10.1136/bmjopen-2019-034485 From NLM.
14. Organization, W. H. WHO global strategy on people-centred and integrated health services: interim report; World Health Organization, 2015.
15. Plöthner, M.; Schmidt, K.; De Jong, L.; Zeidler, J.; Damm, K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. BMC Geriatr 2019, 19 (1), 82.
16. Morgan, S.; Yoder, L. H. A concept analysis of person-centered care. Journal of holistic nursing 2012, 30 (1), 6-15.
17. Kodner, D. L. The quest for integrated systems of care for frail older persons. Aging clinical and experimental research 2002, 14 (4), 307-313. Toscan, J.; Mairs, K.; Hinton, S.; Stolee, P.; Team, I. R. Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. International journal of integrated care 2012, 12. Kodner, D. L.; Spreeuwenberg, C. Integrated care: meaning, logic, applications, and implications–a discussion paper. Int J Integr Care 2002, 2.
18. Sousa, S. M.; Bernardino, E.; Peres, A. M.; Martins, M. M.; Gonçalves, L. S.; Lacerda, M. R. The role of nurses in the integration of care for people with chronic noncommunicable diseases. Rev Esc Enferm USP 2021, 55, e20200131. DOI: 10.1590/1980-220x-reeusp-2020-0131 From NLM.
19. Mustafa, M.; Adams, S.; Bareham, C.; Carryer, J. Employing nurse practitioners in general practice: an exploratory survey of the perspectives of managers. J Prim Health Care 2021, 13 (3), 274-282. DOI: 10.1071/hc21036 From NLM.
20. Van Wilder, A.; Vanhaecht, K.; De Ridder, D.; Cox, B.; Brouwers, J.; Claessens, F.; De Wachter, D.; Deneckere, S.; Ramaekers, D.; Tambuyzer, E. Six years of measuring patient experiences in Belgium: Limited improvement and lack of association with improvement strategies. PLoS One 2020, 15 (11), e0241408. Van Humbeeck, L.; Malfait, S.; Holvoet, E.; Vogelaers, D.; De Pauw, M.; Van Den Noortgate, N.; Van Biesen, W. Value discrepancies between nurses and patients: A survey study. Nursing ethics 2020, 27 (4), 1044-1055.
21. Forman, D. E.; Maurer, M. S.; Boyd, C.; Brindis, R.; Salive, M. E.; Horne, F. M.; Bell, S. P.; Fulmer, T.; Reuben, D. B.; Zieman, S.; et al. Multimorbidity in Older Adults With Cardiovascular Disease. J Am Coll Cardiol 2018, 71 (19), 2149-2161. DOI: 10.1016/j.jacc.2018.03.022 From NLM.
22. Craig, P.; Dieppe, P.; Macintyre, S.; Michie, S.; Nazareth, I.; Petticrew, M. Developing and evaluating complex interventions: the new Medical Research Council guidance. Bmj 2008, 337.
23. Lindseth, A.; Norberg, A. A phenomenological hermeneutical method for researching lived experience. Scandinavian journal of caring sciences 2004, 18 (2), 145-153. DOI: 10.1111/j.1471- 6712.2004.00258.x From NLM.

24. Tong, A.; Sainsbury, P.; Craig, J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International journal for quality in health care 2007, 19 (6), 349-357.p
25. Iglesias, F. H.; Celada, C. A.; Navarro, C. B.; Morales, L. P.; Visus, N. A.; Valverde, C. C.; Dorado, V. M.; Muñoz, M. L. M.; Pueyo, C. B.; Ramírez, E. L. Complex care needs in multiple chronic conditions: Population prevalence and characterization in primary care. a study protocol. International journal of integrated care 2018, 18 (2).
26. Morgan, D. L.; Ataie, J.; Carder, P.; Hoffman, K. Introducing dyadic interviews as a method for collecting qualitative data. Qual Health Res 2013, 23 (9), 1276-1284.
27. Lincoln, Y. S.; Guba, E. G. Criteria for Assessing Naturalistic Inquiries as Reports. 1988.
28. Noël, P. H.; Frueh, B. C.; Larme, A. C.; Pugh, J. A. Collaborative care needs and preferences of primary care patients with multimorbidity. Health Expect 2005, 8 (1), 54-63. DOI: 10.1111/j.1369- 7625.2004.00312.x From NLM.
29. Timpel, P.; Lang, C.; Wens, J.; Contel, J. C.; Gilis-Januszewska, A.; Kemple, K.; Schwarz, P. E. Individualising Chronic Care Management by Analysing Patients' Needs - A Mixed Method Approach. International journal of integrated care 2017, 17 (6), 2. DOI: 10.5334/ijic.3067 From NLM. Epstein, R. M.; Street, R. L. The values and value of patient-centered care. Annals Family Med: 2011.
30. Hashim, M. J. Patient-centered communication: basic skills. American family physician 2017, 95 (1), 29-34. Zoffmann, V.; Hörnsten, Å.; Storbækken, S.; Graue, M.; Rasmussen, B.; Wahl, A.; Kirkevold, M. Translating person-centered care into practice: A comparative analysis of motivational interviewing, illness-integration support, and guided self-determination. Patient Education and Counseling 2016, 99 (3), 400-407. Zoffmann, V.; Harder, I.; Kirkevold, M. A person- centered communication and reflection model: sharing decision-making in chronic care. Qual Health Res 2008, 18 (5), 670-685.
31. Lopez Hartmann, M.; Anthierens, S.; Van Assche, E.; Welvaert, J.; Verhoeven, V.; Wens, J.; Remmen, R. Understanding the experience of adult daughters caring for an ageing parent, a qualitative study. J Clin Nurs 2016, 25 (11-12), 1693-1702. DOI: 10.1111/jocn.13195 From NLM.
32. Berntsen, G.; Hoyem, A.; Lettrem, I.; Ruland, C.; Rumpsfeld, M.; Gammon, D. A person- centered integrated care quality framework, based on a qualitative study of patients' evaluation of care in light of chronic care ideals. BMC Health Serv Res 2018, 18 (1), 479. DOI: 10.1186/s12913- 018-3246-z From NLM.
33. Organization, W. H. Framework for action on interprofessional education and collaborative practice; World Health Organization, 2010. van Dongen, J. J. J.; Habets, I. G. J.; Beurskens, A.; van Bokhoven, M. A. Successful participation of patients in interprofessional team meetings: a qualitative study. Health Expectations 2017, 20 (4), 724-733. Dixe, M. d. A. C. R.; da Conceição Teixeira, L. F.; Areosa, T. J. T. C. C.; Frontini, R. C.; Peralta, T. d. J. A.; Querido, A. I. F. Needs and skills of informal caregivers to care for a dependent person: a cross-sectional study. BMC geriatrics 2019, 19 (1), 1-9.
34. Norouzinia, R.; Aghabarari, M.; Shiri, M.; Karimi, M.; Samami, E. Communication Barriers Perceived by Nurses and Patients. Global journal of health science 2015, 8 (6), 65-74. DOI: 10.5539/gjhs.v8n6p65 PubMed.
35. Rocque, R.; Leanza, Y. A systematic review of patients' experiences in communicating with primary care physicians: intercultural encounters and a balance between vulnerability and integrity. PloS one 2015, 10 (10), e0139577. Morgan, K. H.; Barroso, C. S.; Bateman, S.; Dixson, M.; Brown, K. C. Patients' experiences of interprofessional collaborative practice in primary care: a scoping review of the literature. Journal of patient experience 2020, 7 (6), 1466-1475.
36. Lim, C. Y.; Berry, A. B. L.; Hirsch, T.; Hartzler, A. L.; Wagner, E. H.; Ludman, E. J.; Ralston, J. D. Understanding What Is Most Important to Individuals with Multiple Chronic Conditions: A Qualitative Study of Patients' Perspectives. Journal of general internal medicine 2017, 32 (12), 1278-1284. DOI: 10.1007/s11606-017-4154-3 From NLM.
37. Doble, S. E.; Santha, J. C. Occupational well-being: rethinking occupational therapy outcomes. Can J Occup Ther 2008, 75 (3), 184-190. DOI: 10.1177/000841740807500310 From NLM.
38. De Vriendt, P.; Cornelis, E.; Vanbosseghem, R.; Desmet, V.; Van de Velde, D. Enabling meaningful activities and quality of life in long-term care facilities: The stepwise development of a participatory client-centred approach in Flanders. British journal of occupational therapy 2019, 82 (1), 15-26.
39. White, C.; Lentin, P.; Farnworth, L. An investigation into the role and meaning of occupation for people living with on-going health conditions. Australian occupational therapy journal 2013, 60 (1), 20-29.
40. McCormack, B.; McCance, T. V. Development of a framework for person-centred nursing. J Adv Nurs 2006, 56 (5), 472-479. DOI: 10.1111/j.1365-2648.2006.04042.x From NLM.
41. Bassett, R.; Bourbonnais, V.; McDowell, I. Living long and keeping well: elderly Canadians account for success in aging. Can J Aging 2007, 26 (2), 113-126. DOI: 10.3138/cja.26.2.113 From NLM.
42. Entwistle, V. A.; Carter, S. M.; Cribb, A.; McCaffery, K. Supporting patient autonomy: the importance of clinician-patient relationships. J Gen Intern Med 2010, 25 (7), 741-745. DOI: 10.1007/s11606-010-1292-2 From NLM.
43. Dodds, S. Social contexts and health. Glasgow Centre for Population Health, Glasgow 2016. Marmot, M.; Bell, R. Fair society, healthy lives. Public health 2012, 126, S4-S10.
44. Gignac, M. A.; Cott, C.; Badley, E. M. Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. J Gerontol B Psychol Sci Soc Sci 2000, 55 (6), P362-372. DOI: 10.1093/geronb/55.6.p362 From NLM. Ridgeway, J. L.; Egginton, J. S.; Tiedje, K.; Linzer, M.; Boehm, D.; Poplau, S.; de Oliveira, D. R.; Odell, L.; Montori, V. M.; Eton, D. T. Factors that lessen the burden of treatment in complex patients with chronic conditions: a qualitative study. Patient preference and adherence 2014, 8, 339.
45. Lorig, K. R.; Holman, H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003, 26 (1), 1-7. DOI: 10.1207/s15324796abm2601_01 From NLM.

46. Baltes, P. B.; Baltes, M. M. Psychological perspectives on successful aging: The model of selective optimization with compensation. 1990.
47. McGilton, K. S.; Vellani, S.; Yeung, L.; Chishtie, J.; Commisso, E.; Ploeg, J.; Andrew, M. K.; Ayala, A. P.; Gray, M.; Morgan, D.; et al. Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: a scoping review. BMC Geriatr 2018, 18 (1), 231. DOI: 10.1186/s12877-018-0925-x From NLM.
48. Feder, S. L.; Kiwak, E.; Costello, D.; Dindo, L.; Hern; ez-Bigos, K.; Vo, L.; Geda, M.; Blaum, C.; Tinetti, M. E.; et al. Perspectives of Patients in Identifying Their Values-Based Health Priorities. J Am Geriatr Soc 2019 67 (7), 1379-1385. Mold. Goal-directed health care: redefining health and health care in the era of value-based care. Cureus 2017, 9 (2).
49. Moudatsou, M.; Stavropoulou, A.; Philalithis, A.; Koukouli, S. The role of empathy in health and social care professionals. In Healthcare, 2020; Multidisciplinary Digital Publishing Institute: Vol. 8, p 26.
50. Franklin, M.; Lewis, S.; Willis, K.; Rogers, A.; Venville, A.; Smith, L. Controlled, Constrained, or Flexible? How Self-Management Goals Are Shaped By Patient-Provider Interactions. Qual Health Res 2019, 1049732318774324.
51. Kuluski, K. Relationships and Communication—the core components of person-centred care. Health Expectations: An International Journal of Public Participation in Health Care and Health Policy 2020, 23 (5), 977.
52. Ricci-Cabello, I.; Pons-Vigués, M.; Berenguera, A.; Pujol-Ribera, E.; Slight, S. P.; Valderas, J. M. Patients' perceptions and experiences of patient safety in primary care in England. Fam Pract 2016, 33 (5), 535-542. DOI: 10.1093/fampra/cmw046 From NLM. Clarke, R.; Bharmal, N.; Di Capua, P.; Tseng, C. H.; Mangione, C. M.; Mittman, B.; Skootsky, S. A. Innovative approach to patient- centered care coordination in primary care practices. Am J Manag Care 2015, 21 (9), 623-630. From NLM.
53. McCormack, B. Person-centredness in gerontological nursing: an overview of the literature. J Clin Nurs 2004, 13 (3a), 31-38. DOI: 10.1111/j.1365-2702.2004.00924.x From NLM.
54. Hiss, R. G.; Armbruster, B. A.; Gillard, M. L.; McClure, L. A. Nurse care manager collaboration with community-based physicians providing diabetes care a randomized controlled trial. The Diabetes Educator 2007, 33 (3), 493-502.
55. Barry, M. J.; Edgman-Levitan, S. Shared decision making--pinnacle of patient-centered care. The New England journal of medicine 2012, 366 (9), 780-781. DOI: 10.1056/NEJMp1109283 From NLM.
56. Kuluski, K.; Guilcher, S. J. T. Toward a Person-Centred Learning Health System: Understanding Value from the Perspectives of Patients and Caregivers. HealthcarePapers 2019, 18 (4), 36-46. DOI: 10.12927/hcpap.2019.26030 From NLM.
57. Cater, J. K. Skype a cost-effective method for qualitative research. Rehabilitation Counselors & Educators Journal 2011, 4 (2), 3. Deakin, H.; Wakefield, K. Skype interviewing: Reflections of two PhD researchers. Qualitative research 2014, 14 (5), 603-616.
58. Bartlett, G.; Blais, R.; Tamblyn, R.; Clermont, R. J.; MacGibbon, B. Impact of patient communication problems on the risk of preventable adverse events in acute care settings. Cmaj 2008, 178 (12), 1555-1562. DOI: 10.1503/cmaj.070690 From NLM.
59. Damarell, R. A.; Morgan, D. D.; Tieman, J. J. General practitioner strategies for managing patients with multimorbidity: a systematic review and thematic synthesis of qualitative research. BMC Family Practice 2020, 21 (1), 1-23.
60. Schulman-Green, D.; Jaser, S.; Martin, F.; Alonzo, A.; Grey, M.; McCorkle, R.; Redeker, N. S.; Reynolds, N.; Whittemore, R. Processes of self-management in chronic illness. Journal of Nursing Scholarship 2012, 44 (2), 136-144. Audulv, Å.; Asplund, K.; Norbergh, K.-G. The integration of chronic illness self-management. Qualitative health research 2012, 22 (3), 332-345.
61. Tinetti, M. E.; Naik, A. D.; Dindo, L.; Costello, D. M.; Esterson, J.; Geda, M.; Rosen, J.; Hern; ez- Bigos, K.; Smith, C. D.; et al. Association of Patient Priorities-Aligned Decision-Making with Patient Outcomes and Ambulatory Health Care Burden among Older Adults with Multiple Chronic Conditions: A Nonrandomized Clinical Trial. JAMA Internal Medicine 2019.
62. Reeves, S.; Pelone, F.; Harrison, R.; Goldman, J.; Zwarenstein, M. Interprofessional collaboration to improve professional practice and healthcare outcomes. Cochrane Database of Systematic Reviews 2017, (6).

Appendix Chapter 2

Supplementary file 1: Consolidated Criteria for Reporting Qualitative Research (COREQ)

Available at https://pubmed.ncbi.nlm.nih.gov/35178849/

Chapter 3

Self-management support in Flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach.

Published as:
Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B; Primary Care Academy. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022 Mar 31;23(1):63. doi: 10.1186/s12875-022-01652-8. PMID: 35361118; PMCID: PMC8968094.

Abstract

Background

Coping with a chronic disease can be really challenging. Self-management represents a promising strategy to improve daily life experiences. The role of primary healthcare professionals cannot be underestimated in supporting self-management. Due to a shortage of theory, implementation of self-management support is hindered in primary care practice. The aim of this study is to create a conceptual model for self-management support by analysing patients' care experiences towards self-management support.

Methods

An explorative-descriptive qualitative study was conducted in Flanders, Belgium. Semi-structured interviews were performed with 16 patients and their informal caregiver (dyads) using a purposive sampling strategy and processed by an inductive content analysis, according to Graneheim and Lundman.

Results

Interviews revealed in-depth insights into patients' care experiences. A conceptual model was developed for primary care practice, including five fundamental tasks for healthcare professionals - Supporting, Involving, Listening, Coordinating and Questioning (SILCQ) – contributing to the support of self-management of chronic patients.

Conclusion

This qualitative paper emphasises the use of the SILCQ-model to develop optimal roadmaps and hands-on toolkits for healthcare professionals to support self-management. The model needs to be further explored by all stakeholders to support the development of self-management interventions in primary care practice.

Keywords

Self-management, Patients, Primary health care, Health personnel, Qualitative research

Background

There is a growing number of people worldwide living with multiple chronic conditions(1,2). Approximately one on three adults has to face the challenges of living with multimorbidity(3). In Europe, this number of people is estimated at more than 50 million(4). Chronic conditions are defined by the World Health Organization (WHO) as long standing and slowly deteriorating diseases(5). Due to this chronic character, the impact on a patient's daily life cannot be underestimated.

The consequences of chronic diseases are generally reflected in limited capacity, reduced functionality and productivity, reduced quality of life and increased healthcare costs(6,7). As a result, chronic diseases require intensive management. Multiple interventions have been developed in order to support people with chronic diseases(7–9). Key roles are mainly reserved for the healthcare professionals and the social environment of the patient(10–14) but even more important in the care process is the role of the patient himself(15). By taking charge of their own chronic diseases, patients fully commit in their own care(16). This responsibility helps them to function in daily life activities, to experience interdependency throughout the care process, and offers the possibility to optimize patient's own care(17). In addition, taking charge of their own health contributes to the development of self-management(18).

Self-management is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Barlow *et al*. 2002)(19). Patients can be assisted in this process of taking ownership by healthcare professionals. Health care systems are gradually changing as to support these professionals in taking up this role. This change is defined as "the process of making and refining multi-level changes in healthcare systems (and the community) to facilitate patients self-management" (Glasgow *et al*. 2003)(20). Self-management support implies intensive cooperation among patients, healthcare professionals and the healthcare system(21). Primary healthcare professionals are well-positioned to help patients developing the ability of self-management, since primary care often serves as the first point of contact in the care system(22). They have the opportunity to encourage patients to take part in their own care process. As a result, patients feel empowered and can actively be involved in their health care(23–25).

Several models have been developed to guide self-management support interventions for patients with chronic conditions. For example, the WISE-model (Thompson *et al*., 2018) aims to support patients by focussing on active counselling by trained healthcare practitioners(26). The model seeks to encourage practices to incorporate patient-centred care. The five A's Model

(Glasgow *et al.*, 2003) also focusses on patient counselling(20). In this model the creation of a personal action plan informed by 5 A's elements (i.e., assess, advise, agree, assist and arrange) is central, which is considered as essential to facilitate patient self-management(20). Various other approaches to self-management support are presented in literature. In 2017, the strategic international chronic condition self-management support framework (Mills *et al.*) formulated guiding principles and strategic directions prior to the establishment of self-management support initiatives(27). A comparative overview for different support frameworks exists and aims to create a platform for researchers to operationalise frameworks (O'connell *et al.*, 2018)(28).

Although they are designed to be applicable in primary care practice, self-management support interventions are not yet optimal in use and their effectiveness is questioned(29–32). The models and frameworks described in literature tend to focus on the implementation of self-management support rather than on underlying mechanisms, such as the interaction between healthcare professionals and their patients. However, understanding these mechanisms is of great importance in effective self-management support(33).

In addition, existing models are drawn up by researchers based on cooperation with healthcare professionals, instead of with patients. Since patients act as equal partners in a collaboration on shared responsibility(34), the importance of involving them in research cannot be underestimated. More insights are required to explore patients' experiences towards this partnership to self-manage a chronic condition(25). Therefore, there is a need to investigate not only the underlying mechanisms that help people to self-manage a chronic condition, but also to listen to the voice of the patients themselves. These understandings should supplement insights from existing models and orientate the further development of new self-management support interventions.

This study offers an exploratory view on patient's self-management and on the support by primary healthcare professionals. The aim is to create a conceptual model for self-management support by analysing patients' experiences. The research question addressed in this study is, "What do we learn from patients' care experiences about the interaction with care professionals related to self-management support?". This study is part of a larger research project of the Primary Care Academy (PCA) that aims to explore patients' experiences towards primary care in Flanders (Belgium).

Methods

Study design

This qualitative study explored experiences of chronic patients and their informal caregivers, so called dyads, with primary healthcare in Flanders. The aim of the study was to explore specific experiences regarding self-management support by healthcare professionals. For this purpose, a qualitative content approach was used to analyse the transcripts (Graneheim et al., 2017)(35).

Study participants

The dyads were purposively sampled. The inclusion criteria applied to the patients and were defined based on the definition of patients with complex care needs operationalized by Iglesias(36) and adapted to the specific research question. We did not set out specific criteria for the informal caregivers.

Inclusion criteria

The interviewed patients were purposively recruited and had to meet all the following criteria: (1) aged 18 years or above, (2) suffering from a single severe chronic condition or two or more stable chronic conditions (defined as multimorbidity), and (3) receiving support from at least three primary healthcare disciplines, in addition to the support of an informal caregiver.

To achieve a heterogeneous maximal variation sample, the patients had to meet one of the following additional criteria: (1) taking four or more different medications related to their chronic condition(s), (2) demanding a higher need of care, (3) living in a low socio-economic situation, (4) estimated to have limited or low health literacy, or (5) tending to need more care according to at least one member of their primary care team.

Exclusion criteria

Exclusion criteria were defined for either ethical or practical reasons and assessed by the entire research team: (1) patients legally incapacitated to participate, (2) patients incapable to reason about care for various reasons (e.g., severe mental illness, cognitive impairment), (3) patients incapable of being interviewed during the predetermined time frame, (4) patients unable to give permission by the informed consent form, and (5) patients with terminal illness.

Dyads were approached by health and welfare organisations or by their General Practitioner (GP), who provided general information on the study. Oral permission of the dyads to their GP was required for the research team to contact the participants. The researcher explained the

informed consent form and provided additional information on the project. The dyads were assured participation was completely voluntary and their informed consent was obtained before the beginning of the interviews.

Data collection

Semi-structured interviews were organised with dyads in their home setting or due to the COVID-19 pandemic by using video conferencing platforms. The interviews were conducted between January 2020 and August 2020 and were supported by an open-ended interview guide. Questions focused on patients' primary care experiences and their interaction with healthcare professionals. More specifically, open-ended questions in the interview related to 1) daily experiences of living with a chronic condition; 2) structure and functioning of the care network; 3) empowerment, involvement, and participation in care processes; 4) needs, goals and wishes towards primary care and 5) guidance and support strategies in primary care. Every interview was scheduled to last no more than one hour a half. The interviews were addressed to the patient, but the informal caregiver was offered the possibility to add input or support the conversation to improve patient understanding. The collection of data was pilot tested, and the first interviews were conducted by two researchers of the team (DB, MS, and LT) together. The subsequent interviews were conducted independently by one researcher of the same team, individually recorded and transcribed verbatim.

Data analysis

To address the research question in this paper, a qualitative inductive content analysis was undertaken by the main researcher LT (Graneheim et al., 2017)(35). First, transcripts were read multiple times to gain an overall naive understanding. Afterwards, the data were reduced into meaningful units addressing patients' self-management support experiences. Subsequently, units were condensed and labelled with codes. Thereafter, the codes were compared and allocated into subcategories by classifying the codes according to similarities and differences. Similar subcategories were merged into each other and categorized into main categories. Finally, a reverse approach was used, and the overall main categories were tailored to the initial data. Data analysis was conducted using an Excel spreadsheet. Meaningful units, condensations, subcategories, and categories were checked by the principal investigator (BS) and confirmed to increase the credibility of the results. We considered data saturation as the end point of data collection and analysis, meaning no new data were generated from the interviews.

Trustworthiness

To prove trustworthiness of the data, the criteria of credibility, transferability, dependability and confirmability were applied in this study (Guba and Lincoln)(37). To enhance credibility of the analysis, we used member-checking to ensure accuracy. Member-checking of the findings was performed by presenting the model and findings to a minority of participants. In addition, maximum variation sampling was applied to recruit the interview participants. To increase the transferability, participants of different age, socioeconomic level, educational level, living and health status were chosen. Moreover, we tried to ensure this transferability of the data by including direct quotations in the manuscript. To enhance dependability of our data, the interviews were carefully recorded and transcribed verbatim. In addition, the analysis was checked by qualitative experts in the field, which has also contributed to the confirmability of our data. The latter criterion was further increased by including appropriate samples with maximum variation.

Research team

The interviews were collected by DB, MS, and LT; the analysis of the experiences towards self-management support was performed by the main researcher LT in close collaboration with the entire research team. Before the project initiation, the team received a training on the principles and methods in qualitative research to assure a certain level of standardization.

Ethics

Ethical approval for the original study was obtained from the Ethical Committee of University of Antwerp (B300201942302). All methods were carried out in accordance with relevant guidelines. The entire study was in accordance with the Helsinki Declaration.

Results

In total, 16 interviews with a patient-informal caregiver dyad were performed. The interviews lasted from 58 to 90 min. Although the interviews were conducted with patients in the presence of their informal caregivers, the results presented in this paper entirely focus on the patient's experiences towards self-management support. Involving the informal caregivers helped patients in formulating their story and to feel at ease.

Characteristics of study participants

A total of 32 persons were interviewed, including 16 patients and 16 informal caregivers. Most patients were living together with their informal caregiver (11 out of 16 patients). The characteristics of the participants are summarized in Table 1.

Table 1: Characteristics of the participants

	Patients	Informal caregivers
Gender		
Male	5	7
Female	11	9
Mean age	67.5	66.8
Additional inclusion criteria		
Patients taking four or more different medications	11	-
Patients demanding a higher need of care	6	-
Patients of low socio-economic situation	3	-
Patients estimated to have limited or low health literacy	3	-
Patients tending to need more care according to at least one member of their primary care team	2	-
Employment		
Employed	0	1
Unemployed	0	1
Unemployed due to disability	3	3
Retired	13	11

Structural analysis

The inductive content analysis of the interview data resulted in five main categories regarding the role of healthcare professionals in reinforcing patients' self-management: supporting, involving, listening, coordinating, and questioning. The main categories are the result of breaking down the interview transcripts into meaning units, further condensed into multiple subcategories, and finally encapsulated into main categories (Table 2). In some cases, a subcategory applies to multiple main categories since the main categories are not strictly delineated and overlap slightly. Table 3 provides an overview of the main categories and subcategories. The categories exclusively focus on interactions between patients and their healthcare professionals.

The healthcare professional network consisted in many cases of the same key actors including a GP, a pharmacist, a home nurse, and a medical specialist related to a specific disease. Typically, the primary care professionals acted as the first and central point of contact for patients. Depending on patients' case, other primary healthcare professionals were also involved like social workers, physiotherapists, speech therapists, members of the pain clinic, dietitian, etc. A patient with Parkinson's disease, for example, would be additionally supported by a physiotherapist and a speech therapist. In a limited number of interviews, there was also guidance by a psychologist or psychiatrist. In the following section, the different categories are presented with examples of verbatim quotes.

Table 2: Example of the inductive content analysis

Meaning unit	Condensation	Subcategory	Main Category
"She [GP] helped me… I can always go to visit her or call if I do not feel okay. Not for the prescription of my medications, but to meet for a talk." **(Patient – P4)**	The doctor is both physically and by telephone accessible for not only the prescription of medication, but also for a listening ear.	Accessibility Understanding	Coordinating Listening
"I have balance problems. If the physiotherapist comes at home, our first exercise is on it." … "We walk around. She stands behind me when she sees me shaking so she can quickly grab me." **(Patient – P2)**	Treatment of the physiotherapist with supportive exercise (balance problems)	Practical support Formal support	Supporting
"When I was first diagnosed, I had many questions. And I gave them to him [doctor]." … "That doctor just answered the questions he wanted to respond. And when the doctor's appointment was over, I never received the answers on the questions, he did not likely formulate a response on. So yes, that was a mess … and I did not feel good about it." **(Patient – P6)**	Patient used to write the questions down before an appointment. The doctor just answered the questions he wanted to answer and then the appointment was over. Patient didn't feel good about it.	Dialogue Information	Questioning

Table 3: Overview of subcategories and main categories resulting in an overall core category

Subcategory	Main category	Core category
Practical support	Supporting	The role of healthcare professionals in self-management support
ADL support		
Physical support		
Household support		
Medical support		
Information exchange		
Clinical expertise		
Follow-up		
Communication tools	Involving	
Shared decision-making		
Participation		
Cooperation		
Care continuity		
Freedom of choice		
Taking time	Listening	
Empathy		
Understanding		
Listening ear		
Dealing with help requests		
Emotional support		
Listening to questions		
Listening to expectations		
Listening to wishes and goals		
Listening to care barriers and facilitators		
Accessibility	Coordinating	
Care continuity		
Deliberation		
Stability		
Collaboration		
Time management		
Support network		
Teamwork		
Point of contact		
Follow-up		
Dialogue	Questioning	
Information		
Questioning expectations		
Questioning experiences		
Questioning wishes and goals		
Questioning care barriers and facilitators		

Supporting

Within our study context, we defined supporting as all elements supplied by a healthcare professional related to treatment, follow-up, and guidance. The participating patients indicated to be accompanied by a team of healthcare professionals. According to the interview data, the main actors involved in the active support were nurses, GPs, and physiotherapists. Their support was experienced as essential to fit the chronic condition into daily life. In essence, essential to self-manage the disease.

"For my care… I don't think other persons are involved beside my physiotherapist, the home nurse and my GP." (patient)

Besides delivering physical care (e.g., diagnosis, treatment, symptom control), various other support elements came up in the interviews. More specifically, supporting was about actively guiding through the delivery of practical tools (e.g., a wheelchair), health-related information, medical assistance (e.g., medicines) and the set-up of home care. Home health care represented most of the support. The frequent visits by home care nurses ensured a better disease management.

"And then in the evening, the physiotherapist comes to visit at home. And he provides exercises for my back and my neck and he applies a bandage with a tape."
… "It really helps me. He supports me well." (patient)

"The purpose of the nursery is to make the physical condition as good as possible. That goal has been realized." (patient)

Involving

Involving was defined as working in (co-)partnership with patients. Participants described explicitly the wish to be involved in their care. Patients experienced feelings of respect and equality when being actively engaged in health care. It gave them a chance to participate in their own care and to self-manage their chronic condition. The involvement seemed to be mostly related to medical decision making. For example, patients longed for a freedom of choice related to medical treatment options. In addition, the wish was expressed to be involved in decisions concerning the support of daily life activities. Well-informed decisions did arise when there was room for open conversation and discussion. The extent to which patients wanted to be involved depended on the patient.

"If I have an appointment with D. [the doctor], he asks me if I want to try the proposed medicine or if I prefer something else. So yes, I'm taking part in the decisions he makes." (patient)

Moreover, patients strived for involvement throughout the entire care process. To overcome the pitfall of a provider-centred management, patients indicated empathy and understanding as essential components of good collaboration. The participants expressed the wish to share their concerns to feel comfortable in the care they receive.

"No, I make decisions together. Uh, for example… They have asked me a couple of times what I think about a DBS [Deep Brain Stimulation]. Uh, I am quite reluctant towards it and therefore, I have made it clear to the doctor." (patient)

Listening

Listening seemed one of the most talked-about components, defined as the act of giving an audience and paying attention to someone. Patients expected from their healthcare professionals to listen to what they need, what they want and to what they strive for. Only in this way patients felt supported to manage the chronic disease. In addition, the interviews emphasised the importance of encountering a professional with a listening ear to be able to express concerns. The interview participants pointed towards the home care nurse, a psychologist, or the GP as the ideally positioned sounding board.

"She [GP] helped me… I can always go to visit her or call if I do not feel okay. Not for the prescription of my medications, but to meet for a talk." (patient)

Listening to patients was defined as taking time and being into an accessible mindset. Furthermore, listening means patients felt heard. Participants clearly mentioned that plenty of opportunities can arise from open-minded interactions between care professionals and care receivers.

"You have the feeling that those doctors are making time for you. It's not that you walk in their practice and they immediately start looking at the clock… If the doctor comes here for a home visit, and he always comes here, he'll just sit down for half an hour, at least, and tell you all kind of things. He is also a nice person… and he listens to you and gives advice." (patient)

The listening aspect was also mentioned in the interviews when talking about emergency situations. Patients were in need to contact their care professionals if they experienced problems. Dealing with help requests included active listening to all actors involved. The GP mostly acted as the central contact person in these cases.

Coordinating

Coordinating was defined as guiding responsibilities in the entire care process. According to the participants, coordinated care contributed to coping with their chronic condition, and consequently, to self-manage the chronic condition. Patients expected healthcare professionals to assume responsibility to keep the care network running. An effective follow-up was fundamental by means of coordination between the professionals. Furthermore, patients expressed the importance of being able to make an appeal to their formal network. Again, the central connection was the patients' GP.

"They work well together. P. [GP1] is the one who coordinates everything a bit. J. [GP2] has been away for a year because she had a baby. P. and J. used to come around. During the holidays we received a letter that someone is stepping in. They are all good doctors. They coordinate with each other very well." (patient)

According to the participants, the act of coordinating involves communication and discussion between different actors through the entire care process. Participants experienced benefits of information exchange since it guaranteed care continuity. In addition, coordinating included collaborating among the healthcare professionals with a focus on the chronically ill patient. This could be facilitated using digital tools (e.g., digital patient file, electronic health platforms). The interview conversations highlighted the significance of a well-functioning structured care system, in which effective and clear agreements are made. Finally, coordinating also meant that there was good overview of all care actors involved.

"Doctor X [GP1] and doctor Y [GP2], they come here for a home visit. And they have their computers with them. They contain the entire patient file. Everything is written inside that has happened. And if someone [one of the two central GPs] cannot come to us, there are always others doctors available. You see, that's how our doctors are here." (patient)

Questioning

For the current analysis, we defined questioning as a type of communication giving raise to conversation by using interrogation. Patients expected the care professionals to ask them questions. Posing questions created a genuine momentum between care professionals and patients. It resulted in an interactive conversation about patient's wishes, goals, and expectations. Furthermore, formulating questions to the patient initiated valuable conversations about the care process: what goes well and what could be improved? Do patients feel comfortable in their care, do they understand the medical treatment or are there any ambiguities? Additionally, a question could boost the mechanisms of information transfer between patients and their care professionals.

"A great healthcare professional takes time, poses question and talks." (patient)

Conceptual model

Using in-depth interviews, insights into patients' primary care experiences related to self-management support were gained. We learned that patients could manage their chronic disease more effectively if they feel supported, involved in the care process, listened to, if their care is coordinated and if they are questioned. Based on these five main categories, we were able to identify and formulate concepts to describe the key characteristics in the support of self-management. The conceptual model for primary care practice includes five fundamental tasks that need to be performed by healthcare professionals - Supporting, Involving, Listening, Coordinating and Questioning (SILCQ) – that contribute to efficiently supporting chronic patients' self-management. These tasks were incorporated into the model as the acronym 'SILCQ' (Figure 1).

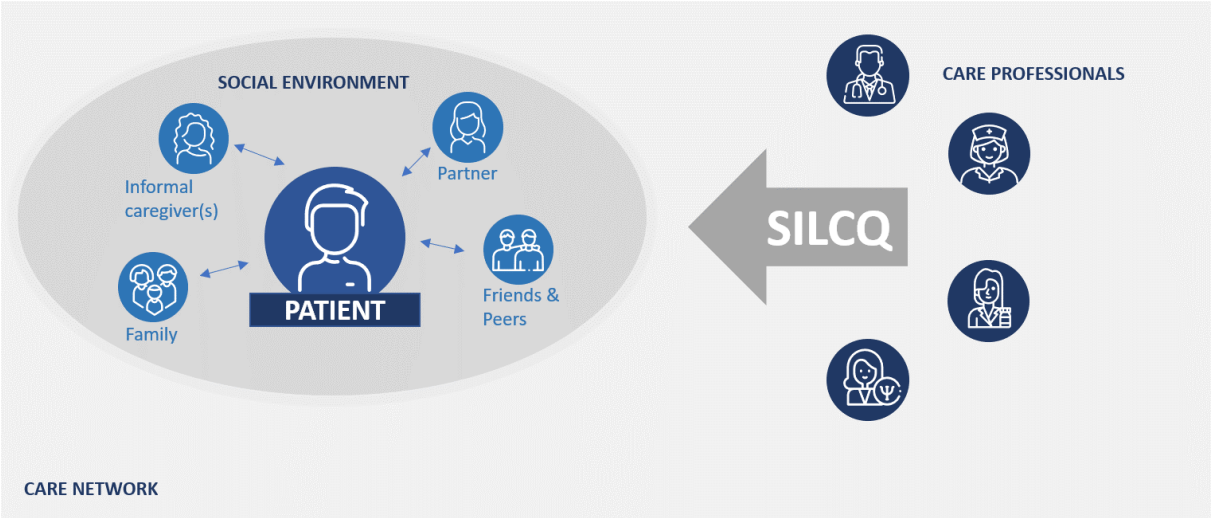


Figure 1: Conceptual model on the support of self-management
Abbreviations: S = Supporting; I = Involving; L = Listening; C = Coordinating; Q = Questioning
Icon made by Freepik from www.flaticon.com

Patients are in most cases connected to a social network. We defined this network as 'the social environment'. According to the participants, the social environment consists of the closest surroundings of a patient. The composition of the social environment varied and was different depending on the patients. Possible members were relatives, friends, and partners. This network was reinforced by peers in some cases. In this close environment, someone had taken upon the role of informal caregiver.

"I am in contact with the health insurance fund.
Also, with my parents, of course, and my friends and family...
And the nurses for appointments and to accompany me to scans etc.
And my home help... And the family doctor." (patient)

"I think that fellow sufferers are important. Like the pain society... That's very good because there you get to know people who also understand you and who are also going through the same thing to some extent. I find the support of those people enormous." (patient)

Being able to manage a chronic condition is closely related to support by the entire care network, including the social environment. The proposed model considers these interactions in a patient-centred care network.

"And if she suddenly has a disease flare, I call the medical practice to ask for help. Afterwards, I can get a medicine from the pharmacist, because in those situations she is out of medication. When I call, the doctor says: 'Yes, go ahead.' So, I call the pharmacist and I say to them: 'I have a problem, but I don't have the prescription for the medication yet. Can I already pick up the medication?' I'll bring it later, and that is not a problem." (informal caregiver)

Discussion

The findings highlight healthcare professionals' role in supporting self-management of chronic conditions. These roles are reflected in the proposed SILCQ-model. Unfortunately, important components such as arranging follow-up are often ignored in practice(38). Due to the high demands for time and attention, the focus during clinical encounters is mainly on the current problems of patients(39). The adoption of follow-up with healthcare professionals is additionally challenged because it may be difficult for patients to understand the concept or may be considered an unacceptable intrusion into daily life(40). Nevertheless, our study emphasises the importance of active support from healthcare professionals during both treatment and follow-up. Providing medical information and tools is part of the support. Our study demonstrates that supporting means that the necessary guidance is provided or built up around a patient. In this environment, healthcare professionals and patients should act as equal partners. Fu *et al.*(41) also revealed the importance of patients' partnerships with healthcare professionals on the ability to self-manage. Our interview participants expressed the desire to be involved in the entire care process. The challenge seems to shape this collaboration and define the contribution of the patient himself(15,42). A balance must be achieved between respecting patients' autonomy and encouraging their active contribution in healthcare(43). A recent systematic review on patient involvement identified factors that determine involvement in medical performance, namely the attitudes of the individual healthcare professional, the patient characteristics, the understanding of the purpose of involvement and the key relationships (i.e., doctor-patient relationship and the profession-public relationship)(44). According to our interview data, the extent to which involvement contributes to self-management depends very much on the individual patient. Consequently, determining patients' wishes and goals is an important component of self-management support. Several studies confirm this association with

goal-oriented care(45,46). Because of the strong association, healthcare professionals are challenged to actively question patients to determine goals. Conversation is shaped using interrogation. This questioning aspect was strongly emphasised in the interviews. Open-ended questions enable physicians to obtain crucial and sufficient health information from patients(47). An essential condition for this is that healthcare professionals commit to active listening. Unfortunately, healthcare professionals are used to telling, rather than actively questioning, what patients want or what feels good for them(48). Miles *et al.*(49) confirms these findings by identifying communication as crucial for effective self-management. The study analyses patients' experiences and reveals that patients expect to be listened to. Remarkable, our interview participants consider listening to patients as a natural one-way behaviour in providing good care, which also includes supporting self-management(50). However, being in the position to listen to patients depends on various aspects. These aspects are not only related to the commitment and skills of healthcare professionals. In primary care practice, listening is additionally hampered by various factors, such as limited skills of patients and limiting contextual factors (e.g., doctor's mood, workload, lack of time)(51,52). Moreover, asking question and listening are not stand-alone elements to facilitate dialogue(53). Integrating moments of silence and paying attention to nonverbal communication significantly contributes to patient-centred communication(54–56). In addition, dealing with patients' cues and concerns is a foundation listening skill for GPs(51). Unfortunately, there is evidence that these cues and concerns are not picked up or even ignored in daily primary care consultations(57,58). More training is needed to develop communication competences and skills of healthcare professionals beyond asking questions and offering a listening ear. To optimally deliver self-management support, a multidisciplinary approach is required. Tocchi *et al.*(59) described a positive effect of multidisciplinary teams on self-management of symptoms. Our research emphasises the role of a central healthcare professional to coordinate care. According to the interview data, the main actor in supporting self-management is context and patient dependent. Nevertheless, we can argue that in most cases the GP is mentioned as the pivotal figure. Unfortunately, not all GPs are able to fulfil this pivotal role(60,61). This must be considered when organising care around chronic patients. GPs must be taught the necessary competencies and skills in leadership(62).

Although our findings are in agreements with other studies regarding self-management support, most studies focus on one single aspect of the support. Few comprehensive models have been designed that include multiple aspects (20,26,27). In addition, most models don't target multimorbidity and only focus on self-management support from a specific healthcare professional(28). Our SILCQ-model addresses this issue by providing insights into the fundamentals of support strategies, independent of the type of disease and healthcare

professional. Self-management support interventions are not applicable to every patient and subject to change(63). Therefore, it is important to consult the SILCQ-model which represents the foundation on which to build interventions.

Strengths and limitations

Some limitations should be mentioned. First, patients were interviewed in the presence of their informal caregiver for additional support. This may have caused the participants withholding personal stories resulting in some bias. However, involving the care network of patients resulted in valuable insights. It should be noted that these insights only apply to patients. No conclusions about informal care can be drawn from this study. To be as comprehensive as possible, we continued to interview dyads until saturation of data was reached. Since in the last interviews, no new information on the topic of self-management support appeared, we decided the stop data collection after interviewing 16 dyads. Secondly, since participation in this research was completely voluntary, volunteer bias can occur. However, our research sample can be considered clinically representative in the international primary care context, when focusing on patients with complex care needs (i.e., mostly an aging population). Thirdly, the SILCQ-model is the result of discussions only with patients. Not including healthcare professionals allowed patients' voice to be the focus of the model. Involving healthcare professionals should be the next step to validate the results. Fourthly, the SILCQ-model does not provide any recommendations for future self-management support interventions. We aimed to provide insights, rather than formulate specific guidelines because effectiveness of interventions is highly context and patient dependent. In addition, we believe that the SILCQ-components are the fundaments of every self-management support intervention in primary care. Lastly, the choice to conduct a qualitative content analysis limited the generalisability of the results. However, rather than generalising we aimed to undertake a proof of concept to understand the features of self-management support more in depth.

Implications for research and practice

The SILCQ-model provides a holistic approach to self-management support, while focusing on the central interaction in the care network between healthcare professionals and patients. Programme developers are encouraged to keep the formulated elements in mind when setting up new self-management support interventions in primary care. Further research is required to understand how these SILCQ-elements are implemented in care practice and contribute to self-management outcomes.

Conclusion

This qualitative paper highlights the importance of the SILCQ-elements – Supporting, Involving, Listening, Coordinating and Questioning – when reinforcing patients' self-management. In providing good care, healthcare professionals are expected to prioritize these actions. The model should be further explored by all stakeholders to support the development of self-management interventions in primary care practice.

References

1. Kuluski K, Ho JW, Hans PK, La Nelson M. Community care for people with complex care needs: Bridging the gap between health and social care. Int J Integr Care. 2017 Jul 1;17(4):2.
2. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. Lancet. 2012;380(9836):37–43.
3. Hajat C, Stein E. The global burden of multiple chronic conditions: A narrative review. Prev Med Reports. 2018;12:284.
4. Van Der Heide I, Melchiorre MG, Quattrini S, Boerma W. Innovating care for people with multiple chronic conditions in Europe An overview. 2015.
5. Alliance E chronic disease. Chronic disease & Policy - European chronic disease alliance [Internet]. 2020 [cited 2020 Oct 12]. Available from: https://alliancechronicdiseases.org/chronic-disease-policy/
6. Devins GM, Binik YM, Hutchinson TA, Hollomby DJ, Barré PE, Guttmann RD. The emotional impact of end-stage renal disease: Importance of patients' perceptions of intrusiveness and control. Int J Psychiatry Med. 1983;13(4):327–43.
7. Megari K. Quality of life in chronic disease patients. Heal Psychol Res. 2013;1(3):e27.
8. Baker JM, Grant RW, Gopalan A. A systematic review of care management interventions targeting multimorbidity and high care utilization. BMC Health Serv Res. 2018;18(1):65.
9. Barlow JH, Sturt J, Hearnshaw H. Self-management interventions for people with chronic conditions in primary care: Examples from arthritis, asthma and diabetes. Health Educ J. 2002;61(4):365–78.
10. Zapka JG, Lemon SC. Interventions for patients, providers, and health care organizations. Cancer. 2004;101(5 SUPPL.):1165–87.
11. Dwamena F, Holmes-Rovner M, Gaulden CM, Jorgenson S, Sadigh G, Sikorskii A, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. Cochrane Database Syst Rev. 2012;12(12).
12. Latkin CA, Knowlton AR. Social Network Assessments and Interventions for Health Behavior Change: A Critical Review. Behav Med. 2015 Jul 3;41(3):90–7.
13. Coster S, Norman I. Cochrane reviews of educational and self-management interventions to guide nursing practice: A review. Int J Nurs Stud. 2009 Apr;46(4):508–28.
14. Alvarez C, Greene J, Hibbard J, Overton V. The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. BMC Health Serv Res. 2016 Mar 11;16(1):85.
15. Coulter A, Ellins J. Patient-focused interventions A review of the evidence [Internet]. 2006 [cited 2021 Mar 30]. Available from: www.health.org.uk/QQUIP
16. Funnell MM. Helping Patients Take Charge of Their Chronic Illnesses. Fam Pract Manag. 2000;7(3):47.
17. McWilliam CL. Patients, persons or partners? Involving those with chronic disease in their care. Chronic Illn. 2009 Dec;5(4):277–92.
18. Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). Med Care. 2005 May;43(5):436–44.
19. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
20. Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. Jt Comm J Qual Saf. 2003 Nov 1;29(11):563–74.
21. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. Eff Clin Pract. 2001;4(6):256–62.
22. Samuelson M, Tedeschi P, Aarendonk D, De La Cuesta C, Groenewegen P. Position Paper of the European Forum for Primary care Title: Improving inter-professional collaboration in Primary Care. 2012.
23. Dent M, Pahor M. Patient involvement in Europe – a comparative framework. J Heal Organ Manag. 2015;29(5):546–55.
24. Greenhalgh T. Patient and public involvement in chronic illness: beyond the expert patient. BMJ. 2009;338:b49.
25. Salemonsen E, Førland G, Hansen BS, Holm AL. Understanding beneficial self-management support and the meaning of user involvement in lifestyle interventions: A qualitative study from the perspective of healthcare professionals. BMC Health Serv Res. 2020;20(1):1–12.
26. Thompson DG, O'Brien S, Kennedy A, Rogers A, Whorwell P, Lovell K, et al. The WISE model of self-management support. NIHR Journals Library; 2018.
27. Mills SL, Brady TJ, Jayanthan J, Ziabakhsh S, Sargious PM. Toward consensus on self-management support: the international chronic condition self-management support framework. Health Promot Int. 2017;32(6):942–52.
28. O'connell S, Mc Carthy VJC, Savage E. Frameworks for self-management support for chronic disease: a cross-country comparative document analysis. BMC Heal Serv Res. 2018;18(1).
29. Lindsay S, Kingsnorth S, Mcdougall C, Keating H. A systematic review of self-management interventions for children and youth with physical disabilities. Disabil Rehabil. 2014;36(4):276–88.
30. Wong SKW, Smith HE, Chua JJS, Griva K, Cartwright EJ, Soong AJ, et al. Effectiveness of self-management

interventions in young adults with type 1 and 2 diabetes: a systematic review and meta-analysis. Diabet Med. 2020;37(2):229–41.
31. Jonkman NH, Westland H, Trappenburg JCA, Groenwold RHH, Bischoff EWMA, Bourbeau J, et al. Characteristics of effective self-management interventions in patients with COPD: individual patient data meta-analysis. Eur Respir J. 2016;48(1):55–68.
32. Smith SM, Wallace E, Clyne B, Boland F, Fortin M. Interventions for improving outcomes in patients with multimorbidity in primary care and community setting: a systematic review. Syst Rev. 2021;10:271.
33. Franklin M, Lewis S, Willis K, Bourke-Taylor H, Smith L. Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. Chronic Illn. 2018;14(2):79–103.
34. Chertoff J. The evolving physician-patient relationship: equal partnership, more responsibility. Qual Prim Care. 2015;23(1):1–3.
35. Graneheim UH, Lindgren BM, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. Nurse Educ Today. 2017 Sep 1;56:29–34.
36. Iglesias FH, Celada CA, Navarro CB, Morales LP, Visus NA, Valverde CC, et al. Complex care needs in multiple chronic conditions: Population prevalence and characterization in primary care. A study protocol. Int J Integr Care. 2018;18(2):16.
37. Lincoln Y, Guba EG. Naturalistic Inquiry. Sage. 1985. 92–109, 357–367 p.
38. Slev VN, Pasman HRW, Eeltink CM, van Uden-Kraan CF, Verdonck-deLeeuw IM, Francke AL. Self-management support and eHealth for patients and informal caregivers confronted with advanced cancer: an online focus group study among nurses. BMC Palliat Care. 2017;16(1):55.
39. Von Korff M, Tiemens B. Individualized stepped care of chronic illness. West J Med. 2000;172(2):133.
40. Brunner-La Rocca HP, Fleischhacker L, Golubnitschaja O, Heemskerk F, Helms T, Hoedemakers T, et al. Challenges in personalised management of chronic diseases—heart failure as prominent example to advance the care process. EPMA J. 2016;7(1):2.
41. Fu Y, McNichol E, Marczewski K, Closs SJ. Exploring the Influence of Patient-Professional Partnerships on the Self-Management of Chronic Back Pain: A Qualitative Study. Pain Manag Nurs. 2016;17(5):339–49.
42. Phillips RL, Short A, Kenning A, Dugdale P, Nugus P, McGowan R, et al. Achieving patient-centred care: the potential and challenge of the patient-as-professional role. Heal Expect. 2015;18(6):2616–28.
43. Wetzels R, Harmsen M, Van Weel C, Grol R, Wensing M. Interventions for improving older patients' involvement in primary care episodes. Cochrane Database Syst Rev. 2007;2007(1):CD004273.
44. Lalani M, Baines R, Bryce M, Marshall M, Mead S, Barasi S, et al. Patient and public involvement in medical performance processes: A systematic review. Health Expect. 2019;22(2):149.
45. Lenzen SA, van Dongen JJJ, Daniëls R, van Bokhoven MA, van der Weijden T, Beurskens A. What does it take to set goals for self-management in primary care? A qualitative study. Fam Pract. 2016;33(6):698–703.
46. Hughes S, Lewis S, Willis K, Rogers A, Wyke S, Smith L. Goal setting in group programmes for long-term condition self-management support: experiences of patients and healthcare professionals. Psychol Health. 2020;35(1):70–86.
47. Takemura Y, Sakurai Y, Yokoya S, Otaki J, Matsuoka T, Ban N, et al. Open-Ended Questions: Are They Really Beneficial for Gathering Medical Information from Patients ? Tohoku J Exp Med. 2005;206(2):151.
48. How to Incorporate Self-Management Support into your Practice (Video Transcript). Content last reviewed February 2016. Agency for Healthcare Research and Quality, Rockville, MD. [Internet]. [cited 2021 Jul 29]. Available from: https://www.ahrq.gov/ncepcr/tools/self-mgmt/how-script.html
49. Miles C, Arden-Close E, Thomas M, Bruton A, Yardley L, Hankins M, et al. Barriers and facilitators of effective self-management in asthma: systematic review and thematic synthesis of patient and healthcare professional views. npj Prim Care Respir Med 2017 271. 2017;27(1):1–21.
50. Bodenheimer T, Wagner EH, Grumbach K. Improving Primary Care for Patients With Chronic Illness. JAMA. 2002;288(14):1775–9.
51. Cocksedge S, May C. The listening loop: a model of choice about cues within primary care consultations. Med Educ. 2005;39(10):999–1005.
52. Cocksedge S. Learning to listen in primary care: some educational challenges. Educ Prim Care. 2016;27(6):434–8.
53. Bensing JM, Deveugele M, Moretti F, Fletcher I, van Vliet L, Van Bogaert M, et al. How to make the medical consultation more successful from a patient's perspective? Tips for doctors and patients from lay people in the United Kingdom, Italy, Belgium and the Netherlands. Patient Educ Couns. 2011;84(3):287–93.
54. Bensing J, Verhaak P. Communication in medical encounters. Heal Psychol. 2004;261–287.
55. Hall J, Roter D, Junghans B. Doctors Talking with Patients—Patients Talking with Doctors: Improving Communication in Medical Visits. Clin Exp Optom. 1995;78(2):79–80.
56. Ong L, de Haes J, Hoos A, Lammes F. Doctor-patient communication: a review of the literature. Soc Sci Med. 1995;40(7):903–18.
57. Campion P, Foulkes J, Neighbour R, Tate P. Patient centredness in the MRCGP video examination: analysis of large cohort. Br Med J. 2002;325(7366):691.
58. Levinson W, Gorawara-Bhat R, Lamb J. A study of patient clues and physician responses in primary care and

surgical settings. JAMA. 2000;284(8):1021–7.
59. Tocchi C, McCorkle R, Knobf MT. Multidisciplinary Specialty Teams: A Self-Management Program for Patients With Advanced Cancer. J Adv Pract Oncol. 2015;6(5):408.
60. Stange KC, Jaén CR, Flocke SA, Miller WL, Crabtree BF, Zyzanski SJ. The value of a family physician. J Fam Pract. 1998;46(5):363–8.
61. Birgitte S, Frank B, Jan D. What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative? A systematic literature review. Scand J Prim Health Care. 2009;27(1):31–40.
62. Grol SM, Molleman GRM, Kuijpers A, Sande R van der, Fransen GAJ, Assendelft WJJ, et al. The role of the general practitioner in multidisciplinary teams: a qualitative study in elderly care. BMC Fam Pract. 2018;19(1):40.
63. Lake AJ, Staiger PK. Seeking the views of health professionals on translating chronic disease self-management models into practice. Patient Educ Couns. 2010;79(1):62–8.

Chapter 4

Self-management support in primary care practice: a qualitative focus group study of care professionals' experiences.

Submitted and under review in BMC Primary Care as:
Timmermans L, Boeykens B, Sirimsi MM, Van de Velde D, De Vriendt P, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Self-management support (SMS) in primary care practice: a qualitative focus group study of care professionals' experiences.

Preprint published and available at https://www.researchsquare.com/article/rs-2888538/v1 (DOI: https://doi.org/10.21203/rs.3.rs-2888538/v)

Adapted version January '24 after feedback from BMC Primary Care reviewers.

Abstract

Background

To support self-management of chronically ill persons, innovative approaches of care practice are being developed. Unfortunately, many self-management supporting interventions struggle to achieve reliable and consistent improvements at various levels (patient, provider and healthcare system level). One possible strategy to facilitate translating theory into practice, is to consider the healthcare professionals' perspective prior to the development of new interventions. An exploration of their knowledge and opinion about barriers and facilitators is necessary before employing any self-management support (SMS) intervention. Therefore, our study aims to explore care professionals' perspectives about SMS within the Flemish primary care setting.

Methods

This study used a qualitative study design to examine SMS in primary care setting. Five focus groups were conducted, grouped into three waves. Participants were healthcare professionals in Flanders representing different disciplines and settings. A maximum variation purposive sampling was used to recruit participants. For the data analysis, the framework of thematic networks by Attride-Stirling was applied.

Results

A total of 34 healthcare professionals participated. Three global themes related to SMS were derived from the thematic analysis: (1) Characteristics, (2) Support strategies, (3) Barriers and facilitators. SMS was characterised as a collaboration-based and person-centred approach. A variety of supporting strategies were mentioned by the focus group participants. Most strategies consisted of informing and educating patients. Complementary to individual strategies, collaborative strategies were deemed necessary to support self-management. Regarding barriers and facilitators, different patient-related factors were identified. Additionally, competencies of healthcare providers and external factors seem to hinder the implementation of SMS in practice.

Conclusions

This focus group study highlights the importance of a collaborative, person-centred approach to SMS in the context of chronic diseases. Our findings point to the need for interventions that raise awareness and address barriers associated with SMS. Since generic SMS does not exist, the road to success is a growth process in which support must be adapted to the individual patient.

Keywords

Self-management support, Healthcare professionals, Primary health care, Qualitative research

Background

The world's population is undergoing a demographic shift. Over 70% of European citizens will be over 65 years old by 2050(1). This poses many challenges to our healthcare system. The evolution will result in an increasing number of people living with a chronic condition. At this moment, chronic non-communicable diseases (NCDs) are among the most prevalent causes of mortality and morbidity in Europe(2). In addition, chronic diseases substantially contribute to the global burden of disease, with cardiovascular disease, cancer, type 2 diabetes, and chronic respiratory disease being the most common ones(3,4).

Various approaches are adopted to prevent diseases, improve diagnostics, and provide more effective therapies(1). In addition, the focus is on patients' involvement and participation in the care process. When provision of care becomes patient-centred, patients feel empowered and become actively involved in their care process(5). Moreover, activating and involving patients contributes to developing patients' self-management strategies(6) and results in improved health outcomes(7). The concept of self-management has been extensively explored in the literature(8). Barlow *et al.* (2002) defined self-management as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"(9). According to literature, self-management could positively influence health service utilization, financial costs, and clinical outcomes (including reduced morbidity and mortality)(10–12). Moreover, a positive impact on various patient-related outcomes (including patients' self-efficacy and activation) and quality of life outcomes is reported.

The ability to self-manage chronic diseases requires six skills that patients should acquire: action planning, decision making, development of a patient–provider partnership, problem solving, self-tailoring, and utilization of resources(13). Various care interventions focus on the further development of these skills in chronically ill patients. Hence, further development and support of self-management skills are a prerequisite for achieving desired health and quality of life outcomes. These skills are not innate and do result from a lifelong learning process and task(8). Involving patients' care team, and fundamentally, the primary care professional, plays a crucial role in developing self-management skills(14,15). More specifically, healthcare professionals can encourage and support patients to develop skills and knowledge needed to manage their condition effectively, and thus engage in self-management(16). Furthermore, healthcare professionals can assist patients in setting goals and developing personalized care plans(17,18). By collaborating with patients, healthcare professionals can help optimise self-management support (SMS) and contribute to improved health and quality of life outcomes. Therefore, the

holistic definition of SMS by Adams *et al.* (2004), which defines SMS as "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support", was used for this study(19).

When implementing SMS approaches, different internal and external factors are taken into account to achieve effective and sustainable interventions tailored to the individual patient's needs and preferences(20–22). Nevertheless, many interventions struggle achieving reliable and consistent improvements in care practice(23). Often, these interventions are designed with only the patient's perspective in mind, without considering the perspectives of the care professionals who have to implement and support these SMS interventions(24). This oversight has led to a notable gap in our understanding, as the experiences, challenges and perspectives of professionals are under-represented. To fill this gap, our study focuses on this caregiving population, shedding light on their prior knowledge and opinions about SMS. Existing literature exploring professionals' perceptions often focuses on higher level concepts such as the provision of beneficial support or the role of professionals(25,26). As a result, there is a distinct lack of foundational insights from professionals at the conceptual level of SMS. In this study, we aim to uncover critical insights that have been overlooked in the current literature, ultimately contributing to a more comprehensive understanding of the factors that influence the successful implementation of SMS interventions. By exploring the experiences of care professionals, our goal is to make a significant contribution to the wider SMS puzzle. In doing so, we aim to create a synergistic relationship where the care professional perspective complements and strengthens the existing patient-centred literature. This study is part of the Primary Care Academy (PCA), a research and teaching network that aims to strengthen the capacity of primary care by developing interventions, optimal roadmaps, and hands-on toolkits for primary care policies, practice, and education, built upon the principles of goal-oriented care (GOC), interprofessional collaboration (IPC) and SMS.

Methods

Design

This paper reports on the results of a study conducted in Flanders, Belgium, where qualitative focus groups with healthcare professionals were carried out to explore the concept of GOC, IPC and SMS. The study contributes to the aim of the PCA and was performed by their main PhD-researchers (DB, LT and MS) under supervision of PDV and DVDV. This paper focusses on the concept of SMS. The study obtained approval from the Ethical Committee of University of Antwerp (B300201942302). The COREQ guidelines were consulted to report this focus group study(27).

Recruitment and participants

A maximum variation purposive sampling was used to recruit the focus group participants, following the principles of Patton *et al.* (2014)(28). The focus was on gathering insights from a wide range of healthcare professionals. More specifically, the recruitment strategy aimed a maximum variation in health and social disciplines, in academics and frontline professionals, in Flemish regions and organizations of employment in primary care via announcements of the PCA (e.g., network of the co-authors) and other healthcare organizations (e.g., the White-Yellow Cross, Flemish Patients' Platform). Professional contacts were used to recruit participants for the focus groups by e-mail.

Five focus groups were performed in an iterative process of three waves among a purposive sample of scholars, academics, and frontline professionals respectively. Participants were included if they met the following predefined criteria. For the **first wave**, participants had to be a member of the PCA consortium with a certain level of expertise in one of the central concepts of GOC, IPC and SMS in primary care. Expertise refers to self-appointed theoretical and practical knowledge gained from professional experience, including research and practice. These individual experts were contacted by the main researchers and composed a heterogeneous group. For the **second wave**, our inclusion criteria consisted of being a frontline care professional and having knowledge because of field experiences. This wave consisted of three homogenous focus groups on GOC, IPC and SMS. Depending on participants' expertise, they were included in one of these three parallel focus groups. For our **third and last wave**, the participants of the previous waves were contacted, and the final panel was heterogeneously composed based on the principles of maximum variation and the level of engagement during the earlier focus groups. The organisation of this last focus group with a mix of topics and expertise, including previous participants, was crucial for refining and validating the ideas and themes. Participants did not

receive a remuneration or compensation for their participation in the study and participation was on voluntary basis.

Data collection

Data were primarily collected through the three waves of focus groups. The first focus group took place at the start to test and finalize the interview guides. The second wave of focus groups built on the first by zooming in on one care concept in more depth. The strategy of focusing on one specific topic typically provides more information than combining multiple care topics during the same amount of time. The third wave consisted of a focus group which was organized to focus on the interactions and overlap between the three central care concepts (namely GOC, IPC and SMS). During this final focus group, findings from the earlier waves were aligned with the panel to validate our data.

Depending on the central concept(s) being covered, participants in the focus groups were asked to answer questions about the application of the care concepts in primary care practice: (1) "How do primary care professionals understand, define and describe GOC and how do they use it in practice?"; (2) "How do primary care providers understand, define and describe IPC, who is involved and how do they experience the collaboration?"; (3) "How do primary care professionals perceive SMS in primary care practice, and what barriers and facilitators affect its implementation?". During the last focus group, the point of saturation was reached as no new ideas emerged and earlier findings were corroborated.

Focus groups were conducted in Dutch between January 2020 and September 2020 by one of the main PhD-researchers (DB, LT, MMS) of the PCA, using precomposed interview guides developed for this study. These guides were meticulously developed through iterative collaborative sessions between the researchers, incorporating evidence from practice and informed by thorough literature analysis. The specific interview guide questions related to self-management support can be found in Supplementary File 1. Dutch, the native language of the participants, was used for the focus group sessions. Before entering the focus groups, participants were asked to read and sign an informed consent form, in which they agreed to participate in the study and approved to be audiotaped. In advance, the research group received a training in qualitative research techniques to guarantee a certain level of expertise. The training covered key elements of focus group facilitation, research strategies and ethical considerations. It also provided a comprehensive exploration of different aspects of qualitative research, covering study designs, methodological approaches and analysis techniques. This training equipped the team with a diverse set of skills essential for effective qualitative research, ensuring their ability to collect nuanced and rich data during the focus group sessions. The

overarching aim was to address all facets of qualitative research and enhance the team's expertise throughout the research process.

Data analysis

The focus groups were audio-taped and transcribed verbatim. Analysis of the data on the topic of SMS was done by the main researcher (LT), in close collaboration with the other investigators (AVH, BS, MV, PD, VF) by means of gatherings to discuss the interpretations. After drafting narrative reports of each focus group, the transcripts were coded and divided into quotations, answering our research question. For the thematic analysis of the data(29), the framework of Attride-Stirling (2001) was applied(30). This method is characterized by a representation of the results in the form of themes. A thematic network was developed by exposing significant themes at different levels. More specifically, we identified basic themes, organizing themes and global themes. The analysing process was built on the principles of grounded theory (Corbin and Strauss, 1990)(31) and contained three different stages comprising 6 iterative steps(30).

Results

A total of 34 participants took part in this qualitative focus group study. Table 1 presents the characteristics of the focus groups, including the professional backgrounds of the participants and their distribution across each wave.

Table 1: Characteristics of focus groups, organized in three waves

First wave			
Focus group 1	**Duration**	**Number of participants**	**Professional backgrounds**
Focus group with experts of the PCA consortium	123 minutes	5	Speech language pathologist Nurse Occupational therapist Pharmacist Physiotherapist
Second wave			
Focus group 2a	**Duration**	**Number of participants**	**Professional backgrounds**
In-depth focus group with frontline professionals with knowledge of SMS	68 minutes	7	Nurse (n = 2) Pharmacist (n = 2) Psychologist Social worker (n = 2)
Focus group 2b *In-depth focus group with frontline professionals with knowledge of IPC*	90 minutes	8	General practitioner Sociologist Pharmacist (n = 4) Psychologist Social worker
Focus group 2c *In-depth focus group with frontline professionals with knowledge of GOC*	119 minutes	8	General practitioner Nurse (n = 2) Occupational therapist (n = 3) Social worker (n = 2)
Third wave			
Focus group 3	**Duration**	**Number of participants**	**Professional backgrounds**
Final focus group to validate with selection of previous participants	107 minutes	6	General practitioner Sociologist Nurse Psychologist Social worker (n = 2)

GOC: Goal-oriented Care; IPC: Interprofessional Collaboration; PCA: Primary Care Academy; SMS: SMS.

After applying the framework of Attride-Stirling, three global themes related to SMS were derived from the thematic analysis: characteristics of SMS, support strategies, barriers and facilitators. We will present each theme in detail, supported by relevant quotes from the focus group discussions.

Characteristics of SMS

The first organizing theme that emerged from the thematic analysis is related to characteristics of SMS (Figure 1). Participants described SMS as a collaboration-based approach (first basic theme), which is person-centred (second basic theme) and starts based on dialogue (third basic theme).

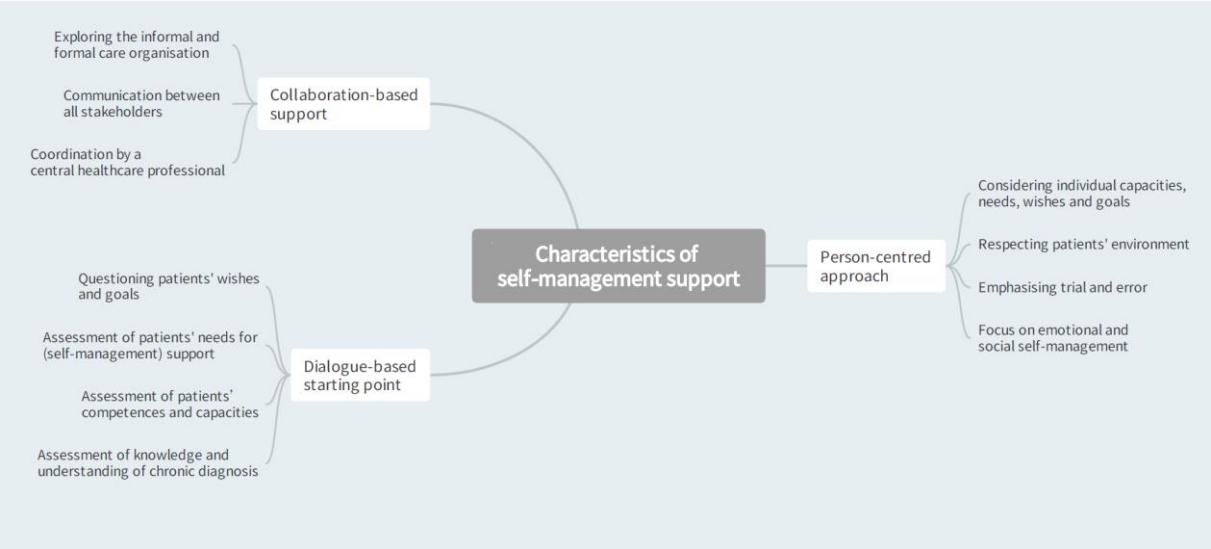


Figure 1: Thematic network: Characteristics of self-management support

During the focus group discussions, the question was raised whether patient care could be delivered '*in tandem*' or in **collaboration** with the whole care team. In the care process, supporting self-management was seen as '*part of the journey*'. Participants stated that healthcare professionals are in charge during the care process but the responsibility for the direction of care belongs mainly to the patients themselves. Although patient-healthcare professional one-to-one interactions were strongly emphasised in the context of SMS, the support is not exclusively restricted to individual consultations. Group education, peer support and e-health were also mentioned.

"But when you start from a context of people who are chronically ill,
to me that's [SMS] really part of the journey.
Where you start from a set of goals that are important to the patient,
and then where you start supporting them." (Wave 2 – Social worker)

Participants perceived supporting self-management as a dynamic, **personalised** process. They indicated that this process is driven by wishes, needs and goals of the individual patient, which may change over time. Therefore, healthcare professionals must engage in **dialogue** to explore patient's goals as a first step towards establishing SMS. Throughout all the conversations, the importance of providing a listening ear was highlighted by the participants.

"It [self-management] is not something black, white, positive, or negative.
It changes. And I think support plays a very important role in this." (Wave 1 – Physiotherapist)

The human factor strongly emerged in the focus group discussions. Participants indicated the importance of paying attention to the patient behind the chronic disease. Healthcare professionals emphasized that a patient is '*a person who has received bad news and needs to deal with this news*'. According to the participants, interpersonal communication and guidance should be central to SMS. The focus should be on social and emotional management, on top of medical management. For them, there is a need to shift away from somatic and technical care as a fundamental premise in the delivery of chronic care.

"We need to be able to make that mental switch as a health care provider
from not sitting there looking at a patient
but looking at a person who has actually received bad news and has to deal with that."
(Wave 2 – Nurse)

SMS strategies

The second theme that emerged from the thematic analysis is related to SMS strategies (Figure 2). Four different types of strategies were identified: individual strategies, collaborative strategies, strategies related to guidance and follow-up, and practical tools.

Figure 2: Thematic network: Self-management support strategies

The strategies discussed in the focus groups focused mainly on the direct **individual** support that professionals could offer to facilitate patient self-management. According to the participants, healthcare professionals were expected to function in a coaching role to support self-management. Regardless of their discipline, participants agreed that every formal care professional should learn to take on this coaching role.

> *"I think the role of coach ... whatever care provider it is, that's a role that we must learn to take on. And that's different than acting and providing medical care." (Wave 2 – Nurse)*

Specific support strategies to offer one-on-one guidance in healthcare practice were mentioned. Most examples given by participants consisted of informing and educating patients. Apart from utilizing teaching and coaching methods, participants indicated that efforts should be made to train patients specific self-management skills (e.g.; managing medication, monitoring health indicators). Practicing specific skills under the supervision of a formal caregiver assures timely adjustment according to the needs and capabilities of the individual patient.

Besides individual support strategies, the strength of **collaboration** in supporting self-management was discussed in the focus groups. According to the participants, healthcare professionals should join forces inter- and multidisciplinary to achieve stronger support for patients' self-management. Central actors cited included the general practitioner, social worker, nurse, pharmacist and medical specialists. In addition to the formal support network, the role of the informal network was highlighted. Participants emphasized on involving the patient's closest environment when supporting self-management. They further stressed that the level of

involvement should always be aligned with patients' values and needs. Involving informal caregivers in the care process was pointed out as an added value in information exchange, education and skills learning. According to the participants, mapping the social network also provides insights into patients' lives. Therefore, it was identified as an essential component of SMS.

"And I think maybe you also need to start looking, and it is not only the family or household context that needs to provide support, but just looking at who is relevant here for that person, who can be helpful here." (Wave 2 – Social worker)

Additional to the patient's closest environment, the importance of peers was also emphasized in the focus groups as part of informal network support. More specifically, the added value of peer support was mentioned in exchanging information on coping with chronic disease and in learning various self-management skills.

"I would like to add that patient associations also play a very important role in learning to take care of yourself, and in self-management. Through contact with peers, a lot of information can be obtained, and I think especially in addition to professional knowledge. Especially around quality of life." (Wave 3 – Sociologist)

Since SMS is a dynamic process, participants indicated that attention should be paid to continued **guidance and follow-up** of patients' self-management skills. Different follow-up strategies were discussed in the focus groups. The use of standardized questionnaires to assess self-management is one such strategy. Moreover, different self-reflection strategies were mentioned to gain insights into patients' self-management skills and to evaluate support. In addition, several feedback strategies were discussed to question patients' experiences regarding SMS. Finally, it was mentioned that practicing skills under supervision of a formal care provider is a low-threshold technique to evaluate patients' progress and identify difficulties.

"I think we also have to be able to let the person that we want to help, to have them look at themselves ... So, to speak, check in with themselves about how far do they think they've progressed ..." (Wave 2 – Nurse)

Complementary to individual and group techniques to support self-management, several **practical tools** were discussed in the focus groups. These included digital apps and tools that can contribute to better follow-up and guidance of self-management. More specifically, practical

tools to support knowledge and information sharing were discussed. For example, the use of visual techniques during medical consultation (e.g., whiteboard, drawings) were mentioned conveying information to the patient in a systematic and accessible manner. Furthermore, the importance of providing reliable sources of information (websites, medical records, leaflets or booklets) that can be consulted to supplement health appointments was highlighted.

Barriers and facilitators to SMS

The last theme addressed in the focus groups concerns barriers and facilitators to SMS (Figure 3). More specifically, several factors were discussed that hamper the implementation of SMS in daily care practice. These factors were grouped into three different basic themes: patient-related factors, competencies and attitudes of healthcare providers and external factors.

Figure 3: Thematic network: Barriers and facilitators to self-management support

According to the participants, difficulties often arise from **patient-related factors**. To overcome these barriers, several key elements were identified that are important for SMS. First, attention should be paid to information transfer in patients with lower health literacy. Assessing full and proper comprehension and interpretation of information was cited as an essential part of SMS.

"I think that's just very different for each patient, what they need." (Wave 3 – Sociologist)

To facilitate understanding, the message must be tailored to the health literacy of the patients. Second, the use of modern support tools requires different digital and technical skills. Consequently, participants in the focus groups concluded that high-tech support tools are only accessible to a limited patient population.

"And of course, with a digital tool, you immediately end up with the digital divide. And the accessibility of that app, and the information around it and whether everyone can work with it." (Wave 2 – Social worker)

Further, participants indicated that patients should be open to SMS. More specifically, specific circumstances (e.g., major life event) may contribute to different care needs and priorities. Besides time-dependent needs and priorities, participants stressed that the patient's personality should always be considered when providing SMS. For instance, some patients prefer outcome-driven support strategies (e.g., setting personalized goals), while others have a greater need for process-oriented strategies (e.g., improving cooperation and communication in the care team). Therefore, SMS should always be tailored to the individual needs, wishes and capabilities of the patient according to the participants.

"If clients/patients are tackling problems, they need to be able to talk about them before they can be open to new ideas." (Wave 2 – Nurse)

In addition to patient-related factors, a variety of **professionals' competencies** that contribute to good SMS were mentioned. First, the role of empathy was emphasized. Healthcare professionals are expected to be able to empathize with the person's feelings behind the patient. According to the participants, these emotions can be explored through an observing and listening attitude. They pointed out that communication is key. Second, several clinical competencies were discussed. Participants argued that these competencies make up only a limited part of SMS. More specifically, they are taught in basic education and further refined in daily care practice.

"I think tailoring communication. Sometimes using some complex words, otherwise simple words. But I think that's a very important one." (Wave 2 – Social worker)

"Especially listening/hearing/reading/... I do think that's important to not fall into the trap of imposing your goals in a manipulative way." (Wave 1 – Physiotherapist)

Participants stated that SMS extends far beyond the good use of clinical skills. The need to shift away from a purely problem-solving mindset in primary care was emphasized. To provide holistic support, attention must be paid to contextual factors affecting patient's ability to self-manage a chronic condition. Creativity and innovative thinking empowering care professionals to tailor each patient's unique situation could contribute to personalized support strategies. Finally,

participants indicated that support is a growth process in which care providers must engage with a willingness to learn and optimize their support.

"Surely a competency could be to move away from purely problem-solving thinking. And learn not to think in somatic or technical terms, but rather yeah... have the ability to assess the mental status of the person." (Wave 2 – Nurse)

In addition to patient and care provider-related factors, **external factors** contributing to SMS were also discussed. For instance, policy-related factors in primary care that hamper good support were discussed. According to the participants, becoming familiar with self-management and support strategies takes time and effort. Therefore, it was indicated that the short duration and low frequency of patient-provider encounters impedes sustained SMS. In addition, limited financial resources were also mentioned as an obstacle. Finally, participants indicated that there are still too few communication channels to support multidisciplinary SMS.

"But I think there should also be room for patients to become familiar with some tools or resources." (Wave 1 – Speech language pathologist)

Discussion

Summary of results

An in-depth understanding of how professionals perceive SMS in primary care practice, and what barriers and facilitators affects its implementation is invaluable for achieving effective sustainable SMS in healthcare practice(32,33), especially since care professionals play a crucial role in self-management(14). Therefore, this paper aimed to explore in detail healthcare professionals' perceptions of SMS before developing new interventions and optimising existing ones. The goal is to expand upon prior research that theoretically investigated the ingredients of effective SMS in practice(10,34). We learned that self-management is a collaborative, person-centred approach that starts with dialogue, and that this support does not take place exclusively in face-to-face consultations. SMS is part of a bigger picture, is a dynamic concept, making proper follow-up and temporary adjustment of care essential. SMS starts with questioning the patient's goals and the focus should be on the person rather than the case, moving away from medical management. The role of the professional is described as that of a coach applying different supporting strategies depending on the person. Collaboration with the informal support network is considered invaluable. Finally, the use of practical tools to support self-management

was discussed, as well as other barriers and facilitators to SMS. External factors such as policies and health structures were mentioned as additional challenges for SMS.

Comparison with literature

According to the focus group participants, SMS is described as a personalised process. This is also reflected in previous research emphasising support is highly patient-dependent, since 'the patient' does not exist(35,36). In addition, professionals in the focus groups discussed that supporting self-management is a learning process. An essential starting point seems a good understanding of the concept as no uniform description emerged from the focus groups. On one hand, for example, it is suggested that healthcare professionals are 'in charge' of self-management. On the other hand, it is emphasized that SMS should be delivered collaboratively, in tandem, with the entire care team. Unfortunately, even in literature, the concept of self-management (support) seems ambiguous, complex and even without consensus(8,37). This can cause different interpretations and misconceptions among healthcare professionals. To monitor SMS, focus group participants emphasise the use of practical tools and devices. Although this can be very useful, it is important to approach it cautiously(38,39), especially since several support techniques require digital skills from patients(40). In addition, the use of questionnaires to guide this dynamic process is well-described in literature and was also mentioned by the focus group participants(41,42).

When developing interventions to encourage self-management in care practice, the needs of patients, the care receivers(24,43), must be considered in addition to the input of professionals, the caregivers(32). According to the participants, support is ideally tailored to the goals, capabilities and needs of each patient. In a previous qualitative study, we developed a conceptual model, the SILCQ model, which describes ideal SMS from the patient perspective, based on dyadic interviews(15). Five actions of care professionals are presented as fundamentals: the act of supporting, involving, listening, coordinating and asking questions to patients. Different parallels can be drawn when considering the voice of the professional in the focus groups. For instance, the act of supporting and coaching patients is mentioned several times by our participants. More specifically, emphasis is placed on supporting social and emotional management as part of SMS, on top of medical support. However, when discussing SMS strategies, medical approaches were primarily cited, such as learning practical techniques and practicing skills. Regarding the involving fundament in the SILCQ model, this aspect to encourage self-management similarly emerged from the focus group discussions. It was suggested that for perfect cooperation, care should be organized in tandem by providers and patients. Finally, the focus groups highlighted providing a listening ear to the patient. This is

reflected in many other studies, which emphasises the importance of listening to both patients and their informal network(44,45). Paying attention to and engaging this informal network is an essential part of SMS(46,47).

As noted by our participants, SMS strategies mainly consisted of informing and educating patients. The effectiveness of education has been thoroughly researched in recent years and seems promising(17,48,49). Participation of peers and expert patients yielded positive outcomes in previous research(50,51). When discussing challenges, three main requirements for SMS were expressed in the focus groups: patient readiness, professional' competences and a supportive health system. The latter in particular is a much-debated topic in Europe(52).

Strengths and limitations

Some limitations should be mentioned. First, due to a high pressure on healthcare professionals generated by the COVID19-pandemic, the number of participants in the focus group discussions was rather limited. Last-minute cancellations due to illness or high workload was a remarkable barrier for conducting this study. Despite this, we were able to gather a sufficient number of participants to conduct the focus groups. It is worth noting that having more participants may not have necessarily been beneficial, as it can reduce the dynamics and effectiveness of the discussions. Second, the duration of the focus groups varied widely and different topics were combined. This may have affected the depth of discussions. However, our subsequent analysis of the data revealed a wealth of information and made us decide not to further investigate the topics among professionals after the third wave. Also, participants emphasised the value of exploring issues that are related to each other such as GOC, IPC and SMS. We strongly believe that optimising care is only possible through cooperation. One possible strategy is to consider care from a more holistic approach. An approach that transcends individual care concepts. Third, since participation in this study was completely voluntary, volunteer bias may occur. However, our research sample can be considered clinically representative with a variety of healthcare professionals included. Finally, applying the method of thematic analysis poses some challenges. The main one is the challenge of inconsistency when developing themes. However, thematic analysis provides the advantage of flexibility and promotes richness of data(53). The Attride-Stirling thematic analysis method is strengthened by its iterative process and ongoing validation by multiple researchers, which enhances the credibility and reliability of the analysis.

Implications for research and practice

Our study provides in-depth insights into healthcare professionals' experiences related to SMS. To address the identified gaps and challenges, an appropriate next step is to brainstorm and

develop new SMS interventions that build upon the insights gained in the focus groups. In addition, more awareness and understanding of the concept of SMS is needed, as well as the barriers and facilitators associated with it. To this purpose, interventions should be developed to raise awareness among healthcare professionals and patients and to equip them with knowledge and skills needed to apply self-management strategies effectively. The implementation of SMS can only be successful if all persons involved have a good understanding of the concepts and of what barriers and facilitators affect implementation in the intended setting.

Conclusions

This focus group study highlights the importance of a collaborative, person-centred approach to self-management in the context of chronic diseases. Our findings point to the need for interventions that raise awareness and address barriers associated with SMS. Since generic SMS does not exist, the road to success is a growth process in which support must be adapted to patients' individual goals, needs and capabilities. When developing new interventions, it is of utmost importance to build on the strengths of current approaches and addressing identified gaps and challenges.

References

1. Commission E. Horizon 2020 [Internet]. 2020 [cited 2020 Dec 22]. Available from: https://ec.europa.eu/programmes/horizon2020/en/area/health
2. Busse R, Blümel M, Scheller-Kreinsen D, Zentner A. TACKLING CHRONIC DISEASE IN EUROPE Strategies, interventions and challenges.
3. WHO. The European health report 2018.
4. Efpia. IT'S TIME TO POWER UP HEALTH SYSTEMS: a vision for future-proof health systems [Internet]. [cited 2022 May 29]. Available from: https://www.efpia.eu/about-medicines/use-of-medicines/healthcare-systems/introduction/
5. Farrell C. Patient and public involvement in health: the evidence for policy implementation: a summary of the results of the Health in Partnership research programme. Department of Health; 2004. 69 p.
6. Glasgow RE, Wagner EH, Schaefer J, Mahoney LD, Reid RJ, Greene SM. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). Med Care. 2005 May;43(5):436–44.
7. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: A review. Iran Red Crescent Med J. 2014;16(1):12454.
8. Van De Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: A concept analysis. BMJ Open. 2019;9(7):e027775.
9. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
10. Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. PLoS One. 2019;14(8):e0220116.
11. Panagioti M, Richardson G, Small N, Murray E, Rogers A, Kennedy A, et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: A systematic review and meta-analysis. BMC Health Serv Res. 2014 Aug 27;14(1):356.
12. Allegrante JP, Wells MT, Peterson JC. Interventions to Support Behavioral Self-Management of Chronic Diseases. Annu Rev Public Health. 2019 Apr 1;40:127–46.
13. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7.
14. Alvarez C, Greene J, Hibbard J, Overton V. The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. BMC Health Serv Res. 2016 Mar 11;16(1):85.
15. Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, et al. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022;23(1):1–13.
16. Salemonsen E, Førland G, Hansen BS, Holm AL. Understanding beneficial self-management support and the meaning of user involvement in lifestyle interventions: A qualitative study from the perspective of healthcare professionals. BMC Health Serv Res. 2020;20(1):1–12.
17. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Vol. 26, Annals of Behavioral Medicine. Lawrence Erlbaum Associates Inc.; 2003. p. 1–7.
18. Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. Jt Comm J Qual Saf. 2003 Nov 1;29(11):563–74.
19. K A, AC G, JM C. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities. 1st Annu Crossing Qual Chasm Summit. 2004 Sep 13;
20. Amati F, McDonald AM, Majeed A, Dubois E, Rawaf S. Implementation and evaluation of patient centred care in experimental studies from 2000-2010: systematic review. Int J Pers Cent Med. 2011 Jun 10;1(2):348–57.
21. Jacobsen ET, Rasmussen SR, Christensen M, Engberg M, Lauritzen T. Perspectives on lifestyle intervention: The views of general practitioners who have taken part in a health promotion study. Scand J Public Health. 2005;33(1):4–10.
22. Moffatt S, Wildman J, Pollard TM, Penn L, O'Brien N, Pearce MS, et al. Evaluating the impact of a community-based social prescribing intervention on people with type 2 diabetes in North East England: Mixed-methods study protocol. BMJ Open. 2019 Jan 1;9(1).
23. Reed JE, Howe C, Doyle C, Bell D. Successful Healthcare Improvements From Translating Evidence in complex systems (SHIFT-Evidence): simple rules to guide practice and research. Int J Qual Heal Care. 2019;31(3):238–44.
24. Dwarswaard J, Bakker EJM, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: A thematic synthesis of qualitative studies. Heal Expect. 2016 Apr 1;19(2):194–208.
25. Salemonsen E, Førland G, Hansen BS, Holm AL. Understanding beneficial self-management support and the meaning of user involvement in lifestyle interventions: a qualitative study from the perspective of healthcare professionals. BMC Health Serv Res. 2020 Feb 5;20(1):88.
26. Franklin M, Willis K, Lewis S, Rogers A, Smith L. Between knowing and doing person-centredness: A qualitative examination of health professionals' perceptions of roles in self-management support. Health (London). 2021 May 1;25(3):339–56.

27. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Heal Care. 2007 Dec;19(6):349–57.
28. Patton. Qualitative Research & Evaluation Methods [Internet]. 2014 [cited 2021 Jan 19]. Available from: https://us.sagepub.com/en-us/nam/qualitative-research-evaluation-methods/book232962
29. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
30. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. Qual Res. 2001 Dec 7;1(3):385–405.
31. Strauss, A., & Corbin JM. Basics of qualitative research: Grounded theory procedures and techniques. Sage Publications, Inc. 1990. 456 p.
32. Lake AJ, Staiger PK. Seeking the views of health professionals on translating chronic disease self-management models into practice. Patient Educ Couns. 2010 Apr;79(1):62–8.
33. Yoon S, Ng JH, Kwan YH, Low LL. Healthcare Professionals' Views of Factors Influencing Diabetes Self-Management and the Utility of a mHealth Application and Its Features to Support Self-Care. Front Endocrinol (Lausanne). 2022 Feb 24;13:793473.
34. Franklin M, Lewis S, Willis K, Bourke-Taylor H, Smith L. Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. Chronic Illn. 2018;14(2):79–103.
35. Disler RT, Gallagher RD, Davidson PM. Factors influencing self-management in chronic obstructive pulmonary disease: an integrative review. Int J Nurs Stud. 2012 Feb;49(2):230–42.
36. Schulman-Green D, Jaser SS, Park C, Whittemore R. A metasynthesis of factors affecting self-management of chronic illness. J Adv Nurs. 2016;72(7):1469–89.
37. Fletcher S, Kulnik ST, Demain S, Jones F. The problem with self-management: Problematising self-management and power using a Foucauldian lens in the context of stroke care and rehabilitation. PLoS One. 2019 Jun 1;14(6):e0218517.
38. Morton K, Dennison L, May C, Murray E, Little P, McManus RJ, et al. Using digital interventions for self-management of chronic physical health conditions: A meta-ethnography review of published studies. Patient Educ Couns. 2017 Apr 1;100(4):616–35.
39. Lancaster K, Abuzour A, Khaira M, Mathers A, Chan A, Bui V, et al. The Use and Effects of Electronic Health Tools for Patient Self-Monitoring and Reporting of Outcomes Following Medication Use: Systematic Review. J Med Internet Res. 2018;20(12):e294.
40. Wu Y, Wen J, Wang X, Wang Q, Wang W, Wang X, et al. Associations between e-health literacy and chronic disease self-management in older Chinese patients with chronic non-communicable diseases: a mediation analysis. BMC Public Health. 2022 Dec 1;22(1):2226.
41. Hudon É, Hudon C, Lambert M, Bisson M, Chouinard MC. Generic Self-Reported Questionnaires Measuring Self-Management: A Scoping Review. Clin Nurs Res. 2021 Jul 1;30(6):855–65.
42. Rademakers J, Nijman J, van der Hoek L, Heijmans M, Rijken M. Measuring patient activation in the Netherlands: translation and validation of the American short form Patient Activation Measure (PAM13). BMC Public Health. 2012 Dec 31;12(1):577.
43. Timpel P, Lang C, Wens J, Contel JC, Gilis-Januszewska A, Kemple K, et al. Individualising chronic care management by analysing patients' needs – A mixed method approach. Int J Integr Care. 2017 Nov 1;17(6):2.
44. Francis H, Carryer J, Wilkinson J. Self-management support? Listening to people with complex co-morbidities. Chronic Illn. 2020 Sep 1;16(3):161–72.
45. Johnston S, Irving H, Mill K, Rowan MS, Liddy C. The patient's voice: an exploratory study of the impact of a group self-management support program. BMC Fam Pract. 2012;13:65.
46. Essue BM, Jowsey T, Jeon YH, Mirzaei M, Pearce-Brown CL, Aspin C, et al. Informal care and the self-management partnership: implications for Australian health policy and practice. Aust Health Rev. 2010;34(4):414–22.
47. Vassilev I, Rogers A, Kennedy A, Koetsenruijter J. The influence of social networks on self-management support: a metasynthesis. BMC Public Health. 2014 Jul 15;14(1):719.
48. Otsu H, Moriyama M. Effectiveness of an educational self-management program for outpatients with chronic heart failure. Jpn J Nurs Sci. 2011 Dec;8(2):140–52.
49. Abbasi A, Najafi Ghezeljeh T, Ashghali Farahani M. Effect of the self-management education program on the quality of life in people with chronic heart failure: a randomized controlled trial. Electron physician. 2018 Jul 25;10(7):7028–37.
50. Cordier JF. The expert patient: towards a novel definition. Eur Respir J. 2014 Oct 1;44(4):853–7.
51. McGowan P, Lynch S, Hensen F. The Role and Effectiveness of Telephone Peer Coaching for Adult Patients With Type 2 Diabetes. Can J Diabetes. 2019 Aug;43(6):399–405.
52. Elissen A, Nolte E, Knai C, Brunn M, Chevreul K, Conklin A, et al. Is Europe putting theory into practice? A qualitative study of the level of self-management support in chronic care management approaches. BMC Health Serv Res. 2013;13(1).
53. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. Int J Qual Methods. 2017 Sep 28;16(1).

Appendix Chapter 4

Supplementary file 1: Precomposed interview guide questions on self-management support

Wave 1	• **How do you define and experience the concept of self-management/support?**
	  o **(Setting the stage)**
	  o Exploration of different domains
	• **What specific strategies do you employ to support self-management in patients?**
	• **List one competence that healthcare professionals need to develop to support self-management in patients.** (Repeat until saturation is reached)

Wave 2	• **What do you understand by the concept of self-management? (Setting the stage)**
	  o Exploration of different domains
	  o Our research group defines self-management in individuals with chronic diseases as their ability to integrate their disease into their lives. Do you recognize your understanding of self-management in this definition?
	• **What specific strategies do you employ to support self-management in practice?**
	  o Is this approach applicable to other target groups or patients?
	  o Barriers/facilitators?
	• **How do you evaluate self-management?**
	  o How do you recognize whether it is successful or not?
	  o How do you adapt your support accordingly?
	• **Discussion on the proposition: "Self-management is something you never do alone."**
	  o Agree or disagree? Explain.
	• **List one competence that healthcare professionals need to develop to support self-management in patients.** (Repeat until saturation is reached)

Wave 3	There were no predefined questions. Findings from the two previous waves will be aligned with the panel to validate the data. Questions will be drafted after the results from the first waves are processed.

Part III. Developing a theory-informed, contextually appropriate self-management support intervention

Chapter 5

Co-creation of an intervention to facilitate self-management support in primary care practice: online nominal group technique.

Methodology published as:
Timmermans L, Huybrechts I, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Recommendations for Researchers on Synchronous, Online, Nominal Group Sessions in Times of COVID-19: Fishbone Analysis. JMIR Form Res. 2022 Mar 25;6(3):e34539. doi: 10.2196/34539. PMID: 35225814; PMCID: PMC8963262.

Output co-creation provided in the annexes of chapter 5

Abstract – methodology co-creation

Recommendations for Researchers on Synchronous, Online, Nominal Group Sessions in Times of COVID-19: Fishbone Analysis

Background

In times of COVID-19, we are challenged to experiment with alternative platforms or software to connect people. In particular, the struggle in health research arose to interact with patients and care professionals. The latter is additionally faced with an extreme workload to fight the pandemic crisis. Creative strategies are developed to continue research among patients and care professionals to improve quality of care. This paper addresses the issue of synchronous online nominal group sessions, a common consensus method used for group brainstorming.

Objectives

The purpose of this study is to share our experiences with performing online nominal group sessions using the video conference software Microsoft® Teams. In addition, we aim to create a practical guide with recommendations for researchers.

Methods

We critically analysed the procedure of the online nominal group technique, according to the Fishbone methodology.

Results

Performing synchronous online nominal group sessions is challenging but offers opportunities. Although interaction with and among the attendees complicates the process, the major advantage of online sessions is their accessibility and comfort because of reduced barriers to participation (e.g., lower time investment). The role of the moderators is of major importance and good preparation beforehand is required. Recommendations for future online nominal research were formulated.

Conclusions

Online nominal group sessions seem to be a promising alternative for the real-life commonly used technique. Especially during the COVID-19 pandemic, the benefits must be highlighted. More expertise is needed to further refine the practical guide for using digital software in research and to achieve optimal performance.

Keywords COVID-19, Fishbone diagram, Nominal group technique, Video conferencing, Primary health care, Qualitative research

Introduction

The outbreak of the coronavirus disease 2019 (COVID-19) has posed multiple challenges. Not only has the pandemic caused a major loss of human life globally, the impact on mental and psychosocial health should not be underestimated(1–4). Apart from the major impact on human health, it also has an impact on health research. More specifically, the limited accessibility of research sources and participants obliges researchers to seek for alternatives to pursue research projects. Due to strict regulations to control the virus transfer, researchers have to rely on creative strategies to involve the research population(5). In-depth interviews and focus groups are conducted by using video conferencing software and platforms but more complex group-based participatory methods have not yet been fully explored online(6–9). The nominal group technique is one of these unexplored methodologies in research. This technique is commonly used to solve problems, determine priorities or generate ideas(10). The main challenge is cooperation in a strict and formal procedure(11). Guidance is provided to a limited extent for face-to-face sessions but the online set-up remains unclear(11–13). There are two different strategies for organising online sessions: asynchronous sessions using of an online platform to communicate in a non-simultaneous way, or synchronous sessions using a video conference software in which participants join simultaneously. Since the nominal group methodology has not yet been extended fully online, very few researchers have utilized it(14,15). Guidelines for recruiting participants, giving informed consent and doing qualitative research with individuals are all based on the assumption of in-person interactions(16). Therefore, there is a need to investigate in-depth the methodological issues of the online set-up. In this paper, we describe the challenges and opportunities of the online form based on our experiences with three synchronous virtual nominal group sessions. In addition, participants' experiences were explored. Finally, a practical guide with recommendations for researchers has been created.

The online sessions were part of a larger study of the Primary Care Academy (PCA) that aims to implement self-management support into primary care practice. Self-management is "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Barlow *et al*. 2002)(17). Self-management of a chronic disease is a process in which healthcare professionals play a crucial supportive role(18–20). The COVID-19 pandemic highlights the importance of self-management since the lock-down of many services resulted in more responsibility regarding handling of chronic diseases(21). Online nominal group sessions were organised to brainstorm on how healthcare professionals can support patients in this self-management process.

Methods

We critically analysed different aspects of synchronous online nominal group sessions, according to the Fishbone methodology. The nominal group sessions aimed to formulate specific actions to support patient's self-management and were part of research to reinforce Flemish' primary care.

Data collection

Data were collected during three online nominal group sessions with healthcare professionals and experts by experience (i.e., patients with knowledge based on personal experiences). Two qualified moderators conducted all the sessions, by use of the video conference software Microsoft® Teams. With the participants' consent, all three sessions were (audio and video) recorded and transcribed verbatim afterwards for qualitative analysis. At the end of each session, participants were offered the opportunity to share their experiences verbally, by use of the chat box or by e-mail afterwards.

Online nominal group sessions

Similar to the classical nominal group technique, the online sessions were structured in four key stages: silent generation, round robin, clarification, and ranking(22). A PowerPoint presentation was used to support this structure and the accompanying storyline. In advance, this slide show was uploaded in Microsoft® Teams instead of sharing the presentation, with the advantage of seeing the participants on the call. The protocol was developed specifically for online use and based upon comprehensive debate within the research group.

Sampling and recruitment

A maximum variation purposive sampling was used to recruit the nominal group participants by e-mail or through healthcare organisations and practices. A flyer was embedded with a registration link. In addition, a call for participants was announced on the internet (website of the PCA). Participants included healthcare professionals and experts by experience from around Flanders. The aim was to have a minimum of 5 and a maximum of 10 participants per session(23).

Procedure

Each session started with a short introduction, including explaining ground rules (which had also been communicated in advance by e-mail) and a roundtable introduction by the attendees. Afterwards, information was provided on the topic of the session (self-management support) and the brainstorming procedure. These initial stages took 20 minutes and were followed by the

active nominal group brainstorming. It started with the presentation of a specific question, related to self-management support, that gave rise to the formulation of ideas during the silent generation phase. This idea generation question (i.e. "What concrete action/interventions can be designed to help patients fit chronic disease(s) into their lives in the most optimal way?") was the impetus for brainstorming. Participants were asked in advance to have their pen and paper ready while brainstorming. To keep everyone's attention, no more than 15 minutes were provided for generating ideas on self-management support. Additionally, the round robin stage in which ideas were exchanged filled in the next 20 minutes. Both moderators took notes during this stage. The formulated ideas were then rephrased by the moderators to make sure everyone gained a full understanding. Then, during a 15-minute clarification phase, there was time to clarify the ideas upon request of the participants. Finally, the nominal group sessions ended with a ranking stage of 5 to 10 minutes, depending on the number of ideas formulated. More specifically, a ranking system created with the online service 'Poll Everywhere' (San Francisco, CA), was included in the slide show to prioritize the ideas generated according to the participants' preferences. A short break of 10 minutes after the generation of ideas gave the moderators the opportunity to process them in the ranking system. The second and third session had an additional phase just before the polling in which the ideas previously formulated were quickly reviewed and included into the ranking system. Each session was planned to last no longer than one hour and a half.

Analysis of the content related to self-management support

Processing the output of the brainstorm sessions (i.e., formulated ideas on self-management support) was performed analogous to the regular methods of the nominal group technique. In summary, the generated ideas were (after performing three brainstorm sessions) organized in themes by qualitative coding of the transcripts and processed in a survey. Participants were asked to identify their favourite idea and to rank the ideas based on their preferences by defined theme. Afterwards, ideas were grouped by the main researcher (LT) following a self-management support model into 5 categories according to the type of primary care action (i.e., supporting, involving, listening to, coordinating or questioning patients). Ideas that were not chosen as favourites were excluded. Subsequently, the table was reviewed by the research team during multiple rounds to reach a consensus on the categorisation. Finally, ideas were further refined according to the survey results and processed for use in a primary care practice intervention related to self-management support. The results of the analysis related to the formulated ideas of the online sessions are beyond the scope of this research paper and will be reported elsewhere.

Ethics

Ethical approval for the brainstorm sessions was obtained from The Ethics Committee Research UZ/KU Leuven (S63890). An informed consent document was sent to the participants in advance by email. It explicitly stated that conversations were (video and audio) recorded during the online sessions. In addition, participants were informed that the content remained internal for scientific research purposes.

The return of a signed copy was required to participate in the online sessions. After confirmation of participation and signing the informed consent form, attendees obtained an invitation link to a Microsoft® Teams live event. Access to the recorded sessions (audio, video, and shared slide show) was limited to the research group. The entire study was conducted in accordance with the Helsinki Declaration.

Outcome measures

We defined 6 different process outcomes to characterise the online nominal group sessions: guidance, engagement, interaction, timing, technology, and participants' experiences. These categories were initially described by the main researcher based on literature analysis and further refined by the research team.

Analysis of the online nominal group procedure

Audio and video recordings, together with written data (i.e., transcripts, Teams chat and e-mail data) of the nominal group procedure, were analysed for the purpose of this study. A deductive "top-down" approach was applied to collect meaningful data from these sources, by exploring the predefined outcomes. More specifically, the Fishbone diagram was used to explore all possible challenges researchers and participants faced when performing/attending the online nominal group sessions, as this methodology helps team members visualize the potential problem sources. The analysis starts by defining a central problem, which is then deeply examined by formulating several causes, organised in different categories(24). A literature search revealed that an online nominal group technique has rarely been performed (and reported); only very few research articles explored this online methodology. This resulted in the definition of our central problem: low uptake of synchronous online nominal group sessions in research practice. The final Fishbone diagram incorporated in the study was reviewed by the entire research team to manage bias and ensure the validy of our findings.

Trustworthiness

To ensure rigor, we applied different strategies to increase trustworthiness of the data. First, a maximum variation sampling was applied to recruit the participants for the nominal group sessions. Participants of different age, sex, region, educational level, and employment were chosen. Second, the three nominal group sessions were fully recorded and transcribed verbatim. In addition, field notes were taken. Third, dependability of the findings was established by providing a detailed description of the online nominal group procedure. Finally, the analysis was checked by qualitative experts in the field.

Research team

LT and IH performed the online nominal group sessions and collected the data. Data analysis and design of the Fishbone diagram was done by LT, in close collaboration with supervisor BS. The entire research team (IH, PD, VF, AVH, MV and BS) reviewed the final diagram, incorporated in this manuscript. This group consists of experienced members in qualitative health research. Before the project initiation, the moderators received an additional intensive training on the principles and methods in qualitative research to assure a certain level of standardization. Both moderators had previous expertise in quantitative and qualitative data collection in a group setting.

Results

After performing three synchronous online nominal group sessions in which individuals brainstormed on specific actions to support patients'self-management, a Fishbone analysis was undertaken. A total of 24 persons participated in the online sessions and therefore contributed to the data collection.

Various causes were identified that positively or negatively challenged the online performance. These causes were clustered under the predefined outcome measures: guidance, engagement, interaction, timing, technology, and participants' experiences. Each outcome measure was thoroughly examined by audio and video analysis, supplemented with input from the chat and via e-mail, to identify the potential causes of the low uptake of online nominal group sessions in research practice. Figure 1 represents the final Fishbone diagram.

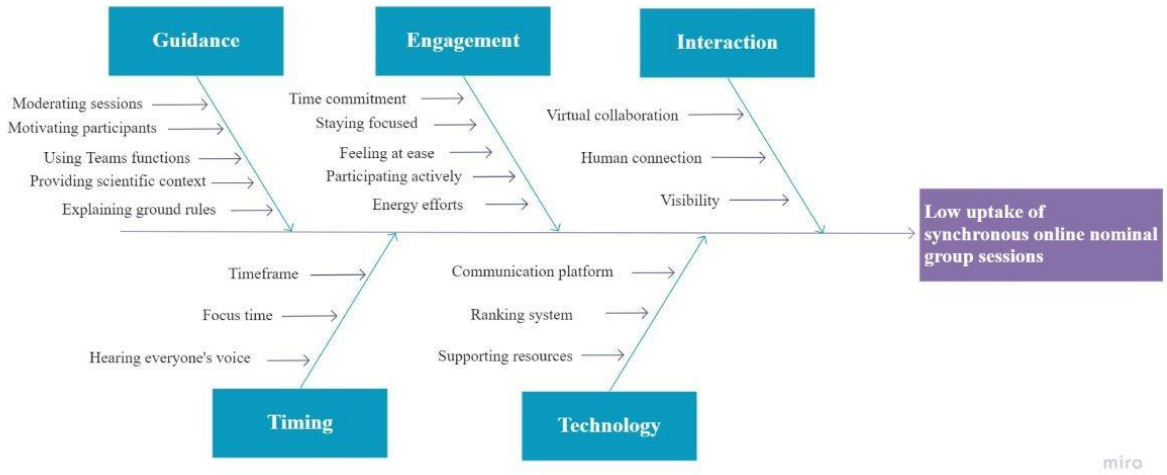


Figure 1: Fishbone diagram representing identified causes challenging the uptake of synchronous online nominal group sessions. Template retrieved from https://miro.com (online collaborative whiteboard)

Guidance

Moderating the online sessions challenged the research team in various ways. The moderators' role was of major importance since they had to guide the discussion in an online setting. The main barrier was managing participants in the brainstorm while not being able to interact directly, both verbally and nonverbally. Participants were encouraged to provide input by elevating a virtual hand using the hand icon of Microsoft® Teams. A moderator then appointed the person to speak at an appropriate time during the session. The importance of guiding participants was especially expressed during the round robin and clarification stage. To ensure everyone could provide their input, participants were indicated one by one to express their ideas on the topic of self-management. Examples of formulated ideas included the following: introducing a buddy system among peers, organising interactive sessions on chronic disease coping strategies, integrating communication aids and strategies in primary care practice, etc. This structured approach while exchanging the ideas seemed to have positively contributed to an equal involvement of all participants, even those who had told us beforehand to be not very articulate. Questions to each other when sharing ideas could often not be answered immediately. In these cases, the use of a chat box could act as intermediate communication medium. Although instructed, this medium was rarely used by the participants.

During the entire nominal group session, attention was paid to expressing the scientific context and methodology in simple terms – for example, the moderators did not use the word self-management itself when guiding conversations and asking the idea generation question. This resulted in an overall understanding of the background information, the set-up and aim of the

nominal group technique. Based on the participants' feedback we received, we can conclude that the absence of real-life interaction emphasized the importance of strictly guided sessions. Also, clear instructions before and at the start were necessary given the simultaneous use of the chat box, hand icon, and PowerPoint presentation by the moderator, while interacting with the audience.

Engagement

During the sessions, engaging participants was challenging because of the online set-up. Some actions by the moderators were observated as a remarkable help, since they triggered the audience to contribute to the conversation. First, the sessions began with a roundtable introduction, encouraging participants to get to know each other in an accessible way. This introduction revealed a variety of backgrounds: project officers of care organisations, general practitioners, nurses, chronic patients and informal caregivers, responsibles of patient associations, lecturers and researchers in primary care, etc. Second, the use of informative PowerPoint slides during the idea generation phase seemed a welcome addition, since all participants indicated to have a full understanding of the brainstorm procedure after displaying a concise information sheet on the general topic and the idea generation question Third, to give participants time to think and to feel at ease, they were asked to switch off the camera during the silent idea generation phase. Fourth, regarding the engagement while exchanging ideas, the use of a round-robin questioning format allowed each participant to provide input. Attendees were motivated to actively participate by emphasising that all input was valuable. However, we noticed the online set-up demanded extra effort from the participants. This was mainly observed at the end of the sessions through a reduced active contribution to the brainstorming. This could be attributed to the long period of attention on the computer screen.

Interaction

The online design challenged the interactive process of brainstorming since participants could not rely on human interaction and the use of sticky notes, both key elements in real-life nominal group sessions. Nevertheless, some elements did contribute to a relatively vibrant process. Slides with strong visuals, including images to supplement content, engaged participants online and resulted in virtual collaboration. Participants also used pen and paper to write down their thoughts. In addition, the hand icon was used to interact with the research team. Unfortunately, active interaction or conversation among participants was not enhanced by the online set-up. The only stage where participants were able to communicate with each other in a coordinated way, was the clarification stage.

A remarkable aspect of the online set-up was how the camera use influenced the level of interaction. A sense of interconnectedness was created when participants were asked to switch on their webcams, determined on the observation that attention increased and the conversation became more lively. Noteworthy is that when sharing the PowerPoint presentation, this connected feeling diminished as the screen was taken up by the shared slides instead of the video streams. To overcome this barrier, screensharing was interrupted while actively brainstorming during the round robin and clarification stages.

Timing

Overall, the timing of the virtual sessions turned out well. Although, moderators were challenged to stick to the schedule in the foreseen period. To maintain the timetable, the entire nominal group session was precisely structured, and every part was delineated according to a strict timeframe. The timing was tuned to the PowerPoint slides. For the moderators, staying within the timeframe was rather challenging since they had to find a balance between providing enough time versus sticking to the strict timeframe. To make sure sessions were not too strenuous, a break of 10 minutes was incorporated in between and appeared to be sufficient. However, the time frame was very tight resulting in a rushed feeling among the moderators and reduced room for unforeseen circumstances (e.g., delayed start). We also noticed that there was not enough time for prioritizing the ideas with the external ranking system. To resolve this, we provided the opportunity to rank immediately afterwards up to a few hours after each session. However, this function was rarely used.

Technology

The online nominal group design challenged the participants since they had to have access to reliable technology to successfully engage within the sessions. In addition, the necessary skills for using the various instruments (i.e., Microsoft® Teams, Poll Everywhere) were expected. Likewise, the moderators had to be able to manage the interaction with the audience, the processing of ideas (i.e., submitting in a ranking system) and the navigation through the slideshow. This emphasized the need for guidance from two moderators. Unfortunately, due to the large number of participants (between seven and ten in each session), not all the faces were visible at the video bar while presenting the slides. This was a disadvantage because visual interaction appeared to contribute to participants' engagement.

Participants' experiences

"I would like to compliment you (i.e., the main moderator/researcher) on the way you took the lead in the session. You gave enough guidance so that it was pleasant to follow at a smooth pace. That is not always evident online." (Participant)

Based on voluntary feedback in the chat, by e-mail or orally, participants' experiences regarding the online sessions were positive overall. Furthermore, participants explicitly indicated they wished to cooperate further on the research project. The only negative feedback was received regarding the large number of ideas that had to be prioritized using the ranking system (Poll Everywhere). Participants verbally indicated that they did not have enough time to rank the ideas in the foreseen time frame. This resulted in confusion for some participants and failure to reach a full consensus at the end of each session, since consensus can only be reached when everyone gives their input. It is possible that participants preferred to have more time in a relaxed atmosphere to rank ideas. This resulted in the development of an additional short survey in Qualtrics (Qualtrics, Provo, UT, USA) after completion of the three sessions, in which all participants had the opportunity to cast their vote on the entire group of ideas (total of three sessions).

Discussion

Guidance for performing online nominal group studies is missing. However, it has been stated that results of the same quality can be achieved with an online approach(25). In addition, studies show that there is no specific need to perform real-life sessions(26). We used a Fishbone diagram to identify all possible challenges that researchers face when performing online nominal group sessions. Based on our findings and experiences with the online setting, we developed a practical guide with recommendations for researchers interested in this type of work. The recommendations were pooled into the main stages of the nominal group: silent generation, round robin, clarification, and ranking (Figure 2). In addition, some general recommendations were formulated.

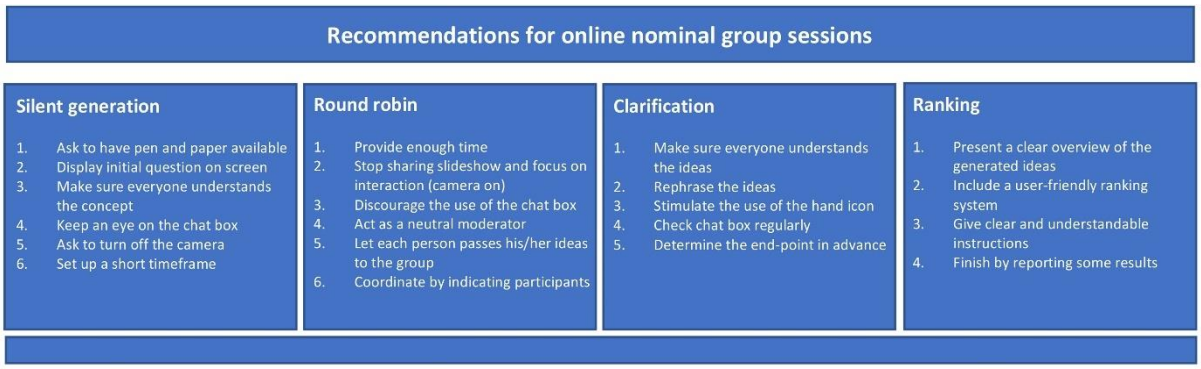


Figure 2: Recommendations for planning and implementing synchronous online nominal group sessions.

Silent generation

At the beginning of the session, the moderators should clearly explain the concept. In the brainstorm, pen and paper are indispensable. Taking notes helps the participants to explore ideas. Instead of classical notes, an online platform or whiteboard can help participants brainstorm but can be more complicated. Displaying the initial question on screen during the generation process adds value. We recommend keeping this phase short, to avoid losing someone's attention. Moderators should encourage participants to use the chat box when personal issues occur. Oral interventions are not recommended. This results in disruption of the individual reflection. An exception should be made for communications that are relevant to the whole group. In addition, switching off the cameras also contributes to thinking in serenity. However, disabling cameras can be discussed as a negative element, as participant's behaviour can no longer be interpreted. In addition, seeing each other visually can result in increased commitment to the idea generation.

Round robin

To engage participants during the round robin, we recommend stopping screen sharing. Switching on the video camera leads to a more interactive conversation. To further increase the level of interaction, try to minimise the use of the chat box while exchanging ideas. If still used during this stage, motivate the chat box user to ask the question out loud. We suggest providing enough time for exchanging the ideas generated so that everyone can have their say and the moderators have the time to take notes. Furthermore, it is essential that moderators act as neutral as possible to avoid judgment and criticism. They should monitor the participants' engagement. Coordination is crucial for every person to pass on their ideas to the group.

Clarification

Collaboration and interaction are highly affected in the online set-up since there is less non-verbal communication. This challenges participants to speak more out loud during the clarification round. Unfortunately, not everyone feels comfortable to do so. The use of the chat box as an intermediate communication platform can counteract this but was rarely used. Moderators should make sure everyone understands the ideas formulated. It helps to reformulate ideas in different ways and to check that those present understand them. Make sure the use of the Microsoft® Teams hand icon is encouraged to avoid a chaotic conversation. Analogous to the regular methods of the nominal group technique, we advise to determine the endpoint of this research phase in advance to prevent clarification from becoming an ongoing process.

Ranking

Some participants are overwhelmed by a multitude of information. Providing a clear overview of the generated ideas at the beginning of the ranking process is helpful. This procedure should be user-friendly, and instructions should be incorporated into the accompanying slideshow. The time it took to rank the ideas generated seemed to be person dependent. Therefore, it's valuable to familiarise with the audience while preparing the online sessions. To finish the brainstorm in a pleasant way, let the participants take a sneak peek into the results. This can be done by reporting the most favourite idea so far (i.e., ranked as number one).

General recommendations

Organising synchronous online nominal group sessions requires a thorough preparation. Guidance by at least two moderators is necessary. Due to the online complexity, moderators can benefit from a special training. Not only are skills required from the research team, but participants also need to develop online competences. Unfortunately, not everyone is able to deal with online platforms. In Belgium, more than 15% of the adult population has a low level of health literacy and in addition, 10% of the households do not have internet connection(27,28). This must be considered when setting up online research with lay participants. Communication with the participants is essential to operate efficiently. More specifically, moderators should provide clear instructions before, at the start and during sessions. Furthermore, it is important to make a detailed schedule and monitor time. To engage participants as much as possible, more emphasis should be put on enhancing human interaction. The format of the nominal group technique is well adapted to empower attendees(26,29). However, it should be mentioned that due to a strict pattern and guidelines, the nominal group technique never allows a lot of

interaction. Not being able to ask each other questions immediately, due to the strict design, might also challenge participants' patience. Starting with a roundtable introduction, switching on the video cameras, and using interactive slides with visual components seem to make attendees feel comfortable. In addition, the possibility can be offered to contact the research team afterwards. Researchers should aim for a meeting moment that works best for the target population and the importance of attending at the scheduled time needs to be emphasized.

Computer screens have been proven to negatively influence the activity of the human brain(30). Therefore, the duration of the meeting should be limited. By contrast, online sessions are less subject to distractions, which means less time is lost and researchers can better stick to the schedule. Unfortunately, the strict timing can result in a rushed feeling. In our opinion, this cannot be compensated by allowing more time for the brainstorm, as we noticed the focus decreased the longer the session lasted. A second break could be a possible solution.

The main advantage of performing online sessions seems to be the flexibility and comfort for both researchers and attendees. The online set-up increased the accessibility for participants who otherwise might have experienced barriers to participation, such as feelings of discomfort in group setting, transportation issues or time(26). Especially for healthcare professionals, who were in the middle of the battle during COVID-19 pandemic, it was a great opportunity to actively participate in research. The flexibility might explain the large turnout and few cancellations. This is in striking contrast to real-life sessions where organisational issues seem the main limitation(11).

Strengths and limitations

Some limitations should be mentioned. First, performing only three online sessions limited the generalisability of the results. However, after performing three sessions we reached a point of saturation regarding both the findings on the topic of self-management support and on the methodological challenges/opportunities. Moreover, we did not compare our findings with real-life nominal group sessions. This paper only elaborates on the synchronous online technique. Based on the performance of three sessions, we were able to gain sufficient input to analyse challenges. Knowledge of the real-life set-up was gained through literature analysis. Furthermore, participants' experiences were not deeply surveyed or explored. However, we achieved a notion of participants' satisfaction by voluntary feedback in the chat, by mail or orally. In addition, the research team reflected critically about the objectivity of the observations during multiple review rounds. Finally, the use of sophisticated online brainstorming tools was not included in our brainstorming procedure. These platforms can increase engagement during brainstorming. However, we deliberately chose simple operating systems (i.e., Microsoft®

Teams, Poll Everywhere), because not everyone is able to work with such tools. By choosing low-threshold systems, a wide target group could participate in the online nominal group sessions.

Practical implications

Online nominal group sessions seem to be a promising alternative for the real-life commonly used technique. This paper provides researchers with recommendations to conduct online sessions, considering the various challenges. In our experience, the online format is highly recommended when looking for research procedures that are very accessible and little time-consuming. Especially during the COVID-19 pandemic, the benefits must be highlighted.

Future research

Future research should focus on refining the online nominal group technique. More expertise is needed to optimise the practical guide and to achieve optimal performance. Comparative studies between the real-life and virtual set-up are required to make statements about the efficiency. Researchers should consider participants' experiences in the design of future online sessions.

Conclusion

Performing synchronous online nominal group sessions is challenging but offers opportunities. One should be aware of the differences between real-life and online sessions. Good preparation is needed to overcome the barriers of the online technique. Our practical guide for researchers offers recommendations to facilitate the process. The role of the moderators is of major importance during brainstorming. Further research should refine the online procedure and make it more accessible for both researchers and the research population.

References

1. Sethi BA, Sethi A, Ali S, Aamir HS. Impact of coronavirus disease (COVID-19) pandemic on health professionals. *Pakistan J Med Sci*. 2020;36(COVID19-S4). doi:10.12669/pjms.36.COVID19-S4.2779
2. Xiong J, Lipsitz O, Nasri F, et al. Impact of COVID-19 pandemic on mental health in the general population: A systematic review. *J Affect Disord*. 2020;277:55-64. doi:10.1016/j.jad.2020.08.001
3. Nicola M, Alsafi Z, Sohrabi C, et al. The socio-economic implications of the coronavirus pandemic (COVID-19): A review. *Int J Surg*. 2020;78:185-193. doi:10.1016/j.ijsu.2020.04.018
4. Tan E, Song J, Deane AM, Plummer MP. Global Impact of Coronavirus Disease 2019 Infection Requiring Admission to the ICU: A Systematic Review and Meta-analysis. *Chest*. 2021;159(2):524-536. doi:10.1016/j.chest.2020.10.014
5. Education responses to COVID-19: Embracing digital learning and online collaboration. Accessed May 5, 2021. https://www.oecd.org/coronavirus/policy-responses/education-responses-to-covid-19-embracing-digital-learning-and-online-collaboration-d75eb0e8/
6. Dos Santos Marques IC, Theiss LM, Johnson CY, et al. Implementation of virtual focus groups for qualitative data collection in a global pandemic. *Am J Surg*. 2020;221(5):918. doi:10.1016/j.amjsurg.2020.10.009
7. Halliday M, Mill D, Johnson J, Lee K. Let's talk virtual! Online focus group facilitation for the modern researcher. *Res Soc Adm Pharm*. 2021;17(12):2145-2150. doi:10.1016/j.sapharm.2021.02.003
8. Jones RE, Abdelfattah KR. Virtual Interviews in the Era of COVID-19: A Primer for Applicants. *J Surg Educ*. 2020;77(4):733-734. doi:10.1016/j.jsurg.2020.03.020
9. Isabel C DSM, Lauren M T, Cynthia Y J, et al. Implementation of virtual focus groups for qualitative data collection in a global pandemic. *Am J Surg*. 2021;221(5):918-922. doi:10.1016/J.AMJSURG.2020.10.009
10. Sara S M, Michelle K, Mary P T. How to use the nominal group and Delphi techniques. *Int J Clin Pharm*. 2016;38(3):655-662. doi:10.1007/S11096-016-0257-X
11. Waggoner J, Carline JD, Durning SJ. Is there a consensus on consensus methodology? Descriptions and recommendations for future consensus research. *Acad Med*. 2016;91(5):663-668. doi:10.1097/ACM.0000000000001092
12. Allen J, Dyas J, Jones M. Building consensus in health care: a guide to using the nominal group technique. *Br J Community Nurs*. 2004;9(3):110-114. doi:10.12968/bjcn.2004.9.3.12432
13. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. *Int J Clin Pharm*. 2016;38(3):655-662. doi:10.1007/s11096-016-0257-x
14. Tseng KH, Lou SJ, Diez CR, Yang HJ. Using online nominal group technique to implement knowledge transfer. *J Eng Educ*. 2006;95(4):335-345. doi:10.1002/j.2168-9830.2006.tb00908.x
15. Kulczycki A, Shewchuk RM. Using Internet-based nominal group technique meetings to identify provider strategies for increasing diaphragm use. doi:10.1783/147118908786000550
16. Isabel C DSM, Ivan I H, Lauren M T, et al. Understanding the Surgical Experience for African-Americans and Caucasians With Enhanced Recovery. *J Surg Res*. 2020;250:12-22. doi:10.1016/J.JSS.2019.12.034
17. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. *Patient Educ Couns*. 2002;48(2):177-187. doi:10.1016/S0738-3991(02)00032-0
18. Alvarez C, Greene J, Hibbard J, Overton V. The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. *BMC Health Serv Res*. 2016;16(1):85. doi:10.1186/s12913-016-1328-3
19. Lorig KR, Sobel DS, Ritter PL, Laurent D, Hobbs M. Effect of a self-management program on patients with chronic disease. *Eff Clin Pract*. Published online 2001. PMID:11769298
20. Samuelson M, Tedeschi P, Aarendonk D, De La Cuesta C, Groenewegen P. *Position Paper of the European Forum for Primary Care Title: Improving Inter-Professional Collaboration in Primary Care*.; 2012. PMID:23113915
21. Danhieux K, Buffel V, Pairon A, et al. The impact of COVID-19 on chronic care according to providers: a qualitative study among primary care practices in Belgium. *BMC Fam Pract 2020 211*. 2020;21(1):1-6. doi:10.1186/S12875-020-01326-3
22. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. *Int J Clin Pharm*. 2016;38(3):655-662. doi:10.1007/s11096-016-0257-x
23. Manera K, Hanson CS, Gutman T, Tong A. Consensus Methods: Nominal Group Technique. *Handb Res Methods Heal Soc Sci*. Published online 2019:737-750. doi:10.1007/978-981-10-5251-4_100
24. Phillips J, Simmonds L. Using fishbone analysis to investigate problems. *Nurs Times*. 2013;109(15). PMID:23696993
25. Lago PP, Beruvides MG, Jian JY, Canto AM, Sandoval A, Taraban R. Structuring group decision making in a web-based environment by using the nominal group technique. *Comput Ind Eng*. 2007;52(2):277-295. doi:10.1016/J.CIE.2006.11.003
26. Kulczycki A, Shewchuk RM. Using Internet-based nominal group technique meetings to identify provider strategies for increasing diaphragm use. *BMJ Sex Reprod Heal*. 2008;34(4):227-231. doi:10.1783/147118908786000550
27. Vlaamse Overheid. Cijfers over geletterdheid. Accessed October 23, 2021. https://onderwijs.vlaanderen.be/nl/cijfers-over-geletterdheid

28. Statbel. Digitaal isolement: bijna een kwart van alleenstaanden heeft thuis geen internet. Accessed October 23, 2021. https://statbel.fgov.be/nl/nieuws/digitaal-isolement-bijna-een-kwart-van-alleenstaanden-heeft-thuis-geen-internet
29. Leslie M, Khayatzadeh-Mahani A, MacKean G. Recruitment of caregivers into health services research: lessons from a user-centred design study. *Res Involv Engagem*. 2019;5(1). doi:10.1186/S40900-019-0150-6
30. Small GW, Lee J, Kaufman A, et al. Brain health consequences of digital technology use. *Dialogues Clin Neurosci*. 2020;22(2):179-187. doi:10.31887/DCNS.2020.22.2/GSMALL

Annex Chapter 5

Annex I: Online nominal group technique – overview of voted ideas

Ideas nominal group sessions, grouped under SILCQ-model, with at least one vote in the final ranking system (survey)

Supporting (medical and practical)	***Involving*** (participation)	***Listening*** (needs, wishes and goals)	***Coordinating*** (guaranteeing continuity and cooperation)	***Questioning*** (progression, evolution and expectations)
Coaching patients on self-management: transfer of patient knowledge, skills and motivation to engage in self-management (By professionals) *(3 votes)*	Tool to support multidisciplinary consultation: help patient formulate wishes and goals (aim = patient has a voice) *(5 votes)*	Action to increase healthcare professionals' willingness to listen *(1 vote)*	Patient-centred self-management counselling (multidisciplinary) *(3 votes)*	Communication starter tool: measurement of treatment outcome + visualisation of patient goals and wishes *(1 vote)*
Guiding patients at the beginning of their diagnosis: helping them learn what self-management is, setting goals and expressing wishes *(3 votes)*	Educational sessions: patient + family members ("What does the patient need, what are the wishes?") (In nursing consultations) *(1 vote)*	Short training for healthcare professionals to create 'holding space' with patients (Being present without judgement, allowing the patient to tell their story freely). *(1 vote)*	Tools that increase the mindset of healthcare professionals to increase collaboration and engagement *(2 votes)*	Tool to support multidisciplinary consultation: help patient formulate wishes and goals *(5 votes)*
Peer-to-peer interaction in general practice: bringing people with chronic pain together, letting them learn from each other and moderating the conversation *(1 vote)*	Tools that strengthen interaction between patient organisations and healthcare professionals *(2 votes)*	Neighbourhoods systematically screened for care needs by volunteers *(1 vote)*	Educational events: healthcare professional collaboration (and learning) around pathologies *(2 votes)*	
Establishing a buddy system among peers *(1 vote)*			Tools that strengthen interaction between patient organisations and healthcare professionals *(2 votes)*	
Organising interactive sessions on interacting with peers and learning from each other *(1 vote)*				
Organising a weekend around mindfulness for actors in healthcare (healthcare professional, informal caregiver with or without patient) *(1 vote)*				
Making budget available for chronic patients (money for meetings, money to free up more time to listen/engage/support) *(1 vote)*				

Note:
Although there was no consensus, the nominal group sessions provided valuable insights into self-management support and highlighted the need for more sustainable interventions, as we saw that a large proportion of ideas were not innovative. This raised questions about why previous interventions were not sustainable and how to engage healthcare professionals in new interventions in the long term.

Annex II: Online nominal group technique – overview of all brainstormed ideas

A summary of all the ideas brainstormed during the nominal group sessions and additional information is available online.

Available at https://drive.google.com/file/d/1UUXyH7HWOWLjTF6OhVAfJHWROoHOtmcg/view?usp=drive_link

Chapter 6

Facilitating self-management support using the behaviour change wheel to address healthcare professionals' behaviour.

Submitted and under review in the International Journal of Educational Research Open as:
Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Facilitating self-management support using the behaviour change wheel (BCW) to address healthcare professionals' behaviour.

Adapted:
- Strengths and limitations
- Footnotes added to clarify behavioural terminology

Abstract

Background

Supporting self-management in healthcare practice is essential to improve chronic patients' daily life experiences. Primary care professionals play an indispensable role in this. Nevertheless, supporting self-management in practice comes with many challenges. The aim of this study is to identify determinants of professionals' supportive behaviour and to develop an intervention that facilitates self-management support in primary care practice.

Methods

To develop the intervention, the Behaviour Change Wheel (BCW) was used which involves eight steps in three stages: (1) Understanding the behaviour using the COM-B model, (2) Identifying intervention options, and (3) Identifying content and implementation options. The theoretical underpinnings for stage 1 included data from interviews, focus groups and brainstorm sessions, incorporated beforehand in a self-management support model. Subsequently, literature analysis, empirical research and expertise from the research group guided stages 2 and 3.

Results

We found that changes in "psychological capability", "physical opportunity", "reflective motivation" and "automatic motivation" are required to optimize professionals' behaviour towards self-management support. The two key intervention functions identified were "enablement" and "education". Therefore, a blended learning trajectory that incorporated these interventional building blocks was developed, integrating specific behaviour change techniques (BCTs) including: (1) Information about social and environmental consequences, (2) Information about health consequences, and (3) Social support (practical). The learning design was finalized by applying the Absorb-Do-Connect learning framework developed by Horton.

Conclusions

Application of the BCW framework shaped a self-management support intervention to educate and enable healthcare professionals. Future research will pilot and refine the intervention.

Keywords

Behaviour Change Wheel, COM-B model, Self-management Support, Intervention

Introduction

More than one-third of EU citizens are facing the challenges of a long-term chronic health problem, such as having one or even multiple chronic diseases(1). The aging population, along with other factors, will even lead to an increase in this number(2). As a result, our healthcare systems are significantly impacted(3). A variety of interventions have been developed in recent years to support healthcare systems and to empower patients in their own care(4–6). With the latter, we refer to the concept of self-management(7).

Self-management is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"(8). This multi-component concept requires different skills from patients, which can be categorised into six groups: action planning, patient–provider partnership development, decision making, problem solving, self-tailoring, and resource utilisation(9).

When confronted with chronic disease(s), self-management leads to better clinical outcomes and improved patients' quality of life(10,11). Given that primary care is often the initial point of contact in the healthcare system, primary healthcare professionals are in a favourable position to help patients self-manage chronic disease(s)(12). Their role is to actively collaborate and involve patients in their own care process(13,14). Specific support strategies are described in the literature encouraging patients to engage in self-management(15–17). Most frequently discussed is the 5 A's model(18). This model is developed to create a personal action plan based on five behavioural strategies (i.e., Assess, Advise, Agree, Assist and Arrange), which are considered essential to facilitate self-management by patients(18). Our previous research resulted in the development of the SILCQ-model, breaking down the concept of self-management support into five fundamental behaviours in primary care practice: supporting patients, involving patients, listening to patients, coordinating care and asking patients questions(19). While these frameworks offer valuable insights into the role of healthcare professionals, their practical application faces numerous challenges(20,21). As a result, successful implementation of self-management support tools and strategies is hindered, even though self-management support interventions incorporating these strategies can yield beneficial results in practice(22). To identify challenges, most research focusses on external barriers and facilitators of implementation of self-management support(23). Beyond this, the patient's capabilities and behaviour are thoroughly examined(24,25).

There is a notable gap in the literature on internal factors related to professionals' behaviour with regard to self-management support. Therefore, this article aims to strengthen existing research by conducting a Behaviour Change Wheel (BCW) analysis, identifying fundamental components underlying self-management supportive behaviour in practice. Complementing previous valuable insights offered by the Self-Determination Theory (SDT) on challenges and within-person factors affecting self-management support(26,27), the BCW has the potential to provide a more comprehensive framework to delve deeper into all components of behaviour and suggests practical interventional strategies. More specifically, the BCW presents a structured approach to developing and implementing behavioural interventions by identifying three fundamental components necessary to enable a specific behaviour: Capability, Opportunity and Motivation (COM-B model). Each component is further divided into two subcomponents: physical and psychological capability, physical and social opportunity, reflective and automatic motivation. The BCW's strength to assess both capability, opportunity, and motivational components that influence behaviour has the potential to enable a detailed examination of the challenges faced by healthcare professionals when engaging in self-management support. Moreover, the analysis promises to result in an intervention to increase the effectiveness of self-management support strategies.

The research questions addressed in this study are, "*What are the key components necessary to enable self-management supportive behaviour among healthcare professionals? How can these components be translated into building blocks of an intervention to create behaviour change among healthcare professionals, to achieve more sustainable self-management support in primary care practice?"*

Methods

Global BCW approach and intervention development

The BCW was applied to analyse behaviours related to self-management support by primary care professionals in Flanders, Belgium. The BCW analysis involves eight sequential steps in three stages: (1) Understanding the behaviour, (2) Identifying intervention options, and (3) Identifying content and implementation options (Figure 1). It is an evidence-based theory-driven step-by-step approach to systematically design a behavioural intervention and it has previously been successfully applied in healthcare.

The overall process of the BCW analysis was guided by a team consisting of researchers and care professionals, within the PCA network. On a quarterly basis, gatherings were organised to share research findings and receive input. Moreover, an annual meeting with members of the PCA's

external advisory board provided additional feedback and strengthened the BCW analysis. The latter group included behavioural experts.

The findings of the BCW analysis shaped an intervention for professionals in primary care practice. Therefore, we aimed at maximum variation of participants across disciplines in health and well-being during the full process of the BCW analysis.

Steps and stages of the BCW process

The BCW analysis was conducted in accordance with the guidelines outlined in the book of Michie (2014)(28). The three stages and eight steps described in this book shaped the development of our self-management support intervention (Figure 1). In the following paragraph, we describe in detail the methodology that was followed for each phase. In subsequent sections, the use of 'we' refers to the collective efforts and actions of the core research team, consisting of LT, PD, VF, AVH, MV and BS.

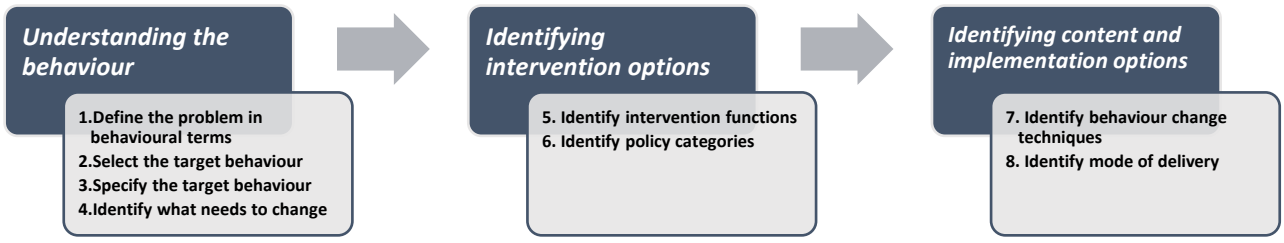


Figure 1: Flowchart to design behavioural interventions according to the Behaviour Change Wheel of Michie (2014)

1. First stage: Understanding the behaviour

Define the problem in behavioural terms

To gain insights into the implementation of self-management support in Flemish primary care practice, we conducted an extensive exploration of the existing literature(29–32). Additionally, we collected input by an online survey to explore the concept across academic programs and courses in higher educational institutions in Flanders(31). By combining the literature insights with the survey results (n = 95 training programs), we identified evidence-practice gaps and formulated our problem statement related to the support of self-management. We then referred to the literature on the concept of self-management support to delineate this statement into specific behavioural components(19).

Select the target behaviour

In a second step, we prioritized the behaviours underpinning self-management support to get a clear focus for the behavioural analysis. We selected the target behaviour based on the criteria proposed by the BCW framework of Michie (i.e.; effect size, likelihood of changing, behavioural spillover score, measurability). This prioritisation was supported by a literature review examining existing self-management support interventions and their impact(22).

Specify the target behaviour

We continued the behavioural analysis by breaking down the target behaviour. This process was guided by six questions: (1) "Who needs to perform the behaviour?"; (2) "What do they need to do differently to achieve the desired change?"; (3) "When do they need to perform it?"; (4) "Where do they need to perform it?"; (5) "How often do they need to perform it?"; (6) "With whom do they need to perform it?". We discussed these questions thoroughly with all members of the research team. To complement, we used data from qualitative interviews with patients and their informal network (n = 16) and from focus groups with care professionals (n = 5) (19,33). Additionally, we enriched the analysis with data from brainstorming sessions (n = 3) in which different stakeholders (patients, informal and formal care providers) discussed interventional strategies to strengthen self-management support in primary care practice(34).

Identify what needs to change

Following the BCW guidelines(28), we applied the COM-B questionnaire to structure data from our self-management support studies. By integrating this questionnaire into our BCW analysis, we gained a comprehensive holistic understanding of the factors influencing self-management supportive behaviour among healthcare professionals. In addition, we explored to what extent there is a need to change these factors referring to the most relevant barriers to self-management support, using data from literature review, interviews, focus groups and brainstorm sessions(19,22,33,34). We categorized these relevant barriers under the COM-B (sub-)components (i.e., Capability, Opportunity, Motivation). As a result, combining qualitative approaches with literature analysis informed the 'behavioural diagnosis'.

2. Second stage: Identifying intervention options

Identify intervention functions

To identify possible intervention strategies, we followed the BCW guidelines(28). We used the matrix proposed by Michie to link the relevant COM-B (sub-)components to nine possible intervention functions (i.e.; Education, Persuasion, Incentivisation, Coercion, Training,

Restriction, Environmental restructuring, Modelling and Enablement). Additionally, we applied criteria (i.e.; APEASE criteria) to select the most appropriate functions. This selection was based on literature analysis, findings from our studies on self-management support(19,22,33,34) and input from expert researchers (both external and internal).

Identify policy categories

In addition to the intervention functions, we identified several policy categories. We questioned which policies would support the implementation of the identified intervention functions. We used Michie's matrix to link the relevant intervention functions to seven candidate policy categories (i.e.; Communication/Marketing, Guidelines, Fiscal, Regulation, Legislation, Environmental/Social planning and Service provision). In addition, we used the APEASE-criteria to select the most appropriate categories. The same supportive sources (literature, own studies, experts) were used for selection as in the previous step.

3. Third stage: Identifying content and implementation options

Identify behaviour change techniques (BCTs)

As suggested in Michie's book, we used the BCT taxonomy to identify content that could best serve the intervention functions(28,35). Prior to the analysis, the main researcher (LT) actively participated in behavioural techniques training. Again, we applied the APEASE criteria to reduce the long list of potential BCTs by assessing accuracy of the individual BCTs. The identification process was guided by three short workshops with patients, health- and welfare professionals and representatives of healthcare organisations(34). The workshops were facilitated by an expert in implementation research and a member of the PCA team. After completing this seventh step, the main researcher drafted and specified the intervention strategy. This strategy was presented to the research team and further refined in discussion.

Identify mode of delivery

The final step in the behavioural analysis involved determining an appropriate mode of implementation of the intervention. Therefore, we used the taxonomy from the BCW book to provide us with a wide range of delivery modes(28). The selection was reduced by applying the APEASE criteria and deliberation with the research team. In addition, we sought external advice from two experts.

Results

The BCW analysis

1. First stage: Understanding the behaviour

Define the problem in behavioural terms

We identified a gap between the level of self-management support provided to chronic patients in practice and the recommended level and strategies in literature. Therefore, self-management support in primary care practice was identified as a problematic behaviour and was used as the starting point for the behavioural analysis. Furthermore, we employed the SILCQ-model, describing five sub-behaviours related to self-management support (i.e., Supporting, Involving, Listening, Coordinating, and Questioning), to guide the analysis.

Select the target behaviour

The research team discussed the long list of potential behaviours, as captured in the SILCQ model, associated with the problem (Table 1). Using Michie's predefined questions in the BCW guidance regarding effect size, likelihood of change, behavioural spillover score and measurability, we prioritised the potential behaviours and recorded the target behaviour as *"support patients' self-management by involving patients more and asking more questions to them"*.

Specify the target behaviour

We broke down the target behaviours *"involving patients more"* and *"asking more questions to patients"* into specific details addressing the actors involved, content, setting, timing and frequency. Table 2 presents the detailed analysis, informed by six predefined questions(28).

Self-management support behaviour	Underlying behaviours	Sub-behaviours
	Supporting	Providing practical support Providing ADL support Providing physical support Providing household support Providing medical support Exchanging information (including the concept of self-management) Transferring clinical expertise Arranging follow-up Transferring skills, tools & motivation
	Involving	Using communication tools Making shared decisions Ensuring participation Ensuring cooperation (including peer organisations) Maintaining care continuity Creating freedom of choice Exchanging information Tailoring care to need and wishes
	Listening	Taking time Being empathic Showing understanding Providing a listening ear Dealing with help requests Providing emotional support Listening to questions Listening to expectations Listening to wishes and goals Listening to care barriers & facilitators Being without judgement Listening to nonverbal cues Screening for social and care needs
	Coordinating	Being accessible Maintaining care continuity Directing and arranging deliberations (sharing concerns/knowledge) Creating stability Gaining collaboration (with other healthcare professionals) Managing time Including the support network Working in team Being the point of contact Arranging follow-up Arranging contact with peers
	Questions	Engaging in dialogue Exchanging Information Questioning expectations Questioning experiences Questioning wishes and goals Questioning care barriers & facilitators

Table 1: Self-management support behaviours, as captured in the SILCQ-model, to define the problem in behavioural terms

Table 2: Selected target behaviours and their characteristics

Target behaviour	**Involving patients more**	**Asking more questions to patients**
Who needs to perform the behaviour?	General practitioners & nurses	General practitioners & nurses
What do they need to do differently to achieve the desired change?	Actively involving patients in the care process, by automatically including them while making care-related decisions. Creating freedom of choice. Accepting that the balance of power is shifting to the patient. Opening up for a more participative approach of delivering care, while ensuring cooperation with peer organisations.	Actively questioning patients' self-management, focussing on both medical, emotional and role management. Informing about the concept of self-management, engaging in dialogue, and asking questions related to patients' care expectations, experiences (i.e., care barriers & facilitators), wishes and goals.
When do they need to do it?	During consultation	During consultation
Where do they need to do it?	Primary care practice or in the home setting	Primary care practice or in the home setting
How often do they need to do it?	Every (home) visit	Every (home) visit
With whom do they need to do it?	Patients, surrounded by their informal caregivers and in team with the other healthcare professionals	Patients, surrounded by their informal caregivers

Identify what needs to change

We structured our data from interviews, focus groups and brainstorm sessions into the COM-B questionnaire to inform the behavioural diagnosis. Barriers to self-management support (specifically to *involving* and *asking questions* to patients) were identified in all components of the COM-B model. After determining which components required change, we concluded that *psychological capability*, *physical opportunity*, *reflective* and *automatic motivation* were relevant for self-management support to occur in primary care practice.

- **Psychological capability**[1]

Three barriers related to *psychological capability* emerged from our data: having knowledge, having confidence and having skills. First of all, it appears from our interviewed stakeholders (patients, informal carers, healthcare providers, healthcare organisation representatives) that a prerequisite for supporting self-management is having knowledge of both the concept and the

[1] *Knowledge or psychological strength, skills or stamina to engage in the necessary mental processes (Michie et al. (28))*

importance (including benefits and outcomes). A lack of knowledge results in several misunderstandings and currently hinder implementation. Knowledge was identified as a barrier not only among healthcare professionals but also among patients themselves. Supporting self-management therefore needs clear guidance.

Secondly, little confidence in both professionals' and patients' capabilities hinder self-management (support). For example, not all interviewed participants believed that the ability to self-manage is something everyone can achieve. Finally, lack of sufficient skills was cited by our participants as a barrier to self-management support.

"As healthcare professionals, we often say quickly and without much thought, 'Well, that won't work for them..."
(Healthcare professional – focus group)

"Perfect care? Well, it's about being able to listen and assess. Sometimes it's about unasked questions and understanding what the patient needs, but that requires experience."
(Patient - interview)

- **Physical opportunity**[2]

When it comes to involving patients as part of self-management support, we identified one central barrier related to *physical opportunity*. According to our participants in the interviews, focus groups and brainstorming sessions, a clear overview of self-management support tools and interventions is missing. In addition, the accessibility and applicability of self-management measurement tools is questioned.

"So much money is being allocated towards wonderful, innovative (self-management support) initiatives, yet we are simply not aware of them."
(Healthcare professional – brainstorming session)

- **Reflective motivation**[3]

With respect to *reflective motivation*, our data revealed that participants lacked motivation to engage in self-management support. More specifically, the positive impact in the patient care process was questioned. In addition, some focus group participants (i.e.; healthcare professionals) expressed that they did not see the added value of training to strengthen their personal support skills. The issue was mainly about learning to ask questions as a fundamental part of self-management support.

[2] *Opportunities provided by the environment, such as time, location, cues and resource (Michie et al. (28))*
[3] *Reflective processes involving plans and evaluations (Michie et al. (28))*

"There are some GPs who have become disengaged from initiatives such as multidisciplinary collaboration (as a tool for stronger self-management support) because they don't immediately see the efficiency or positive outcomes." (Healthcare professional/healthcare researcher – brainstorming session)
"I assume that anyone who chooses to work in healthcare already possesses competencies in that area." (Referring to self-management support) (Representative patient organisation – focus group)

- **Automatic motivation**[4]

According to our participants, future interventions should focus on awareness to target *automatic motivation*. In their opinion, healthcare professionals perceive minimal necessity to pay additional attention towards actions such as actively asking questions to patients and involving them during consultation, although these are defined fundamentals of good self-management support.

A minority emphasized that these self-management supporting actions requires extra effort and thus needs habit formation.

"To empower patients, healthcare professionals must feel empowered. On the one hand psychologically, they need to know what self-management support is and they must have skills to engage in self-management support. But on the other hand, they also need to be structurally empowered" (Healthcare professional – brainstorming session)

"Healthcare providers also need to be open to this (referring to self-management support initiatives) (…) and be able to communicate the importance of it." (Healthcare professional – brainstorming session)

2. Second stage: Identifying intervention options

Identify intervention functions

According to Michie's matrix(28), all nine intervention functions were candidates to target the four components of the COM-B model that were identified as barriers to self-management support and where there was need for change. After applying the APEASE criteria, seven intervention functions were rejected because they were not Effective (n = 1), Practicable (n = 4) or Acceptable (n = 2) in the context of Flemish primary care practice. This resulted in the selected intervention functions of *education*[5] and *enablement*[6] (Table 3).

[4] *Automatic processes involving reactions, desires, impulses and inhibitions (Michie et al. (28))*
[5] *Increasing knowledge or understanding (Michie et al. (28))*
[6] *Increasing means/reducing barriers to increase capability or opportunity (Michie et al. (28))*

Identify policy categories

All seven policy categories could be linked to the selected intervention functions *education* and *enablement* according to the matrix(28). Of these, five policy categories did not meet the APEASE criteria for developing a self-management support intervention in primary care practice. The final selection included *communication/marketing*[7] and *service provision*[8] as policy categories (Table 3).

3. Third stage: Identifying content and implementation options

Identify behaviour change techniques (BCTs)

A total of 17 commonly used BCTs were reported as potentially active components for the selected intervention functions and policy categories(35). Only three techniques met the APEASE criteria and were therefore incorporated for the development of a behavioural self-management support intervention, including *information about social and environmental consequences*[9], *information about health consequences*[10] and *social support (practical)*[11] (Table 3).

Identify mode of delivery

To determine the mode of delivery, we summarised the behavioural analysis and formulated our intervention strategy. This strategy aims to demonstrate how we can provide healthcare professionals with *'information about social and environmental consequences'*, *'information about health consequences'* and *'social support (practical)*', achieved by making *changes to communication* and *service provision*. The goal is to *educate* and *enable* healthcare professionals to actively involve patients more and ask them more questions, as essential fundamentals of self-management support.

Description of the intervention and of the planned pilot study

To translate this strategy into a practical intervention, the development of a blended learning program was chosen. The intervention aims to provide healthcare professionals with *information* about social, environmental consequences and health consequences of self-management support. In addition, it focusses on providing social *support*. By making changes in *communication*

[7] *Using print, electronic, telephonic or broadcast media (Michie et al. (28))*
[8] *Delivering a service (Michie et al. (28))*
[9] *Provide information (e.g., written, verbal, visual) about social and environmental consequences of performing the behaviour (Michie et al. (28))*
[10] *Provide information (e.g., written, verbal, visual) about health consequences of performing the behaviour (Michie et al. (28))*
[11] *Advise on, arrange or provide practical help (e.g., from friends, relatives, colleagues, 'buddies' or staff) for performance of the behaviour (Michie et al. (28))*

and *service provision*, the blended learning program aims to *educate* and *enable* healthcare professionals to deliver more effectively self-management support, fostering patient-centredness and achieving better self-management outcomes for individuals with chronic disease(s).

Following Michie's guidance, the internet was chosen as the most suitable primary medium to deliver the intervention at a population level. Therefore, the learning program was hosted on a knowledge and service-oriented self-management platform. The blended learning program consists of four modules, combining online education (by means of text, audio (i.e., podcasts) and video), real-life reflection and discussion. The duration of the learning trajectory has been estimated to be six hours over an 8-week period. Detailed characteristics of the intervention are presented in the TIDierR-checklist (Supplementary file 1).

Healthcare professionals from different disciplines within primary care will be included for piloting the learning program. These participants will be recruited by contacting community health centres and multidisciplinary health and welfare practices in Flanders, Belgium. The pilot study will enrol at least 5 centres, with a total of no less than 24 healthcare professionals.

Table 3: Overview of identified COM-B component and barriers related to self-management support, linked to the selected appropriate intervention functions, policy categories and BCTs.

COM-B components	Identified barriers for involving patients and asking them questions, *as essential fundamentals of self-management support*	Selected intervention functions	Policy categories through which BCTs can be delivered	BCTs to deliver intervention functions
Psychological capability	Lack of knowledge of the concept of self-management (including the benefits, the importance, etc.) Insufficient skills to ask questions (learn how, when and which questions need to be asked) Limited knowledge of available tools to involve patients (communication techniques, etc.)	Education	Communication/marketing Service provision	Information about social and environmental consequences Information about health consequences
	Lack of confidence in yourself that you can collaborate with patients and have confidence in the patient's abilities Lack of confidence that asking questions results in better healthcare outcomes and benefits the care process Strong urge to follow own judgement/opinion Insufficient skills of empathetic questioning	Enablement	Service provision	Social support (practical)
Physical opportunity	Inadequate access to or non-existence of necessary materials and tools	Enablement	Service provision	Social support (practical)
Reflective motivation	Doubts about the positive impact of involving patients and asking them questions Limited belief in the need for improved skills to involve patients effectively	Education	Communication/marketing Service provision	Information about social and environmental consequences Information about health consequences
Automatic motivation	Lack of established habits for involving patients and asking questions Disregard for the necessity of involving patients and recognizing the importance of questioning	Enablement	Service provision	Social support (practical)

COM-B: Capability, Opportunity, Motivation-Behaviour
BCT: Behaviour Change Technique

Discussion

This paper describes the identification of the necessary building blocks of an intervention to create a behavioural change in healthcare professionals to achieve more sustainable self-management support in primary care practice. The BCW provided a systematic approach to identify these building blocks and translate them into a practical intervention. We found that "psychological capability", "physical opportunity", "reflective motivation" and "automatic motivation" need to change to increase professionals' behaviour towards self-management support. The two key intervention functions identified were "enablement" and "education". Completing the BCW resulted in the development of a blended four-phase learning intervention that incorporates three behavioural techniques, namely informing healthcare professionals about social and environmental consequences of self-management support, informing about health consequences and providing social support. Our preparatory work underpinned this analysis based upon in-depth literature reviews and multiple qualitative studies(19,22,31,33,36).

This paper corroborates previous research on behaviour in healthcare practice. Valuable insights on the topic of self-management support were already obtained using the SDT. For example, Duprez *et al.* (2020) investigated different ways nurses interact with chronic patients while engaging in self-management support(27). The study highlighted the varying profiles of nurses and their associated indicators, and contributed to a better knowledge of professionals' interactions with patients regarding self-management support. Understanding these different profiles can provide a nuanced perspective on how our proposed blended learning trajectory can be adapted and tailored to the specific needs of a healthcare professional, depending on their profile.

Our research introduces the BCW as a valuable addition to the field of Self-Determination by providing a holistic approach that combines the theoretical depth of the SDT with the practical applicability of behaviour analysis. By providing a systematic and comprehensive framework for the development of behaviour change interventions, BCW analysis has the power of enhancing the ability to understand, predict, and effectively influence human behaviour in different contexts. To date, the application of the BCW has not been fully explored to analyse self-management support behaviour in healthcare practice and only a very limited number of studies focus on healthcare professionals' behaviour. Nichols *et al.* (2017) launched a survey to explore the components of the COM-B model capable of changing behaviour among diabetes care professionals(37). They concluded that particularly capacity and opportunity to engage in self-management support were lacking. This was confirmed by our study data, which additionally

highlighted the value of motivation. Similar findings were found in other research in which (controlled) motivation was associated with belief in the importance of self-management support(38). In addition, Lee *et al.* (2021) investigated healthcare professionals' perceptions on barriers to implementing self-management support of asthma patients in primary care, also using the COM-B model(39). Again, comparable findings were found in terms of barriers to capability and motivation. Related to capability, the need of training self-management support skills emerged. In addition, lack of awareness about the benefits of self-management was central to motivation-related barriers. Coventry *et al.* identified barriers to patient engagement in self-management in the context of multimorbidity by exploring the views of both patients and practitioners(40). Although focused on self-management rather than self-management support, similar COM-B related barriers were identified.

A broader analysis of self-management supportive behaviour in practice is found in the review by Tharani et al(20). More specifically, their systematic mixed studies review provides a summary of factors influencing the provision of self-management support by nurses. Their research findings align with our study's results. However, they look at behaviour from a broader perspective which transcends the COM-B model. In their review, they present a framework of interdependent factors influencing nurses' behaviour regarding self-management support. The emphasis is additionally on patient-provider collaboration, patient-related barriers to self-management and impeding healthcare structures. Our analysis focused more in-depth on the healthcare professional, regardless of which discipline, but examines the concept of self-management support from a narrower perspective.

A small number of studies employed behavioural analysis to develop an intervention aimed at empowering professionals. Wuyts *et al.* (2021) adopted the SDT to develop a multifaced need-supportive training program in self-management support for nurses(26). Although drafted from a different behavioural analysis, the objectives of their training are similar, namely to equip participants with attitudes, knowledge, skills and reflection needed to provide patient-centred self-management support. The similarities between both studies reinforce the value of the blended learning trajectory proposed in our analysis. The added value of the BCW consists in providing specific evidence-based intervention functions, policy categories and implementation approaches to underpin the intervention strategy. Porcheret *et al.* (2014) described a case study on the adoption of theory to inform an intervention to enhance self-management support for general practitioners(41). Their theoretical foundation consisted of four different theoretical models, including the Theoretical Domains Framework (TDF) in order to identify relevant determinants of change. Although our study did not use the TDF, our results are consistent with

their findings. Similar behavioural techniques related to information provision were incorporated into the intervention developed to target the domains of knowledge and motivation. This validates our intervention by suggesting that the learning program was well-targeted to the key theoretical domains that influence behaviour of healthcare professionals related to supporting self-management.

Interestingly, there are many other frameworks that can be used for behaviour change interventions. For example, the Theory of Planned Behaviour (TPB) is often used in behavioural research. A study by Anderson *et al.* (2019) applied TPB to explore views of healthcare professionals on self-management support in long-term conditions and found similar results to our study(42). More specifically, weak intentions towards the implementation of self-management support were observed, as there was a lack of belief in their own professional abilities. These findings suggest that, although using more technical frameworks such as the BCW may not be the standard and comes with additional challenges, our analysis was effective in identifying key behavioural factors influencing self-management support.

Strengths and limitations

This study is not without limitations. Bias in the selection of intervention functions and BCTs may have occurred since they were informed by the judgement and experience of the research team. However, we tried to involve as many experts as possible by intensively collaborating with the network of the PCA and by appealing on an advisory board. In addition, we only focussed on healthcare professionals' behaviours, which may have limited the impact on patient outcomes. However, patients' experiences and input were incorporated in the BCW analysis. When talking about professionals, we should also recognise that not all behaviours are universally applicable. However, the analysis aimed to identify common themes and areas for improvement in different contexts. Future research should build on these findings and target specific sectors within primary care. Finally, there are some limitations to the use of the BCW framework. This approach does not provide a detailed analysis of the theoretical structures and mechanisms at the foundation of behaviour change, which can make it challenging to identify the precise factors causing behaviour. Nevertheless, the BCW framework has the strength to provide a very comprehensive and systematic approach, by which we were able to develop an evidence-based intervention for a broad target audience. Further insights into the functioning and impact of our blended learning intervention will be gained through a comprehensive evaluation of the pilot study.

Conclusion

Application of the BCW framework shaped a holistic self-management support intervention to *educate* and *enable* healthcare professionals in primary care practice. This intervention comprises three central BCTs, delivered via a combination of online education, real-life reflection and discussion. Future research will pilot and refine the intervention.

References

1. Eurostat. Self-perceived health statistics [Internet]. 2023 [cited 2023 Apr 13]. Available from: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Self-perceived_health_statistics&oldid=509628
2. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. Lancet. 2012 Jul 7;380(9836):37–43.
3. Union O and E. Health at a Glance: Europe 2018 STATE OF HEALTH IN THE EU CYCLE [Internet]. 2018 [cited 2020 Aug 17]. 212 p. Available from: https://doi.org/10.1787/health_glance_eur-2018-en
4. Van Der Heide I, Melchiorre MG, Quattrini S, Boerma W. Innovating care for people with multiple chronic conditions in Europe An overview. 2015.
5. WHO. WHO global strategy on integrated people-centred health services 2016-2026. 2015;
6. Markwart HI, Bomba F, Menrath I, Brenk-Franz K, Ernst G, Thyen U, et al. Assessing empowerment as multidimensional outcome of a patient education program for adolescents with chronic conditions: A latent difference score model. PLoS One. 2020;15(4):e0230659.
7. Jones MC, MacGillivray S, Kroll T, Psych D, Reza Zohoor A, Connaghan J. A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. J Nurs Healthc Chronic Illn. 2011 Sep 1;3(3):174–85.
8. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
9. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7.
10. Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. PLoS One. 2019;14(8):e0220116.
11. Panagioti M, Richardson G, Small N, Murray E, Rogers A, Kennedy A, et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: A systematic review and meta-analysis. BMC Health Serv Res. 2014 Aug 27;14(1):1–14.
12. Alvarez C, Greene J, Hibbard J, Overton V. The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. BMC Health Serv Res. 2016 Mar 11;16(1):85.
13. van Dongen SI, Stoevelaar R, Kranenburg LW, Noorlandt HW, Witkamp FE, van der Rijt CCD, et al. The views of healthcare professionals on self-management of patients with advanced cancer: An interview study. Patient Educ Couns. 2022 Jan 1;105(1):136–44.
14. Armstrong M, Tuijt R, Read J, Pigott J, Davies N, Manthorpe J, et al. Health care professionals' perspectives on self-management for people with Parkinson's: qualitative findings from a UK study. BMC Geriatr. 2021 Dec 1;21(1):s12877-021-02678-w.
15. Thompson DG, O'Brien S, Kennedy A, Rogers A, Whorwell P, Lovell K, et al. The WISE model of self-management support. NIHR Journals Library; 2018.
16. Mills SL, Brady TJ, Jayanthan J, Ziabakhsh S, Sargious PM. Toward consensus on self-management support: the international chronic condition self-management support framework. Health Promot Int. 2017;32(6):942–52.
17. O'connell S, Mc Carthy VJC, Savage E. Frameworks for self-management support for chronic disease: a cross-country comparative document analysis. BMC Heal Serv Res. 2018;18(1).
18. Glasgow RE, Davis CL, Funnell MM, Beck A. Implementing practical interventions to support chronic illness self-management. Jt Comm J Qual Saf. 2003 Nov 1;29(11):563–74.
19. Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, et al. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022;23(1):1–13.
20. Tharani A, Van Hecke A, Ali TS, Duprez V. Factors influencing nurses' provision of self-management support for patients with chronic illnesses: A systematic mixed studies review. Int J Nurs Stud. 2021 Aug 1;120:103983.
21. McGowan P. The challenge of integrating self-management support into clinical settings. Can J diabetes. 2013 Feb 1;37(1):45–50.
22. Timmermans L, Golder E, Decat P, Foulon V, Van Hecke A, Schoenmakers B. Characteristics of self-management support (SMS) interventions and their impact on quality of life (QoL) in adults with chronic diseases: an umbrella review of systematic reviews. Health Policy (New York). 2023 Jul 25;135:104880.
23. Foo KM, Sundram M, Legido-Quigley H. Facilitators and barriers of managing patients with multiple chronic conditions in the community: A qualitative study. BMC Public Health. 2020 Feb 27;20(1):1–15.
24. Hessler DM, Fisher L, Bowyer V, Dickinson LM, Jortberg BT, Kwan B, et al. Self-management support for chronic disease in primary care: frequency of patient self-management problems and patient reported priorities, and alignment with ultimate behavior goal selection. BMC Fam Pract. 2019 Aug 29;20(1):120.

25. Araújo-Soares V, Hankonen N, Presseau J, Rodrigues A, Sniehotta FF. Developing Behavior Change Interventions for Self-Management in Chronic Illness: An Integrative Overview. Eur Psychol. 2019;24(1):7–25.
26. Wuyts D, Van Hecke A, Lemaire V, Vandepoel I, Duprez V. Development and validation of INTENSS, a need-supportive training for nurses to support patients' self-management. Nurse Educ Today. 2021 Nov 1;106:105042.
27. Duprez V, van der Kaap-Deeder J, Beeckman D, Verhaeghe S, Vansteenkiste M, Van Hecke A. Nurses' interaction styles when supporting patients in self-management: A profile approach. Int J Nurs Stud. 2020 Oct 1;110:103604.
28. Michie S, Atkins L, West R. The Behaviour Change Wheel - A Guide To Designing Interventions [Internet]. London: Silverback Publishing; 2014 [cited 2023 Apr 16]. Available from: http://www.behaviourchangewheel.com/
29. Paulus D, Van den Heede K MR. Organisatie van zorg voor chronisch zieken in België: ontwikkeling van een position paper. Heal Serv Res (HSR) Fed Kenniscentrum voor Gezondheidszorg. 2012;KCE Report:D/2012/10.273/79.
30. Overheidsdienst F. Orientatienota "Geïntegreerde visie op de zorg voor chronisch zieken in België" | FOD Volksgezondheid [Internet]. 2013 [cited 2023 Jul 26]. Available from: https://www.health.belgium.be/nl/orientatienota-geintegreerde-visie-op-de-zorg-voor-chronisch-zieken-belgie
31. Academie Voor De Eerste Lijn. Inspirerende bijdragen voor een sterke eerste lijn in Vlaanderen [Internet]. Uitgeverij ASP nv; 2021. 90–91 p. Available from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.fondsdanieldeconinck.be/app/uploads/2022/01/Inspirerende-bijdragen-voor-een-sterke-eerste-lijn-in-Vlaanderen-Academie-voor-de-eerste-lijn.pdf
32. Gezondheid AZ&. EEN GEÏNTEGREERDE ZORGVERLENING IN DE EERSTE LIJN. 2017.
33. Timmermans L, Mustafa Sirimsi M, De Vriendt P, Van Hecke A, Vermandere Leuven Birgitte Schoenmakers KU Leuven MK, Foulon Leuven VK. Self-management support (SMS) in primary care practice: a qualitative focus group study of care professionals' experiences. Res Sq. 2023 May 8;
34. Timmermans L, Huybrechts I, Decat P, Foulon V, Van Hecke A, Vermandere M, et al. Recommendations for Researchers on Synchronous, Online, Nominal Group Sessions in Times of COVID-19: Fishbone Analysis. JMIR Form Res. 2022 Mar 1;6(3):e34539.
35. Michie S, Richardson M, Johnston M, Abraham C, Francis J, Hardeman W, et al. The behavior change technique taxonomy (v1) of 93 hierarchically clustered techniques: building an international consensus for the reporting of behavior change interventions. Ann Behav Med. 2013 Aug;46(1):81–95.
36. Boeykens D, Sirimsi MM, Timmermans L, Hartmann ML, Anthierens S, De Loof H, et al. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. J Clin Nurs. 2022;00:1–16.
37. Nichols J, Vallis M, Boutette S, Gall Casey C, Yu CH. A Canadian Cross-Sectional Survey on Psychosocial Supports for Adults Living With Type 1 or 2 Diabetes: Health-Care Providers' Awareness, Capacity and Motivation. Can J Diabetes. 2018 Aug 1;42(4):389-394.e2.
38. Wong Chung R, Willemen A, Voorman J, Ketelaar M, Becher J, Schuengel C. Professionals' motivation to support parental self-management regarding children with physical disability in Dutch rehabilitation services: 'Please mind your gap.' Child Care Health Dev. 2021 Sep 1;47(5):685–96.
39. Lee PY, Cheong AT, Ghazali SS, Salim H, Wong J, Hussein N, et al. Barriers to implementing asthma self-management in Malaysian primary care: qualitative study exploring the perspectives of healthcare professionals. NPJ Prim care Respir Med. 2021 Dec 1;31(1):38.
40. Coventry PA, Fisher L, Kenning C, Bee P, Bower P. Capacity, responsibility, and motivation: A critical qualitative evaluation of patient and practitioner views about barriers to self-management in people with multimorbidity. BMC Health Serv Res. 2014 Oct 31;14(1):1–12.
41. Porcheret M, Main C, Croft P, McKinley R, Hassell A, Dziedzic K. Development of a behaviour change intervention: A case study on the practical application of theory. Implement Sci. 2014 Apr 3;9(1):1–11.
42. Anderson N, Ozakinci G. "it all needs to be a full jigsaw, not just bits": Exploration of healthcare professionals' beliefs towards supported self-management for long-term conditions. BMC Psychol. 2019 Jun 24;7(1):1–14.

Appendix Chapter 6

Supplementary file 1: TIDier-checklist (Template for Intervention Description and Replication)

TIDieR
Template for Intervention Description and Replication

Item number	Item	
1.	**BRIEF NAME:** Provide the name or a phrase that describes the intervention.	The MENTOSS intervention (More ENcouragement TOwards Self-management Support): a blended learning program.
2.	**WHY:** Describe any rationale, theory, or goal of the elements essential to the intervention.	Self-management of a chronic condition is a complex phenomenon, which has become increasingly important. However, a supportive attitude and behaviour is hampered by a lack of awareness and knowledge among healthcare professionals. Before launching specific support tools, it is time to clear up misunderstandings and critically examine this concept. A blended learning program focussing on education and proficiency of care providers is developed to strengthen self-management support in primary care.
3.	**WHAT:** Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	The blended learning intervention aims to educate and enable healthcare professionals to support self-management in primary care. The learning program was created following the Absorb-Do-Connect model of Horton. The theoretical underpinnings include data from interviews, focus groups and brainstorm sessions, integrated in the behaviour change model of Michie. The learning program was developed within the UCLL Platform and consists of four modules.
4.	**WHAT:** Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	The MENTOSS intervention consists of the delivery of three Behaviour Change Techniques, delivered via a combination of online education (by means of text, audio (i.e., podcasts) and video), real-life reflection and discussion. The first module is an online team-teased module in which participants get to know the program and the basics of self-management support. The second module is an online platform with videos, course book, and podcast to learn in-depth about self-management support. The third module is an individual reflection task in which participants reflect on how they integrated the fundamentals of self-management support in a real-life situation with a patient. The last module is a real-life group workshop in which participants discuss the topic(s) and difficulties. The head coach will provide feedback and coaching to participants throughout the intervention.
5.	**WHO PROVIDED:** For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	The MENTOSS intervention is provided by a team of experts in self-management support and education. The lead coach for the learning program is a researcher and expert in self-management support. Moreover, the program will be practically supported by another coach, who is an expert in the field of education and works for an educational institution. Additionally, there is an entire research team behind the learning program, with experts in both the topic of self-management support and education, consisting of several healthcare professionals.

6.	**HOW:** Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	The MENTOSS intervention is delivered through a blended learning approach that includes online and real-life components. Participants are guided through the four modules of the intervention, starting with a group-based online module, followed by an online platform (proceeding independently), an individual reflection task, and a real-life group workshop.
7.	**WHERE:** Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	The learning program can be delivered in any primary care setting where multidisciplinary practices are present. No necessary infrastructure or features are required.
8.	**WHEN and HOW MUCH:** Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity, or dose.	The intervention is estimated to take a maximum of six hours over an 8-week period. Participants can complete the online modules at their own pace, and the real-life group workshop can be scheduled at a convenient time for the participants.
9.	**TAILORING:** If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	The intervention was not specifically tailored or adapted to individual participants. Instead, the intervention was designed to be widely applicable and suitable for all professionals in multidisciplinary primary care practices. By developing a program that fits all professionals, the MENTOSS intervention can be implemented more easily and evaluated more objectively. However, participants may still receive personal support and feedback from the head coach and have the opportunity to reflect on their own experiences with self-management support, which can help to facilitate a more personalized learning experience within the broader framework of the intervention.
10.	**MODIFICATIONS:** If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	N/A (intervention not yet delivered to all included participants).
11.	**HOW WELL:** Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	Participants' progress will be monitored throughout the intervention, including their completion of online modules and reflection tasks. To maintain or improve fidelity, the intervention was designed to be structured and standardized, with clear learning objectives, materials, and activities. This was communicated in detail in the first starting session. The intervention was also delivered by experienced coaches (self-management support, education). The coaches followed a detailed implementation manual (behaviour change wheel), which outlined the steps and procedures for delivering the intervention consistently.
12.	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	N/A (intervention not yet delivered to all included participants).

Chapter 7

Transforming healthcare: A pilot study to improve primary healthcare professionals' self-management support behaviour through blended learning.

Submitted and under review in BMC Medical Education as:
Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Transforming healthcare: A pilot study to improve primary healthcare professionals' self-management support behaviour through blended learning.

Preprint published and available at https://www.researchsquare.com/article/rs-3792014/v1 (DOI: https://doi.org/10.21203/rs.3.rs-3792014/v1)

Adapted:
- Abstract
- Methods: study design, data analysis
- Results: quantitative user feedback
- Discussion and Conclusions

Abstract

Background

Self-management of a chronic condition is a complex but increasingly important issue. However, a supportive attitude and behaviour among healthcare professionals is hampered by a lack of awareness, knowledge and motivation. In addition, the role of professionals in supporting self-management seems unclear.

Methods

A blended learning program for primary healthcare professionals was developed to strengthen self-management support in primary care. The program was piloted in community health centres and multidisciplinary medical practices in Flanders. Using the Kirkpatrick model, the impact on healthcare professionals' reaction, learning and behaviour regarding self-management support was evaluated.

Results

A total of 60 healthcare professionals registered for the educational program. Post-learning questionnaires and verbal feedback showed a positive response, with professionals highly appreciating the innovative blended learning approach. In terms of learning, participants showed a good understanding of self-management support, although nuances were observed in the application of acquired knowledge to practice scenarios. Finally, preliminary insights into behavioural change were explored, revealing a positive impact of the intervention on participants' supportive self-management behaviours in healthcare practice.

Conclusions

Our study provides preliminary insights into the outcomes of a blended learning program designed to increase awareness and knowledge of self-management support among professionals. The program needs to be refined for general implementation in primary care.

Keywords

Self-management, Primary healthcare, Educational intervention, Kirkpatrick evaluation model

Background

Worldwide, our healthcare systems are undergoing continuous and fundamental changes in response to various challenges, particularly to the increasing number of people with chronic conditions(1,2). One of the key components of this changing healthcare landscape is the emphasis on self-management support as an essential aspect of healthcare delivery(3). This focus is not only driven by international policy, as evidenced by WHO recommendations(4). Self-management support is also receiving increasing attention at national level, in Belgium(5).

Self-management of a chronic condition is defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (3). Engaging patients in self-managing their chronic condition is beneficial for both health and quality of life(6–8). Healthcare professionals play a crucial role here(9). Despite the clear benefits of self-management support, its successful integration into healthcare practice remains a challenge(10,11). As the role of the primary healthcare professionals is often underestimated, it is essential to empower this group by focussing on their attitudes and behaviour towards self-management support to achieve effective support in practice(12).

Therefore, our research group conducted an in-depth analysis of professionals' behaviour regarding self-management support in primary care practices. Using Michie's behaviour change wheel (BCW)(13), we concluded that to achieve supportive behaviour, there should be a focus on 'education[12]' and 'enablement[13]' of professionals. Indeed, these two components emerged as the key intervention functions from the behavioural analysis. To integrate both education and enablement, we developed an interactive blended learning intervention. Recent research shows that blended learning methods, especially applied to healthcare professionals, are more efficient and lead to greater participant engagement and understanding(14–16). Our choice was also influenced by the advantages of synchronous and asynchronous learning, giving professionals the flexibility to adapt their learning pace to individual needs and time constraints(17,18).

[12] *Increasing knowledge or understanding (Michie et al. (13))*
[13] *Increasing means/reducing barriers to increase capability or opportunity (Michie et al. (13))*

Based on these literature findings and on our own behavioural analysis, we developed a high-quality, theory-based intervention called MEnToSS ("More Encouragement Towards Self-management Support"). It's a blended learning intervention targeted at all types of healthcare professionals and created with input from different stakeholders (patients, informal and formal caregivers, representatives of patient organisations, policy makers, etc). Detailed information on the intervention is provided in the methodology section.

This paper reports on the impact of the MEnToSS intervention. The research question addressed in this paper is: *What is the impact of the MEnToSS learning program on healthcare professionals' attitudes and behaviours to support self-management?*

Methods

Study design

The present study is a pilot study with a mixed-methods design, integrating quantitative and qualitative research methods to provide an in-depth understanding of the outcomes of the MEnToSS learning intervention. Ethical approval was obtained from the Ethical Committee Research of UZ/KU Leuven (S63890). To ensure transparent reporting, this study follows the CRISP (Consensus Reporting Items for Studies in Primary Care) reporting guideline(19) (Supplementary file 1).

Participants

The intervention is tailored for primary healthcare professionals, both health and welfare, in multidisciplinary practices or community health centres providing care to chronic patients with moderate complex care needs, as defined by Iglesias (2018)(20). Participation was limited to teams consisting of a minimum of four healthcare professionals, each of whom represented at least two different healthcare disciplines. Information materials, such as leaflets and a video, were used and distributed through our organisation (i.e., the Primary Care Academy) to recruit participants. In addition, e-mail invitations were sent to various health- and welfare organisations. The study sought to enrol of at least six centres, comprising minimally 24 healthcare professionals.

MEnToSS intervention

a) Intervention

The intervention consisted of a blended learning program that combined asynchronous and synchronous learning. The aim was to educate and enable healthcare professionals to more effectively support self-management in primary care practice.

b) Learning objectives

The intervention was designed to help participants better understand the concept of self-management, the importance of self-management support and define their role as a healthcare professional in it. In addition, they were encouraged to think critically about their own actions in supporting self-management. These objectives contributed to the overall goal of increasing professionals' knowledge, attitudes and perceived behaviour towards self-management support.

c) Theory

The learning program was developed according to Horton's Absorb-Do-Connect (ADC) model(21). The theoretical underpinnings included data from literature analysis, interviews, focus groups and nominal group brainstorming sessions, integrated in Michie's behaviour change wheel framework(22). This evidence-based approach consists of eight steps in three phases to develop sustainable interventions, taking into account input from all actors in the healthcare network (i.e.; patients, informal and formal caregivers, representatives of patient organisations, policy makers). It also focuses on the practical aspects of implementation related to context. This provided the intervention with a solid foundation for behaviour change.

d) Learning materials

The MEnToSS intervention offered three different learning materials. First, a written course provided an in-depth understanding of the topic of self-management, including its origins and significance and the crucial role that healthcare professionals play. In addition, there were informative short video clips that briefly addressed challenges and misconceptions related to self-management (support). Finally, the learning materials included podcasts with healthcare professionals that gave insights into the topic of self-management support.

e) Learning strategies

The learning intervention consisted of multiple steps, represented in Figure 1. Participants received a certificate after completion of the learning program.

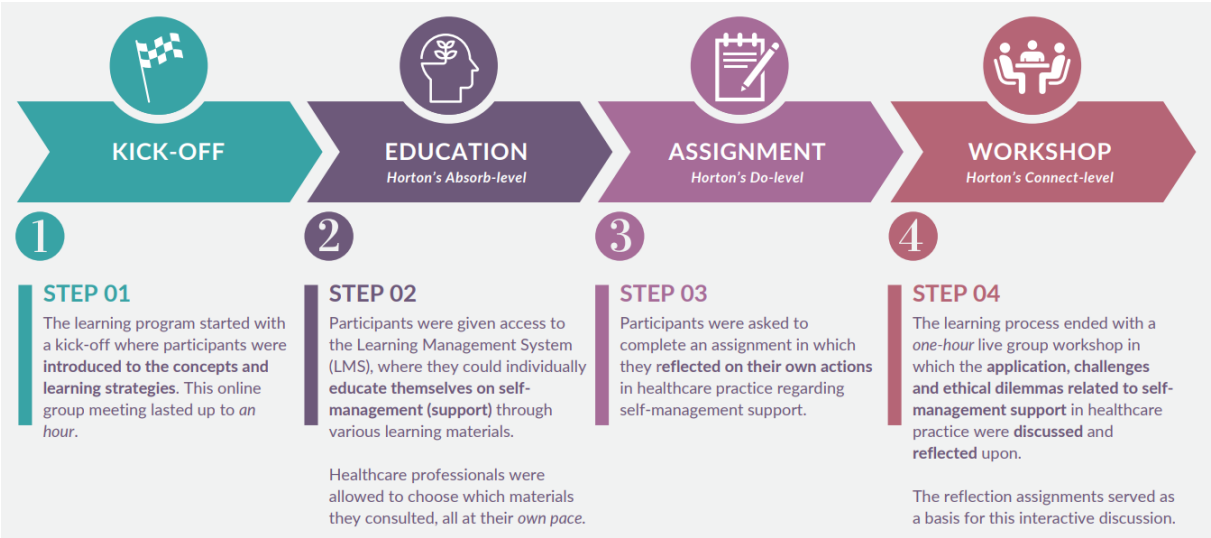


Figure 1: Steps of the blended learning intervention
Template retrieved from ww.canva.com

f) Delivery

The intervention was delivered via a Learning Management System (LMS) (password-protected) over a two-month period, from the starting point to the final workshop. The intervention was initiated at the kick-off and concluded during the final workshop by the main trainer (LT), a primary healthcare researcher and an expert in self-management support. Moreover, this person remained available online throughout the entire learning process to provide ongoing guidance and support. In addition, pedagogical support was received from an assistant trainer with teaching experience (i.e., platform guidance, practical issues, etc.).

Data collection

The Kirkpatrick model was used to evaluate the MEnToSS self-management support intervention at the levels of reaction, learning and behaviour. This choice was based on previous successful and meaningful applications of the model in different healthcare settings, such as primary care. Quantitative data were collected using electronic questionnaires (Qualtrics®) to measure impact (Supplementary files 2-5). Responses were evaluated using a 5 or 7-point Likert scale, with the possibility of making additional comments. To evaluate **reaction**, the Short version of the User Experience Questionnaire (UEQ-S) was distributed immediately after the intervention, complemented by questions on general satisfaction with blended learning (using a

modified version of a validated blended learning questionnaire(23)). In terms of **learning**, participants' self-perceived knowledge and skills related to self-management support were assessed immediately after, with a specific focus on the SILCQ-fundamentals(24), using questions compiled by the research group. These questions included both statements and validations. Finally, participants' self-reported **behaviour** was assessed using another researcher-made questionnaire. These data were collected three months after the intervention. Besides quantitative methods, qualitative verbal feedback was collected. More specifically, participants were invited to share their experiences of the learning trajectory, its impact on their healthcare practice, and any challenges and barriers they encountered in oral feedback sessions. These sessions were organised half an hour before the concluding workshop and were set up as roundtable discussions, using pre-defined questions to encourage in-depth interaction. Discussions were organised by practice/centre, with each group consisting of all participants from the same practice/centre. Although this set-up meant that the workshop itself could not be included in the oral feedback sessions, this information was collected later through the questionnaires that participants filled in after the learning program. This gave us a full picture of how the intervention was received and allowed us to complete the evaluation.

Data analysis

Quantitative data from the questionnaires were analysed using SPSS (descriptive statistics). Medians and interquartile ranges were reported when there was noticeable variability and a lack of consistent agreement among respondents, ensuring a comprehensive understanding of professionals' experiences. Chi-square tests were performed to assess relationships between variables. A p-value of 0.05 was considered as the level of significance. For qualitative data from the feedback sessions, thematic analysis was applied. Input was collected, coded and grouped into themes, which provided insights into participants' experiences, how the intervention influenced their practice and identified obstacles.

Results

A total of 60 healthcare professionals from eight multidisciplinary centres/practices registered for the intervention (Table 1). Of these, 56 participants fully completed the learning program, while four participants (from one centre) dropped out.

Table 1: Information on registered multidisciplinary centres/practices

Groups	Type	Number of participants	Background	Note
Group 1	Community health centre	6	1 x psychologist 1 x dietician 2 x GP 2 x nurse	
Group 2	Multidisciplinary GP practice	4	2 x GP in training 2 x GP	Dropped out[14]
Group 3	Community health centre	4	1 x tobaccologist 1 x nurse 2 x GP	
Group 4	Multidisciplinary GP practice	6	1 x nurse 2 x medical secretaries 3 x GP	
Group 5	Community health centre	9	1 x trainee (discipline unknown) 2 x physiotherapists 2 x nurse 4 x GP	
Group 6	Community health centre	8	1 x GP in training 3 x nurse 4 x GP	
Group 7	Multidisciplinary healthcare practice	17	3 x nurse 3 x GP in training 4 x nurse in training 7 x GP	
Group 8	Multidisciplinary GP practice	6	3 x nurse 3 x GP	

GP: General Practitioner

1. Quantitative user feedback

The first post-intervention feedback questionnaire, focusing on reaction and learning levels according to the Kirkpatrick model, was received from 25 participants. Of these, 72% were female respondents and 28% male respondents, with 64% general practitioners and 24% nurses, as the two largest groups. In terms of learning preference, 24% took an integrated approach to all materials, while 24% combined text with podcasts and 16% took a mix of text and videos. In terms of prior exposure, the initial post-intervention questionnaire revealed that 77% of the participants had previously been exposed to the concept of self-management support, albeit to

[14] *Reason: Discontinuation due to engagement challenges (small group size, self-study, podcast length, etc.) and logistical difficulties in scheduling a concluding workshop.*

a very limited extent. This exposure was mainly through formal education and training, focusing on goal-oriented care and positive health. The chi-square test showed no significant relationship between years of experience (p = 0.165) or professionals' background (p = 0.829) and previous knowledge of self-management support. The second feedback questionnaire, which assessed behavioural levels after three months, was completed by 17 participants. Gender and background remained comparable with the first round of feedback, with female respondents and mainly general practitioners or nurses as background.

Reaction to the learning materials and learning program

For the written learning materials (referred to as "text"), participants rated their experience on average as 5 out of 7 using the UEQ-S (Supplementary file 2). The interquartile range (IQR) of the dataset was 1. Relatively high scores were given to the level of support (Median (Med) = 5, IQR= 1.5), convenience (Med = 5, IQR = 2), clarity (Med = 5, IQR =2.5) and interest (Med = 5, IQR = 1). Opinions were mixed on the level of efficiency (Med = 4.5, IQR = 2), inventiveness (Med = 4, IQR = 2), novelty (Med = 4, IQR = 2) and excitement (Med = 4, IQR = 1). Similar results were found for the videos, but the scores were slightly higher. The median score for these visual learning materials was also 5 out of 7 for the UEQ-S (Supplementary file 2). The IQR of the dataset was 2. High scores were recorded for the level of support (Med = 6, IQR = 3), convenience (Med = 6, IQR = 2) and clarity (Med = 6, IQR = 2). There was a positive trend for level of interest (Med = 4, IQR = 1). Opinions were moderately divided on the level of efficiency (Med = 5, IQR = 2) and strongly divided on inventiveness (Med = 4, IQR = 4) and novelty (Med = 5, IQR = 4). The majority rated the level of excitement as rather neutral (Med = 4, IQR = 2). Finally, the podcasts were rated by the UEQ-S with a median score of 4 out of 7 (Supplementary file 2). The IQR of the dataset was 3. High scores were obtained for the level of support (Med = 5, IQR = 3), convenience (Med = 6, IQR = 2) and clarity (Med = 5, IQR = 1). There were different opinions on the level of interest (Med = 5, IQR = 5), inventiveness (Med = 4, IQR = 5) and novelty (Med = 4, IQR = 3). A slightly decreasing trend was observed in the level of efficiency (Med = 4.5, IQR = 2.5) and excitement (Med = 4, IQR = 4).

In terms of the learning program in general, the analysis of the modified blended learning questionnaire gave a mixed picture of participants' experiences (Supplementary file 3). More specifically, opinions on the perceived effort in getting through the program were strongly divided (statement 1). However, most participants (strongly) agreed that they were satisfied with the level of effort (45%). In contrast, opinions about the collaborative methods during the learning process were positive, with a large majority of participants (strongly) agreeing that they

were satisfied with the process of collaboration (59%) (statement 2). In addition, the quality of interaction between all parties involved was also reported as satisfactory by the majority of participants (64%) (statement 3). A mixed picture emerged regarding the use of blended learning technology (statement 4). Although the majority reported to be satisfied (54%), a few participants (strongly) disagreed that the blended technology encouraged them to learn independently (36%). The accessibility and availability of the learning program team was also rated positively by the majority (59%) (statement 5). Finally, opinions were divided on the willingness to recommend this learning program to others (statement 6).

Learning about self-management and self-management support

Learning outcomes were examined in the post-program questionnaire using statements and validations grouped into three main categories (Supplementary file 4): Relevance of the concepts, including the importance of the SILCQ fundamentals; Knowledge and understanding of the concepts, including being able to unravel misunderstandings; Transferability of knowledge. Medians and interquartile ranges are not presented for the levels of learning and behaviour because participants' responses to the 5-point Likert scale were remarkably homogeneous. Clear consensus and consistent agreement were observed, resulting in minimal variability between respondents.

Relevance. After participating in the learning program, healthcare professionals indicated that they recognised the importance of actively searching for ways to integrate disease and health into patients' daily lives or the importance of supporting patients' self-management (statements 7-8: 76% strongly agreed, 24% agreed). The relevance of the fundamentals of self-management support as described in the SILCQ-model was also widely recognised, with an emphasis on involving patients in decision making, listening to them and asking questions (validations 1-5: 30-65% important, 35-70% very important).

Knowledge. Participants in the MEnToSS intervention indicated that the learning program contributed significantly to their knowledge (statement 19: 52% agreed, 14% strongly agreed). Also, a significant percentage of participants reported having a good understanding of the concepts, with the vast majority agreeing that they know what self-management is, what self-management support is and what the SILCQ fundamentals are (statements 9, 11, 18: 48-76% agreed, 19-24% strongly agreed). This knowledge extended to insights into self-management and self-management support (statements 10 and 12: 76% agreed, 19% strongly agreed). Misunderstanding and misconceptions about self-management (support) were effectively debunked, with high percentages disagreeing or strongly disagreeing (statements 20, 21, 23 and 25), or agreeing or strongly agreeing in the reversed statements (22 and 24).

Transferability. Participants expressed confidence in applying and communicating their knowledge of self-management and self-management support (statements 13, 15-17: 62-76% agreed, 19-24% strongly agreed). They reported a good ability to provide examples from healthcare practice and to articulate specific ways in which they could contribute to self-management support.

Behaviour related to self-management support in practice

Three months after the MEnToSS learning program, the majority of respondents in the second questionnaire indicated that they were able to actively search for ways to integrate disease and health into their patients' daily lives, referring to supporting self-management (statement 26: 82% agreed). In this supportive process, the majority of participants indicated that they were aware of their patients' social environment (statement 27: 24% were neutral, 75% agreed). Most of them also reported being able to cooperate with this social environment (statement 28: 35% were neutral, 65% agreed). In addition to the informal network, professionals reported having knowledge of the formal health and welfare network around their patients (statement 29: 66% agreed). Collaboration with this network was reported to be more moderate (statement 30: 29% were neutral, 59% agreed).

The five specific self-management support behaviours from the SILCQ-model were also examined. Participants reported being able to provide patients with practical tools, resources and information in addition to medical support (statement 31: 76% agreed, 18% strongly agreed). They also reported being able to make care-related choices together with their patients (statement 32: 76% agreed). Furthermore, respondents indicated they could offer a listening ear in healthcare practice (statement 33: 41% agreed, 53% strongly agreed) and play an active role in coordinating care (statement 34: 76% agreed). Finally, they reported having the skills to actively ask their patients questions about what is going well, what is not going well and what their needs are (statement 35: 65% agreed, 29% strongly agreed). The behavioural results are represented in the appendices (Supplementary file 5).

2. Qualitative user feedback

All 50 participants who had completed the MEnToSS intervention provided oral feedback in the structured group discussions at the beginning of the concluding workshop. The intervention received mostly positive responses, with ratings influenced not only by the background of participants, but also by their personality traits, as everyone preferred different learning strategies and methods. The intervention's emphasis on the person behind the patient was highly appreciated.

"The trajectory provides a fresh perspective, and I have gained more attention [for self-management support]." – Medical secretary
"I have learned to actively listen, observe the whole person, and not just the complaint." – GP

However, participants with prior knowledge expressed a desire for more profound insights due to overlap with other learning programs. Nevertheless, participants indicated that the MEnToSS learning program added value on several levels. The flexible format of self-study through videos, podcasts and text was seen as a major strength. In particular, the flexibility of self-study allowed participants to progress at their own pace with the learning material that was most appropriate for each individual. As a result, participants indicated that the learning program provided a deeper understanding of the concept of self-management support and its fundamentals (i.e., SILCQ-model). However, the extensive platform also posed challenges, with participants calling for a stronger storyline, more structure and more case-based learning content.

"I open the platform, but if you only have a quarter of an hour, it is not structured enough to motivate you." – GP

With regard to the learning materials, participants praised the usability and clarity of the podcasts, as well as the short and concise videos, which facilitated independent learning. A minority of participants found the videos too academic and the podcasts boring. To address this, participants suggested making summaries of these learning resources in advance. They wanted to know in advance what would be covered in each video or podcast to assess its relevance, and they also recommended shortening the length of podcast discussions for greater engagement.

"I found the videos concise and, therefore, useful." – Nurse

The breakdown of self-management support in healthcare practice into five actions, referring to the SILCQ fundamentals, received positive feedback for its simplicity and clear structure. In addition, the assignments on these SILCQ actions, as part of the learning program, were well received. This short, powerful reflection after going through one or more learning materials was perceived as valuable.

"Breaking down the consultation into 5 actions makes it clear and manageable." – GP

Finally, participants recognised that navigating through the learning program in such an accessible way increased their awareness of the concept and importance of self-management support. The inclusion of take-home messages was described as a possible beneficial added value in the future.

"This intervention opens our eyes to the importance of focusing on these concepts (self-management, self-management support, etc.)" – Nurse

Discussion

This study aimed to investigate how a blended learning intervention, the MEnToSS intervention, influenced healthcare professionals' reaction, learning and behaviour towards self-management support in primary care practice. At the reaction level (level 1), participants responded generally positive to the innovative approach of the educational program and recognised the importance of self-management support. The reaction was found to be dependent on several factors, including the learning materials consulted, the participant's prior knowledge and individual learning style preferences. In general, watching the videos seemed more appealing and, based on the scores, was slightly better received than the other learning materials. Listening to podcasts, in turn, was described as a considerable effort, although those with prior knowledge found them a valuable addition and found more depth in them. This variability highlights the importance of providing varied learning materials and individually tailoring educational interventions to reach and satisfy a wide range of participants(25). At learning level (level 2), results showed a good understanding of the concept of self-management (support). In addition, the SILCQ-model seemed well understood and was described as a useful tool to reflect on self-management support in practice. At behavioural level (level 3), participants' confidence to apply the acquired knowledge in their healthcare practice were generally positive. Notably, comparisons between the levels of reaction, learning and behaviour reveals interesting patterns. While the majority had a positive response to the learning program and a good understanding of self-management support, responses on knowledge transfer to behaviour in practice showed variation, indicating a possible gap between theoretical knowledge and practical application. Future context analysis should focus on the mechanisms of knowledge transfer to gain deeper insights.

The results of our study are consistent with the conclusion of the systematic review by Collins et al (2021), which examined the impact of primary care professional education on patient self-management in chronic diseases(18). Although our study did not directly assess the impact on patients, we also evaluated a professional education program on self-management support. Similar findings emerge, highlighting the critical need for high quality research to investigate the optimal methods and conditions for training primary care professionals. This reinforces our study's emphasis on nuanced educational approaches. Our learning program differs from previous interventions by using both asynchronous and synchronous learning approaches. We use a variety of learning materials and organise an interactive workshop in a real-life environment. This strategy has been shown to be effective and is in line with the findings of other studies, which show that interactive learning is effective because it reflects the challenges of

real-life situations. It promotes deep learning and intrinsic motivation and can potentially bridge the gap between theory and practice(26). Furthermore, our use of asynchronous components facilitated flexible learning and met participants' preferences for learning at their own pace and independent of location. The blended strategy benefits from flexibility and self-directed learning and is in line with successful healthcare educational programs that focus on tailored, engaging approaches(25). The variety of learning materials in our program, including both audio, visual and written materials, improved accessibility and engagement. According to the literature, offering different options accommodate different learning styles, making interventions more inclusive and appealing to a wider audience(27).

Some limitations should be mentioned. First, the use of self-reported outcomes limits the scope of information, preventing a direct translation of findings into practical implications. However, this strategy focuses specifically on the perspectives and experiences of professionals in supporting self-management. Understanding professionals' perceptions is integral to improving patient self-management support and highlights the importance of their voices in shaping interventions. Secondly, there was no pre-program assessment, which meant that baseline knowledge or behaviour prior to the intervention was not measured. In our case, the decision not to conduct a pre-test was based on the results of an extensive literature review(28), which provided an overview of previous self-management support interventions worldwide. This analysis revealed that our intervention introduced novel approaches and content to self-management support. Consequently, participants' prior knowledge was likely to be minimal to non-existent, making a pre-test insufficiently justified. In addition, our primary focus was on evaluating the impact of the intervention on real-world outcomes, rather than comparing and measuring improvements in participants' skills or competencies. In addition, our study encountered a limitation in that we could not use solely standardised questionnaires for evaluation. Given the unique focus on SILCQ, a self-developed model, there were no existing validated customised questionnaires for this purpose. However, we addressed this limitation by using a combination of standardised questions and self-developed measures, with minimal modifications. Furthermore, it's also worth noting that our evaluation focused primarily on assessing knowledge acquisition and its appropriation, while behavioural analysis is still in its early stages. Future research should aim to delve deeper into behavioural change in order to draw more robust conclusions about the impact of the intervention. Finally, it should be noted that the study may be subject to selection bias, as only a small subset of participants who had completed the intervention provided feedback in the questionnaires.

Above limitations highlight the need for cautious interpretation and point to areas for improvement for future evaluations. Therefore, we recommend examining our learning intervention over a longer period of time, with a larger sample size and a more comprehensive behavioural analysis. In addition, future research should explore the nuances of implementation in different primary care contexts to refine and tailor recommendations for maximum impact. Finally, we recommend that future research should go beyond measuring effects on professionals' self-management support behaviour. It would be valuable to assess the direct effect of our educational intervention in clinical practice by examining how the intervention affects patients' self-management outcomes. This extension would provide more insight into the wider effects of the intervention and underline its value in practice.

Conclusions

The MEnToSS intervention not only generated generally positive feedback and seemed to promote knowledge acquisition, but also participants perceived the intervention as an opportunity to critically reflect on and more effectively apply the learning to real-life situations in healthcare settings. The success highlights the power of interactive educational programs not only to deliver information, but also to trigger truly transformative learning experiences. As a result, the use of the blended learning approach, with its flexibility and interactive components, suggests that there may be greater awareness of the concept of self-management support among healthcare professionals. This makes the intervention a promising step towards continuous improvement of self-management support in healthcare.

References

1. Kuluski K, Ho JW, Hans PK, La Nelson M. Community care for people with complex care needs: Bridging the gap between health and social care. Int J Integr Care. 2017 Jul 1;17(4):2.
2. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. Lancet. 2012 Jul 7;380(9836):37–43.
3. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
4. WHO. WHO global strategy on integrated people-centred health services 2016-2026. 2015;
5. KCE. Performance of the Belgian health system – report 2019 [Internet]. [cited 2021 Mar 31]. Available from: https://www.riziv.fgov.be/fr/statistiques/soinsdesante/2017/Pages/nombre-dispensateurs-soins-
6. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7.
7. Panagioti M, Richardson G, Small N, Murray E, Rogers A, Kennedy A, et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: A systematic review and meta-analysis. BMC Health Serv Res. 2014 Dec 27;14(1):356.
8. Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. PLoS One. 2019;14(8):e0220116.
9. Alvarez C, Greene J, Hibbard J, Overton V. The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. BMC Health Serv Res. 2016 Mar 11;16(1):85.
10. McGowan P. The challenge of integrating self-management support into clinical settings. Can J diabetes. 2013 Feb 1;37(1):45–50.
11. Flanagan S, Damery S, Combes G. The effectiveness of integrated care interventions in improving patient quality of life (QoL) for patients with chronic conditions. An overview of the systematic review evidence. Health Qual Life Outcomes. 2017 Sep;15(1):188.
12. Lake AJ, Staiger PK. Seeking the views of health professionals on translating chronic disease self-management models into practice. Patient Educ Couns. 2010 Apr;79(1):62–8.
13. Michie S, Atkins L, West R. The Behaviour Change Wheel - A Guide To Designing Interventions [Internet]. London: Silverback Publishing; 2014 [cited 2023 Apr 16]. Available from: http://www.behaviourchangewheel.com/
14. Vallee A, Blacher J, Cariou A, Sorbets E. Blended Learning Compared to Traditional Learning in Medical Education: Systematic Review and Meta-Analysis. J Med Internet Res. 2020 Aug 1;22(8):e16504.
15. Lockey A, Bland A, Stephenson J, Bray J, Astin F. Blended Learning in Health Care Education: An Overview and Overarching Meta-analysis of Systematic Reviews. J Contin Educ Health Prof. 2022;42(4):256–64.
16. MacNeill H, Masters K, Nemethy K, Correia R. Online learning in Health Professions Education. Part 1: Teaching and learning in online environments: AMEE Guide No. 161. In: Medical Teacher. Taylor & Francis; 2023. p. 1–14.
17. Sahu PK, Dalcik H, Dalcik C, Gupta MM, Chattu VK, Umakanthan S. Best practices for effective implementation of online teaching and learning in medical and health professions education: during COVID-19 and beyond. AIMS Public Heal. 2022;9(2):292.
18. Collins C, Doran G, Patton P, Fitzgerald R, Rochfort A. Does education of primary care professionals promote patient self-management and improve outcomes in chronic disease? An updated systematic review. BJGP open. 2021 Jun 1;5(3):1–9.
19. Phillips WR, Sturgiss E, Glasziou P, Hartman TC olde, Orkin AM, Prathivadi P, et al. Improving the Reporting of Primary Care Research: Consensus Reporting Items for Studies in Primary Care—the CRISP Statement. Ann Fam Med. 2023 Oct 3;21(6):3029.
20. Iglesias FH, Celada CA, Navarro CB, Morales LP, Visus NA, Valverde CC, et al. Complex care needs in multiple chronic conditions: Population prevalence and characterization in primary care. A study protocol. Int J Integr Care. 2018;18(2):16.
21. Horton W. e-Learning by Design [Internet]. 2012 [cited 2023 Apr 27]. Available from: https://books.google.de/books?hl=en&lr=&id=3EXIYh-2TXYC&oi=fnd&pg=PA1&ots=BOZb-ZxNwW&sig=xPP7DlyKh_54iVUX6ErhVajnXxw&redir_esc=y#v=onepage&q&f=false
22. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implement Sci. 2011 Apr 23;6(1):1–12.
23. Naaj MA, Nachouki M, Ankit A. Evaluating student satisfaction with blended learning in a gender-segregated environment. J Inf Technol Educ. 2012;11(1):185–200.

24. Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, et al. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022;23(1):1–13.
25. Baker R, Camosso-Stefinovic J, Gillies C, Shaw EJ, Cheater F, Flottorp S, et al. Tailored interventions to address determinants of practice. Cochrane Database Syst Rev. 2015 Apr 29;2015(4):CD005470.
26. Alrehaili EA, Al Osman H. A virtual reality role-playing serious game for experiential learning. Interact Learn Environ. 2022;30(5):922–35.
27. Naveed QN, Qureshi MRN, Alsayed AO, Muhammad AH, Sanober S, Shah A. Prioritizing barriers of E-Learning for effective teaching-learning using fuzzy analytic hierarchy process (FAHP). 4th IEEE Int Conf Eng Technol Appl Sci ICETAS 2017. 2018 Jul 2;2018-Janua:1–8.
28. Timmermans L, Golder E, Decat P, Foulon V, Van Hecke A, Schoenmakers B. Characteristics of self-management support (SMS) interventions and their impact on quality of life (QoL) in adults with chronic diseases: an umbrella review of systematic reviews. Health Policy (New York). 2023 Jul 25;135:104880.

Appendix Chapter 7

Supplementary file 1: CRISP reporting checklist

No.	Reporting Item (Not all items apply to all study designs.)	Included Y	N	NA	Section	Notes
1.	**Include "primary care" and/or discipline-specific terms in the title, abstract, and/or key words.**	☒	☐	☐	I	
2.	**Describe the study rationale and importance for primary care.**					
2a.	Explain the rationale for the research question and how it relates to primary care.	☒	☐	☐	I	
2b.	Describe the importance or relevance of the topic under study in the primary care setting.	☒	☐	☐	I	
2c.	Identify any theory, model, or framework used, and explain why it is appropriate to the research question in primary care.	☒	☐	☐	I	
3.	**Describe the research team's primary care experience and collaboration.**					
3a.	Describe the research team's expertise and experience in primary care practice and/or research.	☒	☐	☐	M	
3b.	Describe whether and how primary care patients, practicing clinicians, community members, or other stakeholders were involved in the research process.	☒	☐	☐	M	
4.	**Describe the study participants and populations in the context of primary care.**					
4a.	Use person-focused language to refer to the research populations and participants, or use terms based on patient preferences.	☒	☐	☐	R	
4b.	If reporting personal characteristics of participants, report the source of the data, the rationale for using it, and the rationale for any classifications used.	☐	☐	☒	R	
4c.	Describe the participants and populations in sufficient detail to allow comparison to other primary care patient populations.	☒	☐	☐	R	
4d.	Specify whether participants have preexisting therapeutic relationships with the clinical team or are new patients.	☐	☐	☒	M, R	Participants are healthcare professionals.
5.	**Describe the conditions under study in the context of primary care.**					
5a.	Describe whether the condition under study is acute or chronic.	☒	☐	☐	M, R	
5b.	Report how multimorbidity is considered and how it might affect interpretation of the study findings/results.	☐	☐	☒	M	
6.	**Describe the clinical encounter under study in the context of primary care**					
6a.	Specify whether the study focus is an isolated clinical encounter or a longitudinal course of care. If it is an isolated clinical encounter, specify whether it is the first visit or a follow-up visit for the condition under study.	☒	☐	☐	M	
7.	**Describe the patient care team.**					
7a.	If care is delivered by teams, describe the team members and their roles.	☒	☐	☐	R	
7b.	For each clinician category, report profession, specialty, and qualifications.	☐	☒	☐	R	Information is not relevant in this small-scale pilot project.
8.	**Describe the study interventions in the context of primary care.**					
8a.	Describe interventions and their implementation in sufficient detail to enable the reader to assess applicability in their own setting.	☒	☐	☐	M	
8b.	Describe any clustering or grouping of patients, participants, clinicians, teams, or practices, and how it was addressed in the analysis.	☒	☐	☐	M, R	
8c.	Describe the health care system in sufficient detail to allow comparisons to other systems.	☐	☒	☐	I, D	No impact of system on intervention delivery
9.	**Describe study measures used and their relevance to primary care.**					
9a.	Report whether study measurement tools have been validated in primary care populations or settings.	☒	☐	☐	M	
9b.	Describe how the measurement tools used are meaningful to primary care patients and their care.	☒	☐	☐	M	
9c.	Report findings/results to be clinically interpretable by primary care clinicians and patients.	☒	☐	☐	R	
10.	**Discuss the meaning of study findings/results in the context of primary care.**					
10a.	Discuss implications of the study findings/results for research, patient care, education, and policy with specific focus on primary care.	☒	☐	☐	D	
10b.	Discuss the implications of study recommendations on demands and priorities in primary care practice.	☒	☐	☐	D	
10c.	Comment on any research processes that might influence the applicability of the study findings/results in diverse primary care settings.	☒	☐	☐	D	

CRISP = Consensus Reporting Items for Studies in Primary Care;
D = discussion; I = introduction; M = methods; N = no; NA = not applicable, R = results; Y = yes.

Supplementary file 2: Reaction outcomes (modified UEQ-S)

Text is	1	2	3	4	5	6	7	Median (IQR)
Obstructive/supportive	0 (0 %)	0 (0 %)	2 (10 %)	3 (15 %)	7 (35 %)	6 (30 %)	2 (10 %)	**5 (1.5)**
Complicated/easy	0 (0 %)	1 (5 %)	2 (10 %)	4 (20 %)	5 (25 %)	7 (35 %)	1 (5 %)	**5 (2)**
Inefficient/efficient	1 (5 %)	1 (5 %)	4 (20 %)	4 (20 %)	6 (30 %)	3 (15 %)	1 (5 %)	**4.5 (2)**
Confusing/clear	0 (0 %)	0 (0 %)	3 (15 %)	4 (20 %)	5 (25 %)	3 (15 %)	5 (25 %)	**5 (2.5)**
Boring/exciting	2 (10 %)	0 (0 %)	4 (20 %)	12 (60 %)	0 (0 %)	1 (5 %)	1 (5 %)	**4 (1)**
Not interesting/interesting	1 (5 %)	1 (5 %)	2 (10 %)	5 (25 %)	7 (35 %)	2 (10 %)	2 (10 %)	**5 (1)**
Conventional/inventive	2 (10 %)	1 (5 %)	4 (20 %)	5 (25 %)	7 (35 %)	0 (0 %)	1 (5 %)	**4 (2)**
Usual/leading edge	3 (15 %)	1 (5 %)	2 (10 %)	5 (25 %)	7 (35 %)	0 (0 %)	2 (10 %)	**4 (2)**

Left Column: Categories from the Short version of the User Experience Questionnaire (UEQ-S)
Obstructive/Supportive, Complicated/Easy, Inefficient/Efficient, Confusing/Clear, Boring/Exciting, Not Interesting/Interesting, Conventional/Inventive, Usual/Leading Edge
Top Row: Participants' rating (1-7) for written learning materials
Cells: Absolute counts with corresponding percentages in parentheses for each rating
Data is reported as medians and interquartile ranges (IQR)

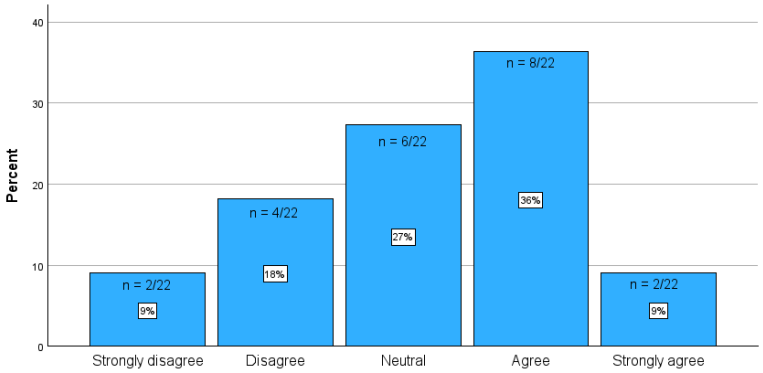
Videos are	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Median (IQR)**
Obstructive/supportive	0 (0 %)	1 (9.1 %)	0 (0 %)	2 (18.2 %)	2 (18.2 %)	3 (27.3 %)	3 (27.3 %)	**6 (3)**
Complicated/easy	0 (0 %)	0 (0 %)	0 (0 %)	1 (9.1 %)	2 (18.2 %)	5 (45.5 %)	3 (27.3 %)	**6 (2)**
Inefficient/efficient	2 (18.2 %)	0 (0 %)	0 (0 %)	1 (9.1 %)	3 (27.3 %)	3 (27.3 %)	2 (18.2 %)	**5 (2)**
Confusing/clear	0 (0 %)	0 (0 %)	0 (0 %)	2 (18.2 %)	1 (9.1 %)	4 (36.4 %)	4 (36.4 %)	**6 (2)**
Boring/exciting	2 (18.2 %)	1 (9.1 %)	1 (9.1 %)	5 (45.5 %)	2 (18.2 %)	0 (0 %)	0 (0 %)	**4 (2)**
Not interesting/interesting	2 (18.2 %)	0 (0 %)	0 (0 %)	4 (36.4 %)	4 (36.4 %)	1 (9.1 %)	0 (0 %)	**4 (1)**
Conventional/inventive	2 (18.2 %)	1 (9.1 %)	1 (9.1 %)	2 (18.2 %)	2 (18.2 %)	1 (9.1 %)	2 (18.2 %)	**4 (4)**
Usual/leading edge	2 (18.2 %)	1 (9.1 %)	1 (9.1 %)	1 (9.1 %)	3 (27.3 %)	1 (9.1 %)	2 (18.2 %)	**5 (4)**

Left Column: Categories from the Short version of the User Experience Questionnaire (UEQ-S)
Obstructive/Supportive, Complicated/Easy, Inefficient/Efficient, Confusing/Clear, Boring/Exciting, Not Interesting/Interesting, Conventional/Inventive, Usual/Leading Edge
Top Row: Participants' rating (1-7) for videos
Cells: Absolute counts with corresponding percentages in parentheses for each rating
Data is reported as medians and interquartile ranges (IQR)

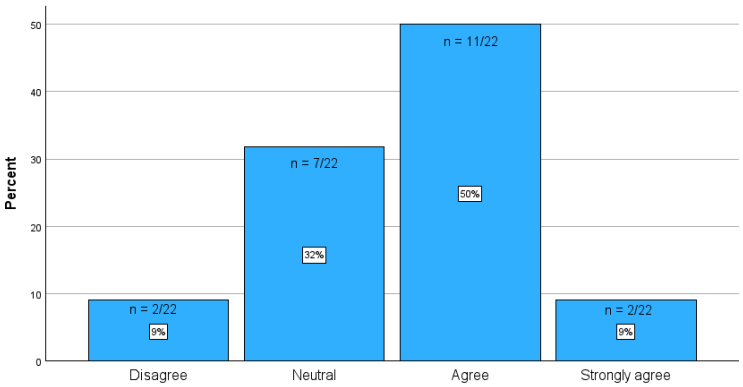
Podcasts are	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Median (IQR)**
Obstructive/supportive	2 (13.3 %)	0 (0 %)	0 (0 %)	5 (33.3 %)	1 (6.7 %)	3 (20 %)	4 (26.7 %)	**5 (3)**
Complicated/easy	0 (0 %)	1 (6.7 %)	0 (0 %)	2 (13.3 %)	5 (33.3 %)	3 (20 %)	4 (26.7 %)	**6 (2)**
Inefficient/efficient	3 (20 %)	1 (6.7 %)	1 (6.7 %)	3 (20 %)	4 (26.7 %)	2 (13.3 %)	1 (6.7 %)	**4.5 (2.5)**
Confusing/clear	0 (0 %)	1 (6.7 %)	0 (0 %)	2 (13.3 %)	5 (33.3 %)	5 (33.3 %)	2 (13.3 %)	**5 (1)**
Boring/exciting	4 (26.7 %)	0 (0 %)	3 (20 %)	4 (26.7 %)	2 (13.3 %)	1 (6.7 %)	1 (6.7 %)	**4 (4)**
Not interesting/interesting	4 (26.7 %)	1 (6.7 %)	0 (0 %)	2 (13.3 %)	3 (20 %)	4 (26.7 %)	1 (6.7 %)	**5 (5)**
Conventional/inventive	4 (26.7 %)	1 (6.7 %)	2 (13.3 %)	2 (13.3 %)	2 (13.3 %)	2 (13.3 %)	2 (13.3 %)	**4 (5)**
Usual/leading edge	3 (20 %)	1 (6.7 %)	2 (13.3 %)	5 (33.3 %)	1 (6.7 %)	1 (6.7 %)	2 (13.3 %)	**4 (3)**

Left Column: Categories from the Short version of the User Experience Questionnaire (UEQ-S)
Obstructive/Supportive, Complicated/Easy, Inefficient/Efficient, Confusing/Clear, Boring/Exciting, Not Interesting/Interesting, Conventional/Inventive, Usual/Leading Edge
Top Row: Participants' rating (1-7) for podcasts
Cells: Absolute counts with corresponding percentages in parentheses for each rating
Data is reported as medians and interquartile ranges (IQR)

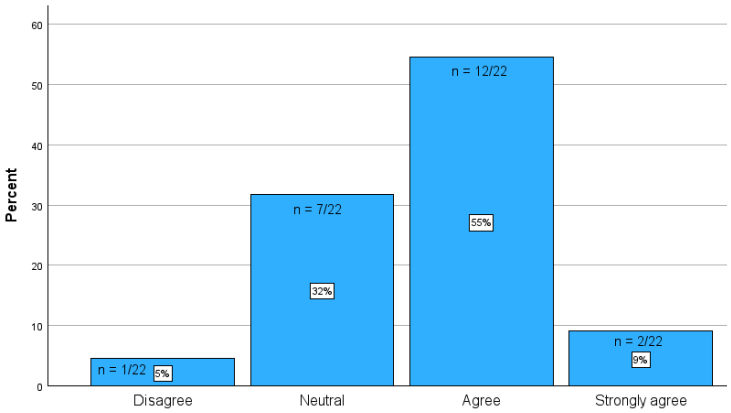
Supplementary file 3: reaction outcomes (modified blended learning questionnaire)



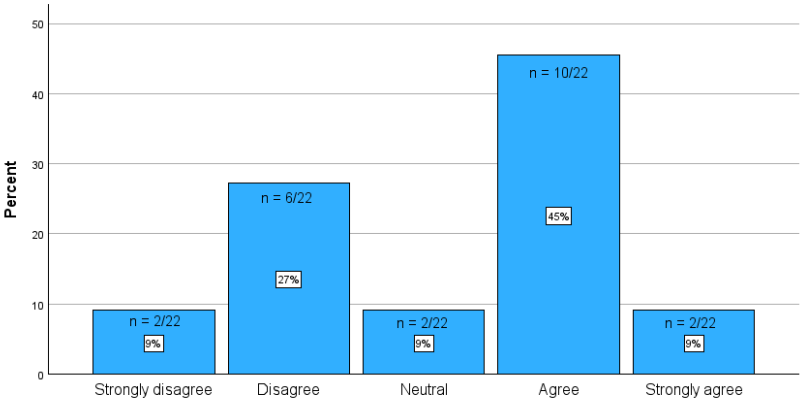
Statement 1: I am satisfied with the level of effort this learning program required.



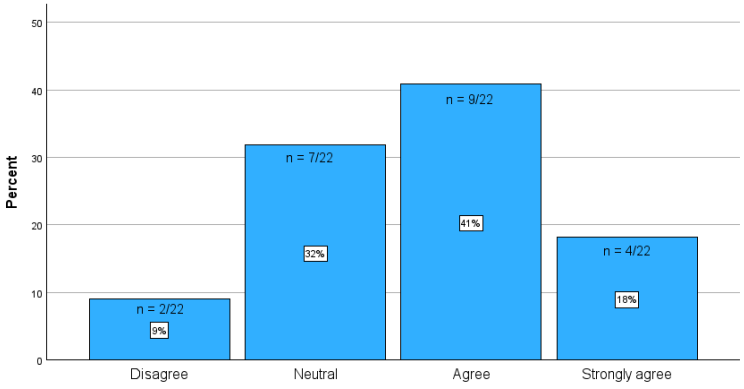
Statement 2: I am satisfied with the process of collaboration during the learning process.



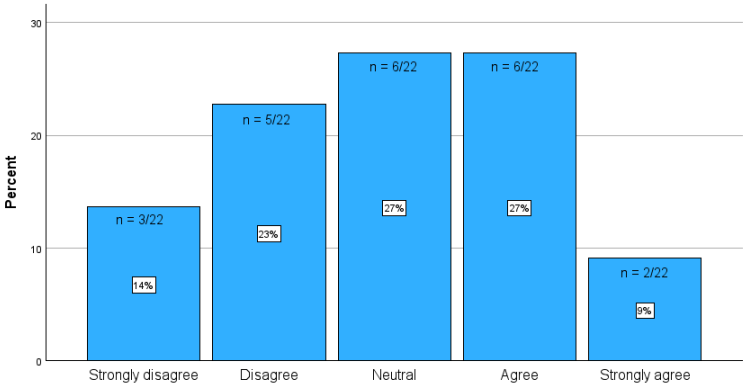
Statement 3: I am satisfied with the quality of interaction between all involved parties.



Statement 4: The use of blended learning technology in this learning program encourages me to learn independently.



Statement 5: I am satisfied with the accessibility and availability of the learning program team.



Statement 6: I am satisfied enough with this learning program to recommend it to others.

X-axis: Agreement Level (Strongly Disagree to Strongly Agree) for statements 1-6
Y-axis: Percentage
Bars represent the distribution of respondents' agreement levels, with percentages and absolute counts displayed on each bar for each of the six charts

Supplementary file 4: Learning outcomes

		Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
Relevance of the concepts	**Statement 7:** I find it important to search with my patients/clients for ways to give disease and health a place in their daily lives.	0 (0 %)	0 (0 %)	0 (0 %)	5 (24 %)	16 (76 %)
	Statement 8: I find it important to support self-management of my patients/clients.	0 (0 %)	0 (0 %)	0 (0 %)	5 (24 %)	16 (76 %)
		Very unimportant	**Unimportant**	**Neutral**	**Important**	**Very important**
	Validation 1: In addition to medical support, space must be made for the provision of practical tools, resources and exchange of information in healthcare practice.	0 (0 %)	0 (0 %)	2 (10 %)	10 (50 %)	8 (40 %)
	Validation 2: Care-related choices should be made together with patients/clients in healthcare practice.	0 (0 %)	0 (0 %)	0 (0%)	9 (45 %)	11 (55 %)
	Validation 3: In healthcare practice, space must be made for offering a listening ear.	0 (0 %)	0 (0 %)	0 (0 %)	9 (45 %)	11 (55 %)
	Validation 4: Healthcare professionals should take an active role to coordinate care around patients/clients.	0 (0 %)	0 (0 %)	0 (0 %)	13 (65 %)	7 (35 %)
	Validation 5: Care professionals should actively ask patients/clients about what is going well, what is not going well, and what their needs are.	0 (0 %)	0 (0 %)	0 (0 %)	6 (30 %)	14 (70 %)
Knowledge and understanding of the concepts		**Strongly disagree**	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
	Statement 9: I know what self-management is.	0 (0 %)	0 (0 %)	1 (5 %)	15 (71 %)	5 (24 %)
	Statement 10: I have insights into self-management.	0 (0 %)	0 (0 %)	1 (5 %)	16 (76 %)	4 (19 %)
	Statement 11: I know what self-management support is.	0 (0 %)	0 (0 %)	1 (5 %)	16 (76 %)	4 (19 %)
	Statement 12: I have insights into self-management support.	0 (0 %)	0 (0 %)	3 (15 %)	13 (65 %)	4 (20 %)
	Statement 14: I understand the importance of self-management support in healthcare practice.	0 (0 %)	0 (0 %)	0 (0 %)	11 (52 %)	10 (48 %)
	Statement 18: I have knowledge of the fundamentals of the SILCQ model.	0 (0 %)	0 (0 %)	7 (33 %)	10 (48 %)	4 (19 %)
	Statement 19: The learning program has strengthened my knowledge of self-management and self-management support.	0 (0 %)	3 (14 %)	4 (19 %)	11 (52 %)	3 (14 %)
	Statement 20: Every person is capable of engaging in self-management to some degree.	0 (0 %)	1 (5 %)	4 (19 %)	7 (33 %)	9 (43 %)
	Statement 21: Self-management is achieved in cooperation with your environment.	0 (0 %)	0 (0 %)	0 (0 %)	9 (43 %)	12 (57 %)
	Statement 22: Self-management is exclusively about "doing it yourself."	6 (29 %)	10 (48 %)	3 (14 %)	0 (0 %)	2 (10 %)
	Statement 23: Self-management goes beyond taking responsibility in medical care and treatment.	0 (0 %)	0 (0 %)	0 (0%)	13 (62 %)	8 (36 %)
	Statement 24: Self-management is an innate skill.	2 (10 %)	13 (62 %)	4 (19 %)	1 (5 %)	1 (5 %)
	Statement 25: It is the role of healthcare professionals to guide patients/clients to increase self-management.	0 (0 %)	0 (0 %)	2 (10 %)	11 (52 %)	8 (38 %)
Transferability of knowledge	**Statement 13:** I can illustrate self-management support with an example from healthcare practice.	0 (0 %)	0 (0 %)	2 (10 %)	13 (62 %)	6 (29 %)
	Statement 15: I know in what specific ways I can contribute to self-management support.	0 (0 %)	1 (5 %)	2 (10 %)	13 (62 %)	5 (24 %)
	Statement 16: I can explain to my environment what self-management is.	0 (0 %)	0 (0 %)	1 (5 %)	16 (76 %)	4 (19 %)
	Statement 17: I can explain to my environment what self-management support is.	0 (0 %)	0 (0 %)	2 (10 %)	15 (71 %)	4 (19 %)

Left Column: Statements 7 – 17 and Validations 1 – 5
Top Row (Statements): Agreement Levels (Strongly Disagree to Strongly Agree)
Top Row (Validations): Importance Levels (Very Unimportant to Very Important)
Cells: Absolute counts with percentages in parentheses representing respondents' distribution for each statement and validation

Supplementary file 5: Behavioural outcomes

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Statement 26: I can search with my patients/clients for ways to give disease and health a place in their daily lives.	0 (0 %)	0 (0 %)	1 (6 %)	14 (82 %)	2 (12 %)
Statement 27: I am aware of the social environment of my patients/clients.	0 (0 %)	0 (0 %)	4 (24 %)	13 (76 %)	0 (0 %)
Statement 28: I cooperate with the social environment of my patients/clients, subject to their approval.	0 (0 %)	0 (0 %)	6 (35 %)	11 (65 %)	0 (0 %)
Statement 29: I know which health and welfare professionals are involved in the care of my patients/clients.	0 (0 %)	0 (0 %)	1 (6 %)	15 (86 %)	1 (6 %)
Statement 30: I have contact with the other health and welfare professionals of my patients/clients.	0 (0 %)	0 (0 %)	5 (29 %)	10 (59 %)	2 (12 %)
Statement 31: In addition to medical support, I can also offer my patients/clients practical tools, resources and exchange information.	0 (0 %)	0 (0 %)	1 (6 %)	13 (76 %)	3 (18 %)
Statement 32: I am able to make care-related choices together with my patients/clients.	0 (0 %)	0 (0 %)	2 (12 %)	13 (76 %)	2 (12 %)
Statement 33: I am able to offer a listening ear to my patients/clients.	0 (0 %)	0 (0 %)	1 (6 %)	7 (41 %)	9 (53 %)
Statement 34: I am able to take an active role in coordinating care around my patients/clients.	0 (0 %)	0 (0 %)	2 (12 %)	13 (76 %)	2 (12 %)
Statement 35: I can actively ask my patients/clients questions about what is going well, what is not going well, and what their needs are.	0 (0 %)	0 (0 %)	1 (6 %)	11 (65 %)	5 (29 %)

Left Column: Statements 26 – 35
Top Row: Agreement Levels (Strongly Disagree to Strongly Agree)
Cells: Absolute counts with percentages in parentheses representing respondents' distribution for each statement and validation

General discussion

General discussion

The adoption of person-centred approaches, in which patients are actively involved, have triggered a fundamental shift in healthcare delivery(1). The support of self-management by healthcare professionals has become a vital part(54). Numerous interventions have been developed to promote self-management support and, as a result, improve patients' health and welfare outcomes(48,49). However, the uptake by professionals remains a challenge. There are several barriers to successful self-management support in healthcare practice, including lack of awareness and knowledge of the role of healthcare professionals, the traditional consultation model, lack of clear guidelines and models, and limited accessibility and applicability of supportive interventions(55–57). A thorough understanding of complex dynamics within this field is needed to improve the implementation of self-management support. In this thesis project, we therefore explored how we can guide healthcare professionals to support people with moderate complex care needs (referred to as 'chronic patients') to achieve adequate self-management by providing comprehensive insights and usable strategies for primary care practice. In this final chapter, we discuss our key findings, formulate recommendations and present methodological considerations.

Key findings

In the following pages, we elaborate on the key findings of our studies. An overview is presented in Figure 1.

Figure 1: Key findings self-management support in primary care practice

We begin by discussing the changing landscape of chronic healthcare (key finding 1). In addition, we address the challenges of the diversity of self-management support interventions (key finding 2). Next, we discuss the SILCQ-model for self-management support (key finding 3), before delving deeper into this concept as a collaborative approach (key finding 4). We then shift the focus on the need for behavioural change among healthcare professionals (key finding 5). Finally, we discuss the added value of a multidisciplinary educational intervention on delivering self-management support in primary care practice (key finding 6).

1. Changing chronic care landscape emphasizes patients' power

Through our research, we have gained a better understanding of the rapidly evolving landscape of chronic healthcare. Previously focused on medical treatment, we now see a shift towards a more biopsychosocial model that focuses on collaboration with the patient, referring to the concept of self-management. This concept was explored in depth in our review to better understand its characteristics and effectiveness (Chapter one). We identified a variety of support interventions for chronic patients with a mixed picture of their impact. The diversity of interventions not only reflects a dynamic healthcare landscape, but also emphasises the power of the patient in their own care process. Building on this understanding, we explored in our next step the concept of self-management support from the patient's perspective (Chapters two and three). We found that patients increasingly value autonomy, in which they themselves actively participate in their care process. Chronic patients seek activities that give them a sense of fulfilment, and our interviews illustrated the growing demand for self-management support and person-centred care in modern healthcare systems. To highlight the other side of the story, we then looked at the changing landscape of chronic care through the eyes of healthcare professionals (Chapter four). Discussions with professionals showed that they too were moving with these changes. We learned that healthcare professionals must now provide a coordinated and holistic approach, with patients taking a more active role in their own care process. New models that differ from traditional approaches need to be embraced. In addition, challenges of implementing these changes were revealed, with potential resistance in practice and the need for education of healthcare professionals (Chapter six). Also, professionals indicated that these challenges are forcing them to be more innovative and flexible in their approach to care. It requires rethinking of structures and practices to make healthcare more responsive to the changing needs of chronic healthcare, while focusing on supporting self-management.

Our findings confirm previous research indicating a dynamic phase of transformation in chronic healthcare(58). These changes are driven by the ongoing development of various initiatives with the aim of improving quality of care while focusing on the person behind the patient(59,60). The evolutions reflect a shared ambition to improve modern healthcare systems(61), shifting the emphasis from a traditional medically-oriented model to a more emotionally and socially oriented care approach(62). Such a holistic approach to care emphasises that patient wellbeing is not limited to purely medical treatment(63). In a changing chronic care environment, joining forces and promoting research that works closely with healthcare stakeholders is a crucial step in increasing quality of care(64). Moreover, a shift towards active participation has been observed, with patients increasingly involved in research(65). In line with our findings, patients

value maintaining their independence, making their own decisions and having the freedom to engage in meaningful activities(66). This highlights the increasing emphasis on self-management in modern healthcare, where patients are active participants in their healthcare process. More specifically, our findings reflect a shift towards shared responsibility as an essential element of the changing healthcare landscape(67,68). Our identified barriers and enabling factors to self-management support highlight the complexity of this transition and stress the crucial role of healthcare professionals in this process. However, as we move towards more person-centred care with a focus on self-management support, it is essential to involve and engage all the actors in care(69). Therefore, our dyadic interview study focused on the role of informal caregivers in the chronic care network, reflecting the broader literature on redefining informal caregivers as partners(70). For these reasons, the further development of care practices requires an ongoing effort to realise healthcare that puts patients and their needs at the centre, with all stakeholders actively contributing to the changing landscape of chronic healthcare.

2. The diversity of support interventions introduces challenges in chronic care

In the context of developing new care practices, the heterogeneity of self-management interventions is evidence of a dynamic healthcare landscape. A review of these interventions revealed a wide range of approaches and methods used to promote patient self-management (Chapter 1). However, as well as providing opportunities, this diversity also has limitations, as it is not possible to compare interventions or draw firm conclusions about the most effective interventions within this wide range. Nevertheless, the review highlighted the wealth of approaches to supporting patient self-management and provided evidence that there is no 'one size fits all' approach. This finding inspired the next steps in our research project, where we deliberately chose to involve all stakeholders in the healthcare network in order to develop the best possible intervention that would appeal to a wide audience.

Our review highlighted a number of concerns. These findings are consistent with previous research. Most of these relate to the integration of evidence into healthcare practice. One concern is that many interventions are underreported in literature. This was also explicitly mentioned in a previous review aimed at providing an overview of integrated care interventions, of which self-management support is a component(32). In addition, follow-up information often seems to be missing, which calls into question the sustainability of the positive effects achieved(71). Quality remains important, as some interventions lack methodological rigor. The fact that only a minority of the included studies rely on a theoretical framework highlights the need to strengthen the scientific underpinnings of self-management support interventions(72).

In addition, the ongoing development of numerous initiatives points to a challenge within the chronic healthcare landscape, namely the lack of overview and applicability(73). This highlights the need to synthetize information and research, with the ultimate goal of drawing informed conclusions and providing practical recommendations(74). However, the fact that such a variety of approaches and tools have been developed in recent years illustrates creativeness and innovation in healthcare(59). In addition, the diversity and variability of interventions highlights the need to focus on personalized approaches when developing and implementing new interventions. This should take into account both the individual patient and the healthcare context(75). To create synergy, research needs to be synthesized and collaboration needs to be encouraged.

3. The SILCQ-model emerges as a comprehensive framework for self-management support

In the search for synergy, literature analysis identified the need for a comprehensive approach to self-management support, achieved through co-creation. We therefore conducted semi-structured interviews with chronic patients and their informal caregivers (Chapters two and three). By exploring their needs and experiences, we were able to identify and formulate concepts to describe the key features of self-management support. Specifically, we learned that five fundamental roles for healthcare professionals - Supporting, Involving, Listening, Coordinating and Questioning (SILCQ) – are essential for engaging chronic patients in their own care, referring to self-management. These roles have given rise to our SILCQ-model. The model creates clarity and simplicity compared to other interpretation-sensitive models, which is crucial for finding a common language and breaking down barriers. Despite existing practices and training, SILCQ emphasises the need to get all healthcare actors on the same page so that they can work together to support self-management. Reflecting on actions in practice within the SILCQ-model constitutes peer supervision and provides a basis or starting point for using specific tools, resources and interventions to support self-management. The model was further refined following discussions with healthcare professionals in focus groups (Chapter four). Through co-creation, the SILCQ-model was enriched with additional input from patients, informal caregivers, health and welfare professionals and representatives of healthcare organisations (Chapter five). This extension builds on the principle of co-creation, where different stakeholders work together to refine the model and develop practical applications. While there may not be a 'definitive model', the SILCQ-model continues to evolve and adapt to ongoing input from different stakeholders.

This process of co-creation is essential because, in line with the dynamic changes in modern healthcare towards more collaborative approaches, it includes valuable input from both patients and healthcare professionals(64). The SILCQ-model therefore emphasizes the importance of mutual engagement and collaboration rather than a unilateral approach(76). It shows that self-management is a shared responsibility and that both patients and professionals need to contribute actively(26). Furthermore, our model emphasises the need for a support system from primary healthcare professionals for chronic patients, as self-management often depends on the availability and effectiveness of this supportive environment(29). In addition, the model adds value to existing frameworks and models of self-management support, which are sometimes too complex, vague or theoretical and often do not take into account the input of end-users (i.e., patients, formal and informal caregivers). As a result, the implementation in practice is challenging. The comprehensiveness of our model can also be seen in the explicit addition of the letters 'Q' and 'C'. More specifically, the 'Q' component accentuates the questioning aspect of support. This is important because listening and questioning are two different activities that in practice are often separate actions and unfortunately often taken for granted(77). In addition, the model emphasizes the act of coordination ('C'), which is essential in the context of chronic care, where several health professionals are usually involved(78). A notable feature of the SILCQ-model is its focus on the emotional and social aspects of self-management support in addition to the medical aspect. Our model confirms that care is more than just medical interventions and emphasises the importance of emotional and social support in self-management supportive processes(19). In addition, the SILCQ-model acts as a connecting framework, making links with other models of care such as goal-oriented care, interprofessional collaboration and shared decision-making. The potential for reinforcement and connection is invaluable for the profound anchoring of self-management support in practice. In summary, our SILCQ-model of self-management support provides a powerful framework that clearly defines the role of healthcare professionals in facilitating self-management. Through peer supervision, the model encourages self-reflection on the essential tasks of support, involvement, listening, care coordination and questioning. This provides a common language and understanding that enables care teams to work together more effectively and, after reflection, to implement specific tools or interventions to address identified challenges. In this way, the SILCQ-model promotes a proactive approach to self-management support, where patients' active contribution in the care process is facilitated by effective support from healthcare professionals.

4. Self-management support unfolds and integrates through a collaborative approach

This collaborative nature of self-management was emphasized in our umbrella review, which showed that a wide range of stakeholders are involved in the delivery of interventions (Chapter one). Patients in the dyadic interviews enriched these findings by highlighting the value of establishing a relationship with healthcare professionals to enable self-management of a chronic condition (Chapters two and three). This relationship is represented by the SILCQ-model, with each component reflecting an important aspect of collaboration and co-management between patients and healthcare professionals. Furthermore, participants in our focus group discussions also described the concept of self-management support as a collaborative approach, that is additionally person-centred and starts with dialogue (Chapter four). Suggestions for action to improve self-management support interactions between healthcare professionals and patients confirmed this collaborative nature (Chapter five).

Consistent with other studies, our findings emphasise that strengthening this relationship is an essential step in improving self-management support(33). However, it is important to stress that collaboration is not limited to formal healthcare professionals. Other actors in the patient's care network, such as peers and informal caregivers, also play a crucial role in self-management support(79). The complex nature of chronic care requires a comprehensive and well-coordinated team around the patient(78). Each patient is unique and this influences the nature and extent of involvement(24). There is no universal approach to self-management support and it is important to focus on the needs and preferences of the individual patient(75). Our SILCQ-model provides guidance for healthcare professionals to tailor self-management support to the individual patient. The model is not a practical tool, but rather a tool for self-reflection and awareness focussed on defining the ideal support based on the needs and wishes of the person behind the patient. In terms of implementation in practice, the SILCQ-model suggests five basic roles: supporting, involving, listening, coordinating and questioning. These roles serve as a guide for building an effective relationship with the patient, promoting mutual engagement and collaboration. The model places the patient at the centre of the care process, reinforces person-centred care and emphasises that effective self-management support requires a collaborative approach between the patient and their (in)formal network. It encourages discussion and co-creation between healthcare professionals, patients and their networks, which is essential for effective self-management support. Confusion about the terminology of self-management can give the impression that all responsibility lies with the patient(19). This misunderstanding may result in professionals minimising their role in promoting self-management. For this reason, our emphasis is on the importance of clear models, such as our SILCQ-model, to raise awareness of

what self-management support really entails and the roles of professionals in it. It opens the door to discussion and co-creation, where healthcare professionals, patients and their networks work together to achieve effective self-management support. As self-management requires the commitment and involvement of many, creating effective collaboration is a crucial step towards better chronic care(80). This collaborative approach unfolds when self-management support is put into practice.

5. Optimising professionals' behaviour is integral to effective self-management support

Our review findings and the insights from the interviews and focus groups highlighted the complexity of translating self-management support into practice (Chapters one, two, three and four). In this, we learned that there is a need for evidence-based, context-specific interventions to increase the uptake of support. We therefore organised nominal group brainstorming sessions to collect ideas for a theory-informed, contextually appropriate self-management support intervention in Flanders (Chapter five). Although many ideas emerged, we found that a significant number of interventions were not innovative. Despite promising results in small-scale pilot projects, most of these projects seemed to have stalled at some point in the past and did not fully deliver on their promises(81). The brainstorming sessions therefore revealed the important insight that there is a need to focus on why previous interventions were not sustainable and how to engage care professionals in new interventions in the long term. To answer this question, we must shift our attention to behaviour of healthcare professionals. The in-depth analysis of professionals' behaviour was the starting point for the development of a new, innovative intervention to support self-management in practice (Chapter six).

This intervention strategy is reinforced by findings in the literature. More specially, previous research indicates that to enable self-management, we need to look not only at what patients do, but also at what healthcare professionals do or how they behave(82,83). Therefore, behavioural analysis of healthcare professionals is essential(84,85). This analysis should be broader than a specific target group or care setting. It should include a holistic approach that includes professionals from different disciplines and care settings. The goal should be to cultivate a common mindset to actively support self-management. A paradigm shift is needed in healthcare, where self-management support is no longer seen as an additional effort, but as an integral part of care(86). Unfortunately, health professionals face challenges that make behaviour change challenging, ranging from habits and practices to lack of knowledge, motivation, appropriate resources and systematic approaches(42,87,88). Misunderstandings of terminology make it even more difficult to establish supportive behaviour(19,26). It is therefore crucial to explore

behavioural models that take these different barriers into account when analysing behaviour. In this perspective, models such as the Theory of Planned Behaviour (TPB) and the Self-Determination Theory (SDT) are particularly relevant(83,84). The focus of the TPB is on perceived behavioural control, subjective norms and attitude since these three are crucial for behavioural change(89). The SDT, on the other hand, targets intrinsic motivation and the role of autonomy, competence and relatedness in determining behaviour(90). In addition, the COM-B model addressing individuals' capacity, opportunity and motivation is of great value when analysing behaviour(91). In our research project, we deliberately chose to examine behaviour of professionals using this COM-B model as it can capture the challenges and factors influencing behaviour in the complex landscape of self-management support. This model provides a nuanced understanding and addresses not only habitual and practical aspects, but also issues such as knowledge, motivation, appropriate resources and systematic approaches, providing a holistic framework for our analysis(92).

6. Multidisciplinary education adds value to increase self-management support in practice

The need for new innovative interventions for self-management support in Flanders shifted our attention to healthcare professional's behaviour in healthcare practice. As a result, we conducted a behavioural analysis using the COM-B model and applied the Behaviour Change Wheel (BCW) framework to translate this analysis into the systematic development of a practical intervention (Chapter six). Using the BCW framework, we identified two potentially effective intervention functions: 'education' and 'enablement' of healthcare professionals. The intended outcome was to induce a shift in the behaviour of healthcare professionals, fostering increased adoption of self-management support practices. This, in turn, aimed to enhance the effectiveness of support provided, leading to improved health and quality of life outcomes for chronic patients. These two theoretical intervention functions of the BCW were translated into a practical intervention through the development and delivery of a blended educational program in multidisciplinary centres and community health centres. A comprehensive evaluation of the program showed encouraging results (Chapter seven). First, the blended strategy combining online education, real-life reflection and discussion opened up the conversation and suggested that there may be a greater awareness of the importance of self-management support. In addition, the reflective tasks appeared to contribute to participants' understanding of their practice, while the gaining knowledge of the concepts and their practical applications seemed to potentially enhance motivation to support self-management. Although the methods we chose did not allow for objective measurement of behavioural change in practice, our preliminary evaluation in which professionals reported self-perceived results regarding behaviour after

three months seemed promising. Specifically, participants described improved perceptions of self-management support and their actions in practice.

The value of integrating education to improve healthcare quality is well-established in the literature (93). Distinctively, our learning program deviates from previous self-management initiatives in healthcare in several ways. First, the educational aspect is innovative, as previous efforts have mainly focused on educating patients rather than healthcare professionals(94). In addition, the flexibility with which participants could assemble the content of the intervention is a strength, as a standard approach may not be suitable for different healthcare settings and professionals. Unlike many other educational programs, participants could choose from a variety of learning methods, including podcasts, videos and text-based materials. This approach fits well with the reality of healthcare, where there is no "one size fits all"(75). Another distinguishing feature is the foundation of this intervention, shaped by the voices of chronic patients (dyadic interviews) and reinforced by insights from healthcare professionals (focus groups) and other healthcare stakeholders (nominal group sessions). This approach ensured that the intervention matched the needs and challenges in primary healthcare practice more effective and efficient(64,80). Finally, the intervention's unique quality lies in its rigorous development, guided by an evidence-based framework. More specifically, the BCW provided us with a step-by-step approach in order to bridge the gap between theoretical knowledge on self-management support and its application in practice(92). Although we cannot make definitive statements about sustainability at this stage, the use of such well-informed methodologies significantly increases the likelihood of stronger and more sustainable interventions. However, behaviour change is a complex process that requires time and repetition, and long-term effects require further investigation(95). Nevertheless, we conclude that, based on the distinctive nature of our program compared to other self-management support initiatives, is that educating health professionals in multidisciplinary settings, as implemented in our blended learning intervention, is a promising approach and first step towards more self-management support in primary care practice.

Overview of recommendations

Based on the above key findings, we make recommendations on strengthening self-management support for research, practice and education in the next paragraphs. The integration of policy recommendations is organically woven into the proposed recommendations and is not presented separately. This provides a holistic perspective in which the policy dimension is seen as an inherent and inseparable part of efforts to improve self-management support.

Research

Supporting self-management is a complex, multi-behavioural and dynamic process. Before developing new interventions, there is a need for a more detailed operationalisation of the concepts of self-management and self-management support. The use of comprehensible basic models, such as the SILCQ-model, is very important here. Also, a crucial first step is to identify promising components from previous self-management support interventions and integrate them into new initiatives. This integration should not only be practice-oriented, but also have a thorough research-based approach to ensure impact and sustainability. Synthesising relevant studies, as demonstrated in our umbrella review, is essential to provide future researchers with a clear overview and the necessary context for further research efforts. It is important that future research does not just try to create a new synthesis, but rather builds on this existing knowledge base. When conducting research, it is also important to involve all stakeholders. This will help to develop tailored interventions, as a 'one size fits all' approach is not feasible. Future studies should aim to include diverse groups, including chronic patients with limited or no social networks, as well as informal caregivers. In particular, there is currently a lack of evidence-based recommendations for self-management support specifically tailored to the latter group. When developing interventions, researchers should use rigorous evidence-based methods to ensure quality when translating research into practice. Specific examples of useful methods in this context are the BCW or the MRC (Medical Research Council), which can both serve as a framework for integrating effective components into new interventions in healthcare practice. The BCW is suggested since we believe that rethinking and optimising interventions by linking them to behavioural interventions can be an important step towards sustainability. A particular focus of research could be to identify the most effective strategies for integrating behavioural interventions into existing self-management support. In addition, standardisation of self-management (support) terminology and measurement tools, with possibly the development of a fixed set of outcomes, are crucial for comparison and evaluation. The use of existing patients' measurement tools, such as the Patient Activation Measure (PAM), for self-management itself is well known, but there is currently no generic tool for measuring support by professionals. A

specific line of research could focus on identifying and improving measurement tools that can accurately capture the quality of support by professionals. In addition, reporting of interventions, including follow-up data, is essential to evaluate and improve their success. A specific area of research could focus on developing guidelines for standardised reporting of self-management support interventions. Finally, future research should focus on assessing quality of life (QoL) as an essential parameter for incorporating patient feedback. A specific research proposal could be to examine the validity and reliability of existing QoL measurement tools and adapt them for use in the specific domain of self-management support.

Practice

To seamlessly integrate self-management support into daily care practice, we propose strategies based on the understanding and application of the SILCQ-model. The SILCQ-model identifies five fundamental roles for healthcare professionals - Supporting, Involving, Listening, Coordinating and Questioning - that are critical for actively engaging chronic patients in their own care, or self-management. An essential step in this integration is the targeted training and education of healthcare professionals to understand and apply the SILCQ-model in daily practice. This integration can be further strengthened by incorporating the SILCQ-model into existing chronic care protocols and guidelines. For effective implementation of the SILCQ-model, we first propose a self-assessment by healthcare professionals to test their own behaviour against the principles of supporting, involving, listening, coordinating and questioning. The results of this self-assessment serve as a guide for identifying gaps and barriers in the application of the SILCQ-model. These barriers are seen as critical starting points for further improvement and are essential to raise awareness. It is important to look for existing tools and interventions that are specifically designed to address these identified gaps and barriers in practice. An equally important recommendation for practice is to raise awareness among professionals about the crucial role of informal caregivers. Here we suggest organising workshops and training sessions that promote collaboration between formal and informal caregivers. The implementation of communication protocols can facilitate the effective exchange of information between these groups. Furthermore, to promote an integrated collaborative approach, we encourage regular meetings between different care disciplines. In this context, it is crucial to underline the need for additional efforts to engage the social sector, including all welfare actors, as we have observed limited active participation. To make this more practically feasible, an online platform could be developed where different professionals on different care approaches, such as self-management support, could learn from each other through case studies and experiences. Establishing structured protocols for collaboration and

promoting interprofessional teams within healthcare institutions, where each team member has a specific role in self-management support, can also strengthen this interaction. Additionally, a fundamental change in recognising patients as active partners in the care process requires awareness raising and training for professionals. Developing and implementing awareness programs and incorporating training in patient-centred communication and shared decision-making into practice can contribute to this change. Regular evaluation moments with feedback from both healthcare professionals and patients are crucial to assess and continuously improve the implementation of self-management support. To encourage practices to successfully implement self-management support, we suggest sharing best practices and success stories to inspire other healthcare professionals to adopt similar approaches.

Education

To significantly improve education on self-management support, we are advocating a comprehensive approach based on our developed blended learning program for healthcare professionals, which has already been piloted with promising results. Strategically designed to support different learning styles, this educational program integrates online modules, interactive workshops and practical exercises. To ensure optimal use and effective transfer of knowledge, train-the-trainer sessions should be organised to empower educators and equip them with the necessary skills. It is important to recognise that the specific needs of healthcare professionals at different levels of training require a nuanced approach. We therefore suggest tailor-made modules for both undergraduate and postgraduate education. We also recommend that the self-management support cases used in educational programs be tailored to the specific level and context of the health professional (in training). This adaptation of case studies ensures that learning materials are more relevant and applicable to the different levels of education. It also contributes to a better transfer of knowledge and skills to daily healthcare practice. In addition to the use of our blended learning program, other educational content can be developed with the same intention to increase understanding of the concept of self-management support and to promote awareness among (future) healthcare professionals. All these learning materials should include the basic principles of the SILCQ-model and pay attention to its practical application. Notably, our approach goes beyond the classroom and emphasises the integration of educational content into daily practice. Collaboration between educational institutions and healthcare organisations is essential to embed learning in practice. Furthermore, it is recommended to promote collaborative learning environments that actively involve patients in educational initiatives. Incorporating patient perspectives into educational programs can provide a more holistic approach and ensure a comprehensive understanding among healthcare

professionals. Active engagement of healthcare professionals in discussion and reflection is central to our educational philosophy, which goes beyond traditional education. We advocate guided interprofessional supervision where discussions are guided by the principles of the SILCQ-model. Our research confirms the transformative potential of such interactive discussions, which act as a catalyst for behavioural change in healthcare professionals. In our commitment to sustainability, flexible learning pathways are essential to our educational interventions. We avoid a 'one size fits all' approach and offer adaptable learning pathways to ensure lasting educational impact.

Methodological considerations

This final discussion section provides a comprehensive overview of the methodological considerations in our thesis project. We address key aspects related to the population, intervention, outcomes and context of this research.

Population

First of all, it is important to note that the number of participants in the interviews, focus groups and other parts of the qualitative research was rather limited. However, our ultimate goal was to achieve saturation rather than a specific number of participants, which was achieved because we reached the point where no new information emerged each time. Also, there is a need for reflection on the decision to use the same sample for patient interviews. While this method ensures consistency in comparing different aspects of the study and facilitates participant engagement in the research process, it does result in a smaller pool of participants, potentially affecting the depth of the findings. Nevertheless, the validity of the findings has been strengthened through subsequent validation steps involving different stakeholders in the healthcare system. This iterative process ensures the robustness and representativeness of the conclusions. In addition, interviews were conducted with patients in the presence of their informal caregiver. This may raise some concerns about possible social desirability or power dynamics in the responses. However, we emphasise that informal caregivers added value by lowering the interview threshold and also provided valuable insights into self-management (support). Another notable limitation is that our sample of chronic patients may have consisted of the most accessible patients, which may have introduced some bias.

However, by following the definition of patients with complex care needs operationalised by Iglesias et al. (2018)(96) and adapted to include the most vulnerable patients[15], we aimed for diversity in complex care situations. In addition, we aimed to include the voices of the most vulnerable patients through professional representation in the focus groups, which allowed us to include insights from those who may not otherwise have been physically present. In addition, the relevance of our findings to the wider chronic patient population, particularly those with mild or severe psychiatric conditions, needs to be considered. Our initial interviews excluded psychiatric conditions due to specific data collection requirements. However, to gain insight into the applicability of our approach across the chronic patient spectrum, the SILCQ-model derived from our study was integrated into a learning program for healthcare professionals who also treat patients with psychiatric conditions. Discussions with participants in these programs revealed interesting insights, suggesting that the basic principles of the SILCQ-model have wider applicability and relevance beyond a specific subset of chronic patients. Also, another reflection to mention is that chronic patients were generally under-represented in the brainstorming sessions. This was a deliberate choice, as the focus at this stage was on co-creating an intervention with healthcare professionals rather than patients. In moving from patients to healthcare professionals, a notable additional limitation should be mentioned. Specifically, we observed that not all professional disciplines were involved in our learning intervention, despite our efforts to ensure broad representation, as our recruitment strategy included several multidisciplinary approaches (by contacting healthcare networks and patient organisations). GPs and nurses were strongly represented, but a wider involvement of social sector disciplines could have provided more holistic insights. However, we strongly believe in the concept of cross-fertilisation between disciplines, where one discipline can offer insights and ideas to another. We believe that this cross-fertilisation took place sufficiently, as evidenced by the survey results and the discussions at the final workshop of our learning program. Not only in our intervention, but also in the research project as a whole, we note an under-representation of certain research participants, particularly from mental health services. We believe that this is not so much due to a deficiency in our inclusion criteria, but rather to the individual willingness of participants to take part in frontline research, as we recruited widely among health and social care professionals. To increase the representation of participants, both patients and healthcare

[15] Chronic patients in the interviews had to meet all the following criteria: (1) aged 18 years or above, (2) suffering from a single severe chronic condition or two or more stable chronic conditions (defined as multimorbidity), and (3) receiving support from at least three primary healthcare disciplines, in addition to the support of an informal caregiver. To reach out for the vulnerable populations, the patients had to meet one of the following additional criteria: (1) taking four or more different medications related to their chronic condition(s), (2) demanding a higher need of care, (3) living in a low socio-economic situation, (4) estimated to have limited or low health literacy, or (5) tending to need more care according to at least one member of their primary care team(96).

professionals, we suggest targeted efforts such as outreach programs, targeted communication with relevant (patient) networks and organisations, and explicit emphasis on the importance of social care disciplines in supporting self-management. Identifying specific missing disciplines and patients and actively involving them in future research can increase the value of different perspectives.

Interventional strategies, frameworks and methodologies

Our research was shaped by the decisions we made regarding the formulation of our research questions and the selection of methods to answer these questions. These questions were designed to gain a comprehensive understanding of self-management support and the experiences of all those involved in the care process, guided by an exploration of the research area and the aim of filling knowledge gaps. In order to gather a wide range of perspectives, we used a variety of methods. These methods were deliberately chosen for their ability to elicit nuanced insights and broad perspectives. Through this methodological diversity, we aimed to gain a holistic understanding of self-management support, including its challenges and opportunities.

Our research methodology led to the SILCQ-model, the result of an iterative process which has its foundations from interviews with patients and their informal caregivers. A phenomenological approach enabled us to gain in-depth insights into the concept of self-management support. However, it is important to note that we start from our chosen definitions and concepts of chronic patients, self-management and self-management support. This influenced the interpretation of the phenomena we studied. In our case, our findings and conclusions were formed in the context of the Flemish health care system with a specific focus on chronic patients in the home environment. For the definition of self-management, we followed Barlow's holistic definition to get a comprehensive understanding from the interviews(21)[16]. After the interviews, the SILCQ preliminary model was further examined and strengthened through interactive focus groups with a diverse group of healthcare professionals. Additionally, the model underwent further discussion and refinement in brainstorming sessions with healthcare professionals, healthcare organisations and patients. This co-creative process resulted in a rich and contextually relevant framework. Despite the careful development of the SILCQ-model, some limitations must be acknowledged. The model remains at an abstract level and cannot be

[16] Self-management in chronic disease is defined as *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established"*(21)

directly translated into a practical tool. Instead, it acts as a conceptual tool for critical analysis of self-management support behaviour by healthcare professionals. It does not offer specific steps for daily use, but encourages peer supervision and identification of challenges in practice. While it provides insight and clarity, the simplicity of the model can be somewhat daunting for healthcare professionals challenged by complexity. These limitations highlight the importance of guidance and implementation in practice. In our case, the SILCQ-model served as the cornerstone of our intervention, a blended learning targeting healthcare professionals' behaviour. To bridge the gap between theory and practice, we opted for a pilot intervention design in multidisciplinary centres and community health centres. We deliberately chose not to conduct a pre-post study, as such an approach would not be justified given the lack of precedent for this type of intervention in the field of self-management support. Our primary focus was on evaluating the impact of the intervention on real outcomes in the field, rather than comparing participants' skills or competencies before and after the intervention. Therefore, we used Kirkpatrick's method to assess reaction, learning and behaviour targeted by the learning intervention. Finally, in the broader perspective of this doctoral research, we should emphasise that our research project is not an implementation study as the title might suggest. More specifically, our research project represents the essential first step towards the implementation of self-management support in healthcare practice. The first pilot study, using the Kirkpatrick model, provided (first) experiences into responses, learning effects and self-perceived behavioural change. An additional study should be designed to explore the effectiveness of the intervention. Observational studies can provide in-depth insights into the practical application of learned skills, while longitudinal studies and quasi-experimental designs can assess long-term effects and specific aspects of the intervention. This varied approach will provide a holistic understanding of behaviour change and integrates quantitative, qualitative and long-term outcomes. We emphasise the need for a step-by-step approach, with thorough evaluation and optimisation at each stage leading to sustainable implementation in the future.

Outcomes

Our review study initially focused on measuring QoL. However, this was not the main outcome of our intervention. Our blended learning focused on changing professionals' behaviour regarding self-management support. The rationale for choosing QoL in the review as an outcome to measure effectiveness of interventions was based on the desire to stay as close as possible to (the person behind) the patient. Therefore, we chose to capture the impact of self-management on patients' daily lives by using QoL as a valuable patient reported outcome throughout the patient's journey(97,98). Our choice was also further underpinned by the need to look beyond

medical outcomes, as self-management encompasses much more than just the medical aspect(19). On top of this, the importance of QoL was demonstrated in our qualitative dyadic interview study which showed that patients have an intrinsic desire to take up a more active role in their care, referring to self-management, with the aim of improving their QoL. Although our intervention focused on behavioural change in the caregiving population, we believe that the effect of this behavioural change will ultimately be reflected in patients' QoL. Therefore, we consider behaviour an essential intermediate outcome and the evaluation of QoL as the essential first step in future research so that we can investigate how changes in healthcare professionals' behaviour result in improvements in patients' QoL. While we recognise that there are many other important outcomes of self-management, such as satisfaction, engagement, and so on, there was a consistent thematic line in our research that led us to seek to improve QoL in the context of chronic care. As we did not conduct additional literature reviews for these other parameters, we encourage future researchers to conduct more extensive research on these additional outcome measures to gain a broader understanding of the impact of self-management support.

Contextual factors

This thesis project is part of the Primary Care Academy, which results in an emphasis on the specific context of Flemish healthcare, and more specifically Flemish primary care. This means that our findings and intervention are specifically tailored to this environment. They reflect the needs, challenges and opportunities of primary care in Flanders. Nevertheless, we believe that our results are not only applicable to Flemish primary care, as the principles of chronic care and self-management support (included in the SILCQ-model) are universal. We would say that our research and its outcomes transcend national borders and sectors of healthcare, including primary, secondary, and tertiary care. Consequently, we believe that our findings contribute to a broader enrichment of healthcare practice. However, the specific healthcare context needs to be taken into account when developing new interventions(73).

Conclusion

This thesis project deeply explored the complex world of self-management support within the context of chronic care. Table 1 summarises briefly what the thesis adds to existing knowledge. The development and implementation of the SILCQ-model through an educational learning program for primary care professionals resulted in an important contribution to bridge the gap between theory and practice. However, our research is only one crucial step in a much larger journey towards the implementation of self-management support. It will require ongoing adaptation, expansion and refinement of the foundations from our research to facilitate self-management support and to achieve the ultimate goal of improving the quality of life for people with chronic conditions.

Table 1: Thesis insights vs existing knowledge

What was already known?	What does this thesis add?
To achieve better healthcare, we need to put patients first and focus on self-management to achieve better healthcare.	*Emphasis that self-management depends on effective support from healthcare professionals and that highlights the central role of healthcare professionals in guiding and facilitating the self-management process.*
Self-management and self-management support are complex concepts, with multiple models elucidating their principles.	*The SILCQ-model offers a response to the challenges of complicated models and provides an accessible framework for self-management support, bridging the gap between theory and practice. In addition, the model serves as the foundation for peer supervision, a crucial aspect of change.*
Self-management is realized through effective patient education.	*Effective self-management begins with the education of professionals on self-management and self-management support. Discussion and reflection should always be at the heart of this education and different learning strategies should be implemented.*
Existing interventions temporarily contribute to improved self-management.	*Sustainable implementation of interventions requires a change in the attitudes and behaviour of the ones delivering support, namely the healthcare professionals.*

As we navigate the complex landscape of chronic care, this research reminds us that progress is only possible by working together with all stakeholders in care to bring about meaningful change. We therefore believe that the findings and experiences in this thesis will inspire further research, dialogue and collaboration, and ultimately contribute to the full potential of self-management support in healthcare. The journey continues, and it is through collaborative efforts, an unwavering commitment to person-centred care and the promotion of self-management support that we can truly make a difference to the lives of people with chronic conditions.

Personal statement to end with…

"As our knowledge continues to evolve, I believe that developing new tools to support self-management and refining existing methods is only half the battle. A profound shift in our mindset as healthcare professionals is imperative. Existing tools may even not be useful yet.
To make real progress, we must first take a step back and critically reflect on our behaviour as healthcare professionals in practice, especially regarding self-management support.
The foundation of self-management support needs to be reconsidered not only technologically, but more importantly, conceptually. It begins with looking at the patient and interventions with a different perspective, as they otherwise may not be effective. A change in mindset is the key to the success of self-management support."

– Lotte Timmermans

Summary

Background

In a rapidly changing landscape of chronic care, there is a significant shift towards person-centred care, where patients are actively involved. With this evolution, self-management support by healthcare professionals has become a crucial part of healthcare. Despite the development of numerous interventions to promote self-management and thereby improve patients' health and well-being, practical implementation remains challenging. These challenges are compounded by several barriers to the effective implementation of self-management support in healthcare. Barriers such as lack of awareness and knowledge of the role of healthcare professionals, adherence to traditional consultation models, lack of clear guidelines and models, and limited accessibility and applicability of existing support interventions require thoughtful solutions. This thesis project therefore specifically explores how healthcare professionals can be guided to support patients to achieve adequate self-management. A deep understanding of the complex dynamics within this area in the Flemish primary care context is essential to effectively improve the implementation of self-management support.

Methods

This thesis used a stepwise, evidence-based approach to explore and strengthen self-management support in primary care practice. First, an umbrella review was conducted to map the existing literature and provide a comprehensive overview of different self-management support interventions, their characteristics and their impact on patients' quality of life (QoL) (Chapter 1). Second, a phenomenological-hermeneutic study provided insights into the experiences of patients and their informal caregivers, so called dyads, in relation to primary care and self-management support (Chapters 2 and 3). Based on these findings, a qualitative approach was used to develop a preliminary conceptual model describing self-management support in primary care practice. In addition, a qualitative focus group study provided deeper insights into healthcare professionals' experiences of self-management support and enriched our model (Chapter 4). Third, we gathered all available knowledge to co-create an intervention with input from all stakeholders to strengthen self-management support in practice, using nominal group sessions (Chapter 5). These sessions generated insights that led us to the next crucial step: a comprehensive analysis of healthcare professionals' behaviour in relation to self-management support (Chapter 6). We used the Behaviour Change Wheel (BCW) to design a practical intervention, which we then piloted in multidisciplinary health centres. In the final chapter, we examined the outcomes of the developed intervention using the Kirkpatrick framework (Chapter 7).

Results

In Chapter 1, the umbrella review of self-management support interventions provided a multi-faceted overview, the diversity of which presented both opportunities and challenges. This diversity highlighted the richness of approaches, but also the complexity of not being able to adopt a 'one size fits all' approach to self-management support. In Chapter 2, our findings from the dyadic interviews showed that patients seek autonomy and active involvement in their care process, illustrating the growing demand for self-management support and person-centred care in modern healthcare systems. By exploring patients' needs and experiences of self-management support in Chapter 3, we learned that five basic roles for healthcare professionals - Supporting, Involving, Listening, Coordinating and Questioning (SILCQ) - are essential to engaging chronic patients in their own care, with reference to self-management. These roles have led to our SILCQ-model. In Chapter 4, this model was refined following discussions with healthcare professionals in focus groups. These caregiving population described self-management support as a collaborative approach that starts with person-centred dialogue. In Chapter 5, ideas for strengthening self-management support were brainstormed in nominal group sessions with all healthcare stakeholders, based on input from the previous research parts. Due to the large number of ideas, it was not possible to reach a consensus. The sessions emphasised the importance of innovation and sustainability in self-management support, revealing the need for behaviour change among healthcare professionals. Chapter 6 presented an in-depth analysis of self-management support behaviour using the COM-B model within the BCW framework. This analysis led to the identification of two potentially effective intervention functions: 'education' and 'enablement' of healthcare professionals. As a result, we developed a blended interactive educational program for professionals in primary care practice. The final chapter (Chapter 7) provided insights into this program, which was piloted in eight different multidisciplinary health centres in Flanders. It suggested potential improvements in perceptions of self-management support and greater motivation among healthcare professionals. In addition, participants reported self-perceived improvements in their supportive behaviour in practice.

Conclusion

This thesis contributes to the growing understanding of self-management support by highlighting that the success of self-management depends on effective guidance from healthcare professionals who play a central role in facilitating the self-management process. The SILCQ-model addresses the challenges of complex models and provides an accessible framework for self-management support that bridges the gap between theoretical concepts and practical application. It not only serves as a guide for self-management support in practice, but also forms the basis for peer supervision, a crucial aspect of change. In addition to good understanding and evidence, this thesis emphasises that sustainable implementation of self-management support requires changes in the attitudes and behaviours of healthcare professionals. This can be achieved through educational blended strategies. By focusing on discussion and reflection, combined with the use of different interactive learning materials, greater impact can be gained.

References (introduction and discussion)

References (introduction and discussion)

1. Saskatchewan Ministry of Health. Primary Health Care Framework [Internet]. 2012 [cited 2023 Sep 28]. Available from: https://publications.saskatchewan.ca/#/products/88308
2. Organization WH. World report on ageing and health [Internet]. World Health Organization; 2015. 267 p. Available from: https://www.who.int/publications/i/item/9789241565042
3. Hajat C, Stein E. The global burden of multiple chronic conditions: A narrative review. Prev Med Reports. 2018;12:284.
4. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. Lancet. 2012;380(9836):37–43.
5. Institute for Health Metrics and Evaluation – IHME. Global Burden of Disease Collaborative Network, Global Burden of Disease Study 2019 (GBD 2019) Results [Internet]. 2020 [cited 2022 Sep 22]. Available from: https://vizhub.healthdata.org/gbd-results/
6. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: Translating evidence into action. Health Aff. 2001;20(6):64–78.
7. Ekman I, Swedberg K, Taft C, Lindseth A, Norberg A, Brink E, et al. Person-centered care--ready for prime time. Eur J Cardiovasc Nurs. 2011;10(4):248–51.
8. Johnson S, Bacsu J. Understanding complex care for older adults within Canadian home care: a systematic literature review. Home Health Care Serv Q. 2018 Jul 3;37(3):232–46.
9. Morgan S, Yoder LH. A Concept Analysis of Person-Centered Care. J Holist Nurs. 2011 Jul 19;30(1):6–15.
10. Sibbald B, McDonald R, Roland M. Shifting care from hospitals to the community: a review of the evidence on quality and efficiency. http://dx.doi.org/101258/135581907780279611. 2007 Apr 1;12(2):110–7.
11. WHO. WHO | The World Health Report 2008 - primary Health Care [Internet]. World Health Organization; 2013 [cited 2019 Dec 18]. Available from: https://www.who.int/whr/2008/en/
12. The Health Policy Partnership. The state of play in person-centred care [Internet]. 2015 [cited 2023 Sep 28]. Available from: https://www.healthpolicypartnership.com/project/person-centred-care/
13. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. N Engl J Med. 2012 Mar;366(9):780–1.
14. Edmund G Hower. Beyond Shared Decision Making. J Clin Ethics. 2020;31(4):293–302.
15. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared Decision Making: A Model for Clinical Practice. J Gen Intern Med. 2012 Oct;27(10):1367.
16. World Health Organization. Primary health care [Internet]. [cited 2024 Feb 9]. Available from: https://www.who.int/health-topics/primary-health-care#tab=tab_1
17. Samuelson M, Tedeschi P, Aarendonk D, De La Cuesta C, Groenewegen P. Position Paper of the European Forum for Primary care Title: Improving inter-professional collaboration in Primary Care. 2012.
18. Fumagalli LP, Radaelli G, Lettieri E, Bertele' P, Masella C. Patient Empowerment and its neighbours: Clarifying the boundaries and their mutual relationships. Health Policy (New York). 2015 Mar 1;119(3):384–94.
19. Van De Velde D, De Zutter F, Satink T, Costa U, Janquart S, Senn D, et al. Delineating the concept of self-management in chronic conditions: A concept analysis. BMJ Open. 2019;9(7):e027775.
20. Vahdat S, Hamzehgardeshi L, Hessam S, Hamzehgardeshi Z. Patient involvement in health care decision making: A review. Iran Red Crescent Med J. 2014;16(1):12454.
21. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: A review. Patient Educ Couns. 2002;48(2):177–87.
22. Corbin JM, Strauss A. Unending work and care: Managing chronic illness at home. [Internet]. Jossey-Bass. Jossey-Bass Publishers; 1988. 358 p. Available from: https://books.google.co.in/books/about/Unending_Work_and_Care.html?id=RLH8V527HqwC&redir_esc=y
23. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Ann Behav Med. 2003;26(1):1–7.
24. Dwarswaard J, Bakker EJM, van Staa A, Boeije HR. Self-management support from the perspective of patients with a chronic condition: A thematic synthesis of qualitative studies. Heal Expect. 2016 Apr 1;19(2):194–208.
25. K A, AC G, JM C. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities. 1st Annu Crossing Qual Chasm Summit. 2004 Sep 13;
26. Salemonsen E, Førland G, Hansen BS, Holm AL. Understanding beneficial self-management support and the meaning of user involvement in lifestyle interventions: A qualitative study from the perspective of healthcare professionals. BMC Health Serv Res. 2020;20(1):1–12.
27. Regenmortel T Van. Empowerment als uitdagend kader voor sociale inclusie en moderne zorg. J Soc Interv Theory Pract. 2009;18(4):22.
28. Nolte E, McKee M. Caring for people with chronic conditions : a health system perspective. Open University Press; 2008.
29. Alvarez C, Greene J, Hibbard J, Overton V. The role of primary care providers in patient activation and engagement in self-management: A cross-sectional analysis. BMC Health Serv Res. 2016 Mar 11;16(1):85.
30. Richards T, Snow R, Schroter S. Co-creating health: more than a dream. BMJ. 2016 Sep 15;354:i4550.
31. Been-Dahmen JMJ, Grijpma JW, Ista E, Dwarswaard J, Maasdam L, Weimar W, et al. Self-management challenges and support needs among kidney transplant recipients: A qualitative study. J Adv Nurs. 2018 Oct 1;74(10):2393–405.

32. Flanagan S, Damery S, Combes G. The effectiveness of integrated care interventions in improving patient quality of life (QoL) for patients with chronic conditions. An overview of the systematic review evidence. Health Qual Life Outcomes. 2017 Sep;15(1):188.
33. Dineen-Griffin S, Garcia-Cardenas V, Williams K, Benrimoj SI. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. PLoS One. 2019;14(8):e0220116.
34. Panagioti M, Richardson G, Small N, Murray E, Rogers A, Kennedy A, et al. Self-management support interventions to reduce health care utilisation without compromising outcomes: A systematic review and meta-analysis. BMC Health Serv Res. 2014 Aug 27;14(1):356.
35. Allegrante JP, Wells MT, Peterson JC. Interventions to Support Behavioral Self-Management of Chronic Diseases. Annu Rev Public Heal. 2019;40:127–46.
36. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. Health Aff (Millwood). 2013;32(2):207–14.
37. Jones MC, MacGillivray S, Kroll T, Psych D, Reza Zohoor A, Connaghan J. A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. J Nurs Healthc Chronic Illn. 2011 Sep 1;3(3):174–85.
38. Barello S, Graffigna G, Vegni E. Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. Nurs Res Pract. 2012;2012:1–7.
39. WHO. WHO global strategy on integrated people-centred health services 2016-2026. 2015;
40. Warsi A, Wang PS, LaValley MP, Avorn J, Solomon DH. Self-management Education Programs in Chronic Disease: A Systematic Review and Methodological Critique of the Literature. Arch Intern Med. 2004 Aug 9;164(15):1641–9.
41. Rijken, M., Jones, M., Heijmans, M., Dixon A. Supporting self-management. In: Caring for people with chronic conditions: a health system perspective. Berkshire: Open University Press; 2008. p. 116–42.
42. McGowan P. The challenge of integrating self-management support into clinical settings. Can J diabetes. 2013 Feb 1;37(1):45–50.
43. Bodenheimer T, Wagner EH, Grumbach K. Improving Primary Care for Patients With Chronic Illness. JAMA. 2002;288(14):1775–9.
44. O'connell S, Mc Carthy VJC, Savage E. Frameworks for self-management support for chronic disease: a cross-country comparative document analysis. BMC Heal Serv Res. 2018;18(1).
45. Lake AJ, Staiger PK. Seeking the views of health professionals on translating chronic disease self-management models into practice. Patient Educ Couns. 2010;79(1):62–8.
46. Fletcher S, Kulnik ST, Demain S, Jones F. The problem with self-management: Problematising self-management and power using a Foucauldian lens in the context of stroke care and rehabilitation. PLoS One. 2019 Jun 1;14(6):e0218517.
47. KCE. Performance of the Belgian health system – report 2019 [Internet]. [cited 2021 Mar 31]. Available from: https://www.riziv.fgov.be/fr/statistiques/soinsdesante/2017/Pages/nombre-dispensateurs-soins-
48. Van Hecke A, Heinen M, Fernández-Ortega P, Graue M, Hendriks JML, Høy B, et al. Systematic literature review on effectiveness of self-management support interventions in patients with chronic conditions and low socio-economic status. J Adv Nurs. 2017 Apr 1;73(4):775–93.
49. Timmermans L, Golder E, Decat P, Foulon V, Van Hecke A, Schoenmakers B. Characteristics of self-management support (SMS) interventions and their impact on quality of life (QoL) in adults with chronic diseases: an umbrella review of systematic reviews. Health Policy (New York). 2023 Jul 25;135:104880.
50. Boeykens D, Sirimsi MM, Timmermans L, Hartmann ML, Anthierens S, De Loof H, et al. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. J Clin Nurs. 2022;00:1–16.
51. Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, et al. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022;23(1):1–13.
52. Timmermans L, Mustafa Sirimsi M, De Vriendt P, Van Hecke A, Vermandere Leuven Birgitte Schoenmakers KU Leuven MK, Foulon Leuven VK. Self-management support (SMS) in primary care practice: a qualitative focus group study of care professionals' experiences. Res Sq. 2023;
53. Timmermans L, Huybrechts I, Decat P, Foulon V, Van Hecke A, Vermandere M, et al. Recommendations for Researchers on Synchronous, Online, Nominal Group Sessions in Times of COVID-19: Fishbone Analysis. JMIR Form Res. 2022 Mar 1;6(3):e34539.
54. World Health Organization. World report on ageing and health [Internet]. WHO. World Health Organization; 2015 [cited 2019 Dec 18]. Available from: https://www.who.int/ageing/events/world-report-2015-launch/en/
55. Franklin M, Willis K, Lewis S, Rogers A, Smith L. Between knowing and doing person-centredness: A qualitative examination of health professionals' perceptions of roles in self-management support. Health (London). 2021 May 1;25(3):339–56.
56. Ross J, Stevenson FA, Dack C, Pal K, May CR, Michie S, et al. Health care professionals' views towards self-management and self-management education for people with type 2 diabetes. BMJ Open. 2019 Jul 1;9(7):e029961.
57. Johnston SE, Liddy CE, Ives SM. Self-management support: a new approach still anchored in an old model of health care. Can J Public Health. 2011;102(1):68–72.
58. Bookey-Bassett S, Markle-Reid M, Mckey CA, Akhtar-Danesh N. Understanding interprofessional collaboration in the context of chronic disease management for older adults living in communities: a concept analysis. J Adv Nurs. 2017 Jan 1;73(1):71–84.

59. Flessa S, Huebner C. Innovations in Health Care-A Conceptual Framework. Int J Environ Res Public Health. 2021 Oct 1;18(19):10026.
60. Silver I. Bridging the gap: person centred, place-based self-management support. Futur Healthc J [Internet]. 2018 Oct [cited 2023 Oct 23];5(3):188–91. Available from: https://pubmed.ncbi.nlm.nih.gov/31098564/
61. Nilsen P, Seing I, Ericsson C, Birken SA, Schildmeijer K. Characteristics of successful changes in health care organizations: an interview study with physicians, registered nurses and assistant nurses. BMC Health Serv Res. 2020 Feb 27;20(1):1–8.
62. Itchhaporia D. The Evolution of the Quintuple Aim: Health Equity, Health Outcomes, and the Economy. J Am Coll Cardiol. 2021 Nov 11;78(22):2264.
63. Gannotta R, Malik S, Chan AY, Urgun K, Hsu F, Vadera S. Integrative Medicine as a Vital Component of Patient Care. Cureus. 2018 Aug 4;10(8):e3098.
64. Israilov S, Cho HJ. How co-creation helped address hierarchy, overwhelmed patients, and conflicts of interest in health care quality and safety. AMA J Ethics. 2017 Nov 1;19(11):1139–45.
65. Romme S, Bosveld MH, Mulder D, van den Besselaar H, Sehlbach C, van Bokhoven MA. Bevordering van patiëntenparticipatie. TSG - Tijdschr voor gezondheidswetenschappen. 2023 Sep 8;101:124–30.
66. Bassett R, Bourbonnais V, McDowell I. Living long and keeping well: elderly Canadians account for success in aging. Can J Aging. 2007;26(2):113–26.
67. Cordier JF. The expert patient: towards a novel definition. Eur Respir J. 2014 Oct 1;44(4):853–7.
68. Chertoff J. The evolving physician-patient relationship: equal partnership, more responsibility. Qual Prim Care. 2015;23(1):1–3.
69. Raaijmakers LHA, Schermer TR, Wijnen M, van Bommel HE, Michielsen L, Boone F, et al. Development of a Person-Centred Integrated Care Approach for Chronic Disease Management in Dutch Primary Care: A Mixed-Method Study. Int J Environ Res Public Health. 2023 Mar 1;20(5):3824.
70. Jansen L, Eecloo L, Vanwing A, Schoenmakers B. You never walk alone: An exploratory study of the needs and burden of an informal care group. Heal Soc Care Community. 2019 Mar 1;27(2):375–82.
71. Sullivan TR, Yelland LN, Lee KJ, Ryan P, Salter AB. Treatment of missing data in follow-up studies of randomised controlled trials: A systematic review of the literature. Clin Trials. 2017 Aug 1;14(4):387–95.
72. Mills SL, Brady TJ, Jayanthan J, Ziabakhsh S, Sargious PM. Toward consensus on self-management support: the international chronic condition self-management support framework. Health Promot Int. 2017;32(6):942–52.
73. Trappenburg J, Jonkman N, Jaarsma T, van Os-Medendorp H, Kort H, de Wit N, et al. Self-management: One size does not fit all. Patient Educ Couns. 2013 Jul 1;92(1):134–7.
74. Hossain MM. Umbrella Review as an Emerging Approach of Evidence Synthesis in Health Sciences: A Bibliometric Analysis. SSRN Electron J. 2020 Mar 14;
75. Kelly CA, Tsang A, Lynes D, Spencer S. "It's not one size fits all": a qualitative study of patients' and healthcare professionals' views of self-management for bronchiectasis. BMJ open Respir Res. 2021 Mar 4;8(1):e000862.
76. Franklin M, Lewis S, Willis K, Bourke-Taylor H, Smith L. Patients' and healthcare professionals' perceptions of self-management support interactions: Systematic review and qualitative synthesis. Chronic Illn. 2018;14(2):79–103.
77. M Jawad Hashim. Patient-Centered Communication: Basic Skills. Am Fam Physician. 2017;95(1):29–34.
78. Kianfar S, Carayon P, Hundt AS, Hoonakker P. Care coordination for chronically ill patients: Identifying coordination activities and interdependencies. Appl Ergon. 2019 Oct 1;80:9–16.
79. McGowan P, Lynch S, Hensen F. The Role and Effectiveness of Telephone Peer Coaching for Adult Patients With Type 2 Diabetes. Can J Diabetes. 2019 Aug;43(6):399–405.
80. Pascucci D, Sassano M, Nurchis MC, Cicconi M, Acampora A, Park D, et al. Impact of interprofessional collaboration on chronic disease management: Findings from a systematic review of clinical trial and meta-analysis. Health Policy (New York). 2021 Feb 1;125(2):191–202.
81. Overheidsdienst F. Orientatienota "Geïntegreerde visie op de zorg voor chronisch zieken in België" | FOD Volksgezondheid [Internet]. 2013 [cited 2023 Jul 26]. Available from: https://www.health.belgium.be/nl/orientatienota-geintegreerde-visie-op-de-zorg-voor-chronisch-zieken-belgie
82. Tharani A, Van Hecke A, Ali TS, Duprez V. Factors influencing nurses' provision of self-management support for patients with chronic illnesses: A systematic mixed studies review. Int J Nurs Stud. 2021 Aug 1;120:103983.
83. Anderson N, Ozakinci G. "it all needs to be a full jigsaw, not just bits": Exploration of healthcare professionals' beliefs towards supported self-management for long-term conditions. BMC Psychol. 2019 Jun 24;7(1):1–14.
84. Wuyts D, Van Hecke A, Lemaire V, Vandepoel I, Duprez V. Development and validation of INTENSS, a need-supportive training for nurses to support patients' self-management. Nurse Educ Today. 2021 Nov 1;106:105042.
85. Porcheret M, Main C, Croft P, McKinley R, Hassell A, Dziedzic K. Development of a behaviour change intervention: A case study on the practical application of theory. Implement Sci. 2014 Apr 3;9(1):1–11.
86. Wagner E. Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness? Eff Clin Pract. 1998;1:2–4.
87. Potthoff S, Kwasnicka D, Avery L, Finch T, Gardner B, Hankonen N, et al. Changing healthcare professionals' non-reflective processes to improve the quality of care. Soc Sci Med. 2022 Apr 1;298:114840.
88. Lee PY, Cheong AT, Ghazali SS, Salim H, Wong J, Hussein N, et al. Barriers to implementing asthma self-management in Malaysian primary care: qualitative study exploring the perspectives of healthcare professionals. NPJ Prim care Respir Med. 2021 Dec 1;31(1):38.
89. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process. 1991 Dec 1;50(2):179–211.

90. Deci EL, Ryan RM. Self-Determination Theory. International Encyclopedia of the Social & Behavioral Sciences: Second Edition. Elsevier Inc.; 2015. 486–491 p.
91. Michie S, Atkins L, West R. The Behaviour Change Wheel - A Guide To Designing Interventions [Internet]. London: Silverback Publishing; 2014 [cited 2023 Apr 16]. Available from: http://www.behaviourchangewheel.com/
92. Michie S, van Stralen MM, West R. The behaviour change wheel: A new method for characterising and designing behaviour change interventions. Implement Sci. 2011 Apr 23;6(1):1–12.
93. Collins C, Doran G, Patton P, Fitzgerald R, Rochfort A. Does education of primary care professionals promote patient self-management and improve outcomes in chronic disease? An updated systematic review. BJGP open. 2021 Jun 1;5(3):1–9.
94. Lorig KR, Holman HR. Self-management education: History, definition, outcomes, and mechanisms. Vol. 26, Annals of Behavioral Medicine. Lawrence Erlbaum Associates Inc.; 2003. p. 1–7.
95. Kwasnicka D, Dombrowski SU, White M, Sniehotta F. Theoretical explanations for maintenance of behaviour change: a systematic review of behaviour theories. Health Psychol Rev. 2016 Jul 7;10(3):277.
96. Iglesias FH, Celada CA, Navarro CB, Morales LP, Visus NA, Valverde CC, et al. Complex Care Needs in Multiple Chronic Conditions: Population Prevalence and Characterization in Primary Care. A Study Protocol. Int J Integr Care. 2018 May 25;18(2):16.
97. Addington-Hall J, Kalra L. Measuring quality of life: Who should measure quality of life? Br Med J. 2001 Jun 6;322(7299):1417–20.
98. Shofany C. Quality of life among chronic disease patients. Nurs Care Open Access J. 2017 Dec 7;4(2):385–94.

Appendices

Publications

International peer-reviewed publications

a. Publications used in the thesis manuscript

Timmermans L, Golder E, Decat P, Foulon V, Van Hecke A, Schoenmakers B; Primary Care Academy. Characteristics of self-management support (SMS) interventions and their impact on Quality of Life (QoL) in adults with chronic diseases: An umbrella review of systematic reviews. Health Policy. 2023 Sep;135:104880. doi: 10.1016/j.healthpol.2023.104880. Epub 2023 Jul 25. PMID: 37536047.

Boeykens D (joint first author), Sirimsi MM (joint first author), **Timmermans L** (joint first author), Hartmann ML, Anthierens S, De Loof H, De Vliegher K, Foulon V, Huybrechts I, Lahousse L, Pype P, Schoenmakers B, Van Bogaert P, Van den Broeck K, Van Hecke A, Verhaeghe N, Vermandere M, Verté E, Van de Velde D, De Vriendt P; Primary Care Academy. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. J Clin Nurs. 2023 Feb;32(3-4):422-437. doi: 10.1111/jocn.16243. Epub 2022 Feb 17. PMID: 35178849.

Timmermans L, Boeykens D, Sirimsi MM, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B; Primary Care Academy. Self-management support in flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. BMC Prim Care. 2022 Mar 31;23(1):63. doi: 10.1186/s12875-022-01652-8. PMID: 35361118; PMCID: PMC8968094.

Timmermans L, Huybrechts I, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Recommendations for Researchers on Synchronous, Online, Nominal Group Sessions in Times of COVID-19: Fishbone Analysis. JMIR Form Res. 2022 Mar 25;6(3):e34539. doi: 10.2196/34539. PMID: 35225814; PMCID: PMC8963262.

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Facilitating self-management support using the behaviour change wheel (BCW) to address healthcare professionals' behaviour. (2023). SUBMITTED

b. Preprints used in the thesis manuscript

Timmermans L, Boeykens B, Sirimsi MM, Van de Velde D, De Vriendt P, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Self-management support (SMS) in primary care practice: a qualitative focus group study of care professionals' experiences. [Preprint.] May 8, 2023 [accessed 2023 December 15]. Available from: www.researchsquare.com/article/rs-2888538/v1.pdf

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Transforming healthcare: A pilot study to improve primary healthcare professionals' self-management support behaviour through blended learning. (2023). [Preprint.] Dec 28, 2023 [accessed 2024 February 10]. Available from: https://www.researchsquare.com/article/rs-3792014/v1

c. Publications not used in the thesis manuscript

Weersink RA (joint first author), **Timmermans L** (joint first author), Monster-Simons MH, Mol PGM, Metselaar HJ, Borgsteede SD, Taxis K. Evaluation of Information in Summaries of Product Characteristics (SmPCs) on the Use of a Medicine in Patients With Hepatic Impairment. Front Pharmacol. 2019 Sep 17;10:1031. doi: 10.3389/fphar.2019.01031. PMID: 31607904; PMCID: PMC6758592.

Academie Voor De Eerste Lijn. Inspirerende bijdragen voor een sterke eerste lijn in Vlaanderen. Academic & Scientific Publishers. 2021.

Boeykens D, Haverals R, Sirimsi MM, **Timmermans L**, Van de Velde D, De Vriendt P, Boeckxstaens P; Primary Care Academy. Creating space to talk about patients' personal goals: experiences from primary care stakeholders. BMC Prim Care. 2023 Jan 14;24(1):11. doi: 10.1186/s12875-022-01956-9. PMID: 36641431; PMCID: PMC9840292.

Sirimsi MM, De Loof H, Van den Broeck K, de Vliegher K, Boeykens B, **Timmermans L**, Van de Velde D, De Vriendt P, Van Bogaert P. Experiences of care providers regarding patient-centred interprofessional collaboration and integration in primary care. A descriptive qualitative study. (2023). SUBMITTED

(inter)national conferences

Oral/poster presentations at conferences

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Developing and implementing self-management strategies in primary care based on realist evaluation. Presented at International Conference for Realist Research, Evaluation and Synthesis (REALIST 2021), online, 16 Feb 2021 – 18 Feb 2021

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Een focus-groepsstudie over de uitdagingen, succesfactoren en valkuilen van de implementatie van zelfmanagementondersteuning in de eerstelijnszorg. Presented at Eerstelijnsconferentie Academie Voor de Eerste Lijn, online, 18 May 2021 – 21 May 2021

Boeykens B, Haverals R, Sirimsi MM, **Timmermans L**, Van de Velde D, De Vriendt P, Boeckxstaens P. Presented by colleague at World Federation of Occupational Therapy, Paris, 28 Aug 2022 – 31 Aug 2022

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Self-management support: a complex clinician-patient interaction. Presented at 20th International Conference on Communication in Healthcare (ICCH), online, 6 Sep 2022 – 9 Sep 2022

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Self-management support in primary care practice: the development of a preliminary conceptual model. Presented at 10th European Conference on Mental Health (ICCH), Lisbon, 14 Sep 2022 – 16 Sep 2022

Van de Velde D, Boeykens D, **Timmermans L**, Sirimsi MM, Hartmann ML, De Vriendt P. Experiences of people living with chronic conditions and their informal caregiver towards primary care in Flanders. Presented by colleague at European Forum for Primary Care (EFPC), Ghent, 25 Sep 2022 – 27 Sep 2022

Timmermans L, Decat P, Foulon V, Van Hecke A, Schoenmakers B. Unravelling the concept of self-management support in primary healthcare practice. Presented at WONCA Europe, Brussels, 7 Jun 2023 – 9 Jun 2023

Timmermans L, Decat P, Foulon V, Van Hecke A, Schoenmakers B. Theory-based blended learning program to integrate the fundamentals of self-management support in primary care: pilot study. Poster at WONCA Europe, Brussels, 7 Jun 2023 – 9 Jun 2023

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Piloting a theory-based learning program to integrate the fundamentals of self-management support in primary care. Presented at 3rd EURACT educational conference, Bled, 5 Oct 2023 – 7 Oct 2023

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Supporting self-management (4 years research overview). Poster at Primary Care Conference, Brussels, 28 Nov 2023 – 29 Nov 2023

Invited presentations at conferences

Timmermans L, Decat P, Foulon V, Van Hecke A, Vermandere M, Schoenmakers B. Zelfmanagement: "You are not your illness. You have an individual story to tell." Presented at Nefrologiedagen Conference, Veldhoven, 27 Mar 2023 – 29 Mar 2023

Scientific Acknowledgement

This work would not have been possible without the combined efforts of many individuals and organisations, to whom I am very grateful. My sincere thanks go to all the patients, informal caregivers, healthcare professionals, patient organisation representatives, policy makers, experts and other stakeholders who actively participated in our studies. Their contributions were invaluable and provided profound insights into the complexities of self-management support. Special thanks go to those who so generously shared their personal care experiences to inform our research.

I am grateful to the Primary Care Academy - Academie Voor De Eerste lijn - as the organisation within which I was able to conduct my research. Roy and Emily, without you the organisation wouldn't be where it is today. A heartfelt thank you is extended to all the members of the Academy, particularly my fellow doctoral students, whose support has been crucial to the design, evaluation and implementation of our studies. My sincere thanks also go to the Fonds Dr. Daniël De Coninck, managed by the King Baudouin Foundation, for funding the Academy and making our research and projects possible. I would also like to thank the Academy's partners and friends for their representation, input and unwavering support. Special thanks to the Flemish Patients' Platform for strengthening the patient voice throughout the research process. In addition, I would like to express my deep gratitude to my fellow doctoral students and other members of our research department at the Academic Centre for General Practice - ACHG. Your input, guidance and unwavering support throughout my research journey has been priceless. Finally, I would like to thank our research group's advisory board for their annual input, which provided a broad perspective and invaluable insights that guided our research.

Personal Contribution

I, Lotte Timmermans, took the lead in this PhD project. With the invaluable support of my supervisors, enriched by the expertise of Ann Van Hecke, I played the key role in shaping the research ideas, designing the methodologies, data collection and analysis for all studies conducted within this PhD project.

In Chapter 1, for the umbrella review, I collaborated with my supervisor, Birgitte Schoenmakers, in reviewing the literature and screening the results. Elena Golder was actively involved in the critical review of the included studies and the data analysis and extraction.

Chapter 2, a joint effort and joint authorship with colleagues Dagje Boeykens and Mustafa Sirimsi, consisted of additional contributions from Dominique Van de Velde, Patricia De Vriendt and Maja Lopez Hartmann in the conceptualisation and development of the methodology. Dagje Boeykens, Mustafa Sirimsi and I conducted the interviews, led the data collection, analysis and writing of the manuscript, while Dominique Van de Velde, Patricia De Vriendt and Maja Lopez Hartmann provided essential insights during data interpretation and revisions of the manuscript.

For Chapter 3, data collection was a team effort with PhD students Mustafa Sirimsi and Dagje Boeykens. I carried out the data analysis myself, with the invaluable support of my main supervisor, Birgitte Schoenmakers, and the other members of my core research team, including Peter Decat, Veerle Foulon, Ann Van Hecke and Mieke Vermandere.

In Chapter 4, Dagje Boeykens, Mustafa Sirimsi and I conducted focus group discussions under the guidance of Patricia De Vriendt and Dominique Van de Velde. The in-depth analysis was carried out by myself under the guidance of Birgitte Schoenmakers and in close collaboration with the core research team.

Chapter 5 consisted of the organisation of nominal group sessions under my guidance, in collaboration with the implementation expert Ine Huybrechts from the Primary Care Academy. Data analysis was carried out by me under the supervision of Birgitte Schoenmakers and in collaboration with the core research team.

In Chapter 6, I took the lead in conducting a comprehensive behavioural analysis using the BCW framework, under the supervision of Birgitte Schoenmakers and in close collaboration with the core research team. The analysis was enriched by the active participation of researchers and health professionals within the Primary Care Academy network.

In Chapter 7, I led the design and supervision of the pilot projects in collaboration with Anabel Wanzeele and with support from UCLL University of Applied Sciences. The analysis of the projects was carried out by me under the guidance of Birgitte Schoenmakers and the core research team.

Conflict of Interest statement

We declare no potential conflicts of interest associated with this research. The Primary Care Academy, where the research was conducted, is funded by the Fonds Dr. Daniël De Coninck, administered by the King Baudouin Foundation, Belgium. It is important to note that the funder had no involvement in the design, implementation, analysis, or interpretation of the research findings. The grant number associated with this funding is 2019-J5170820-211588.

Lotte Timmermans

03-11-1995

Contact

lotte.timmermans@kuleuven.be

linkedin.com/in/lotte-timmermans-21265a18a

Skills

- Creativity
- Critical thinking
- Leadership
- Computer skills
- Communication skills

Hobbies & interests

Athletics

Graphical design

Volunteering & community involvement
(Akabe scouting, international buddy, CM-volunteer; etc.)

Music

Languages

Dutch	★★★★★
English	★★★★☆
French	★★★☆☆
German	★★★★☆

Awards & recognition

Erasmus Master Thesis Award - **KU Leuven**

Media campaign self-management project - **VPP (Flemish Patients' Platform)**

Education

2019 - present — **KU Leuven**
PhD in Biomedical Sciences
The development and implementation of self-management support in primary care practice

2017 - 2019 — **KU Leuven**
Master in Pharmaceutical Sciences

2018 — **University of Groningen**
Master Thesis - Department of Pharmacy
Information on medication use in liver cirrhosis: a document analysis of the Summaries of Product Characteristics

2013 - 2017 — **KU Leuven**
Bachelor in Pharmaceutical Sciences

2007 - 2013 — **St Joseph's College Aalst**
Latin-mathematics

Experience

Community pharmacist — **2019**
Pharmacie Lemar I Leuven

Student Internship — **2018 - 2019**
Pharmacie Parkpoort I Leuven

Extracurricular activities

Volunteering "Buddyzorg Limburg" — **2023 - present**

Commitment diversity & inclusion — **2022 - present**
Diversity Team I KU Leuven

Representative Academic Biomedical Staff — **2021 - 2023**
Research Policy Council I KU Leuven

Steering Committee Interreg 2 Seas project — **2021 - 2023**
EMPOWERCARE

Poster pitches judge — **2022**
ICCH Conference Glasgow I EACH

Word of thanks

It is with deep gratitude that I write these words, reflecting on the amazing journey of the past four years. This time has been filled not only with scientific discoveries and academic growth, but also with the invaluable essence of human connections and warm friendships.

Four years ago, after studying pharmaceutical sciences at KU Leuven, I found myself at a crossroads. It was then that I decided to apply for a PhD in healthcare. What initially seemed like just an application has, over the past four years, developed into a passionate commitment. I have been blessed with the opportunity to pursue my work with passion and determination, thanks to the inspiring people who have crossed my path and guided me.

First and foremost, I would like to express my deepest gratitude to **Birgitte**. As my main supervisor, you have not only guided me in my research, but also shaped me as an individual. Your mentorship went beyond academic knowledge; it stimulated my personal growth and broadened my horizons. The weekly meetings with you have been a constant source of inspiration and learning. I am immensely grateful for your guidance and expertise, which has made an invaluable contribution to my development as a researcher and as a person.

Co-supervisor, **Veerle**, your support and guidance played a pivotal role in both my PhD research and my pharmaceutical studies. From my time at Erasmus in Groningen to the end of this PhD research, your experience and knowledge have been invaluable. Your input has enriched our work and contributed to the wonderful final result we can now look back on.

Co-supervisor, **Peter**, your input strengthened and complemented our research team. As the only man in our team, you managed to hold your own and create a perfect balance. Your contributions were invaluable and have taken our research to new heights.

Co-supervisor, **Mieke**, your late addition to our team has proven to be a valuable asset. With your critical eye and drive for perfection, you have taken our work to the next level. I am sincerely grateful for your input, which has not only enriched our research, but also shaped and structured my way of thinking.

Ann, your expertise in supporting self-management has deepened our work and broadened our understanding. Your ability to get us to look at things from a different point of view and to encourage me to engage in deep reflection has been so important. I am grateful to call you a member of our team.

The external jury members, **Professor Mieke Rijken** and **Professor Thérèse Van Durme**: thank you for taking the time to read and evaluate my thesis and for providing invaluable feedback. My internal jury members, **Professor Theo van Achterberg** and **Professor Tine Van Regenmortel**:

thank you for your dedication and enthusiasm over the past four years. Your commitment to our annual evaluations has ensured the continuous improvement of my work and I am grateful for your valuable insights.

The **Primary Care Academy** - thanks to this organisation I have been able to carry out my research. Roy, Emily, thanks to your efforts this organisation has flourished and allowed me to carry out this wonderful project over the past four years. I am grateful for the collaboration of so many; unfortunately, the list is too long to enumerate. However, I would like to acknowledge the collaboration with Dagje, Ine and Mustafa. Anabel, it was a real pleasure to develop and carry out our MENTOSS learning program together. Thank you for the many hours of collaboration and the warm contact. I would also like to thank the King Baudouin Foundation (KBS), without whose support the Academy would not exist, nor would my research. I'd also like to thank all the patients, informal caregivers, health and welfare professionals and organisations who participated in our studies. Your time and commitment were invaluable to the success of this research.

And then, of course, there are the colleagues from the **Academic Centre of General Practice** (ACHG). I am grateful for all the interactions in the corridors, for all the pleasant conversations, for the after-work get-togethers, or just for the office banter. There are many of you, and to list them all is to risk leaving someone out. However, there are a few people I would like to mention personally.

Before our department moved to a new building, I shared the office with **Stephanie**, **Lore** and **Hannelore**. A delightful group of women with whom I have warm memories and who got me through the first few months of my PhD. Thank you for giving me a great start! Then, after we moved, I was one of the "bureau chicks" in office 0006 with two wonderful people, **Laura** and **Vasia**. They went the extra mile and made me somewhat addicted to café lattes. Although the many coffees were ideal for taking a break from work and catching up :) Vasia, your hospitality and smile added colour to my PhD. Team curls for the win! **Bram**, your support and care for me has always touched me and I am grateful. With great patience you guided me through my research and always managed to calm me down. Taxi Bram, researcher Bram, hanging around the coffee machine Bram, secretary Bram... Your help was invaluable! I would also like to thank **Katrien** and **Marina** for solving every technical issue and the spontaneous chats. What started out as colleagues has, after four years, become a group of friends for life.

Speaking of friends, this PhD would not have been possible without the support and listening ear of so many of my friends. First, my roommates, with whom I lived for a long time during my PhD. **Jeroen, Tine** and **Andreas**, thank you for listening to my complaints, cooking delicious meals and

entertaining me. **Beeleke**, thank you for the many weekend trips and crazy adventures, for being "the sister from another mister". **Brent**, **Anne-Sophie**, **Iris**... I cannot imagine the past years without you by my side. I am grateful that you see me, that you listen to me and that you are always there for me. Unfortunately, we are not geographically close, but I am grateful for the support from far away and the efforts to plan a crazy adventure or a wonderful evening on a regular basis. **Lore**, it is not easy to live 750 km away from each other as best friends. But a holiday in the snow and mountains on a regular basis is quite fun. Thank you for our 20 years of friendship and for your support in carrying out my research. **Angelina**, we met at a time when my PhD was already at an advanced stage, but you jumped in as if you had been by my side for years. You welcomed me as if we had known each other for years. Above all, you welcomed me when I moved to a place where I knew very few people. Thank you!

In addition to my friends, I am grateful for my family. **Birgit** and **Peter**, you came into my life and filled a warm family role, creating a welcoming home abroad. Birgit, I am grateful for sharing a glass of wine, being spoilt with delicious food, and for the many conversations we've had, all of which made the research journey much more enjoyable. **Keythy** and **Lampi**, I am grateful to call you such a wonderful uncle and aunt. **Mum** and **Dad**, unfortunately we live far away, but luckily there is WhatsApp to keep us updated. I am grateful for your encouragement to follow my dreams, to choose things I am passionate about, including embarking on this PhD journey.

I would also like to acknowledge my brothers who taught me how to stand my ground in this world. **Siemen**, your challenges on the sports field lit a fire in me that also fuelled my research endeavours. **Jakob**, you'll always be my little brother, but your support over the years has been big and my gratitude cannot be greater. Mum and Dad, you've provided us with a warm nest, taught us to take a critical view of the world, and even welcomed not two but three daughters-in-law. **Nele** and **Charlotte**, thanks for being companions during my research years.

Laura, you've been by my side every day for the past four years. I couldn't have done this adventure with anyone else. A PhD is a team effort, but your role over the years has been indescribable. You gave me a home where I could work on my research in peace, develop as a person, and where you always supported me and helped me build towards my dreams. You have often joked that you should be giving the thank-you speech on my defence because you have survived by my side all these years. I suggest you share this sentiment with Birgitte at the reception afterwards; she might agree. But now, without further ado, Laura, for everything you've done for me over the years, through the tears and the laughter, and for the incredible team we've become together, I say a very big thank you as the very last words in my dissertation.