GOAL-ORIENTED CARE
BRIDGING THEORY AND PRACTICE

TOWARDS BUILDING BLOCKS FOR PRIMARY HEALTH CARE INTERVENTIONS

DAGJE BOEYKENS

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Goal-oriented care
Bridging theory and practice

Towards building blocks for primary health care interventions

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ABBREVATIONS

CCM	Chronic Care Model
EBM	Evidence-based medicine
HIS	Health Interview Survey
(HR)QOL	(Health-related) quality of life
MRC	Medical Research Council
PCC	Patient-centered care
PC-IC	Patient-centered integrated care
PPC	Patient Priority Care
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcomes Measures
SDM	Shared-decision making
VBHC	Value-based healthcare
WHO	World Health Organization

VOORWOORD
PREFACE

Ontdekkend onderweg

Er was de moeder en de dochter die hun thuis hadden gevonden in twee woonwagens. Die waren zo bewust opgesteld dat ze elkaar in 't oog konden houden. De draaimolen in miniatuur die op hun voorraadkast pronkte, herinnerde aan het leven dat ze samen rondreizend hadden doorgebracht als foorkramers. Moeder en dochter zijn met het reizen gestopt en vullen hun dagen nu met het breien van dekentjes voor het kinderziekenhuis. Er was ook Koen* die, toen ik het terras opwandelde, me enthousiast tegemoet liep met een zelfgemaakte bloem uit papier-maché. Er waren ook de vele gesprekken met hulpverleners die elke dag het beste van zichzelf geven om zorg te dragen voor deze mensen.

In hun zoektocht naar wat hun dagen betekenis gaf, bleven deze mensen met nood aan ondersteuning zichzelf uitdagen. Ze zochten creatieve oplossingen om binnen de grenzen van hun mogelijkheden en de grenzen die door anderen werden opgelegd om te gaan. Zo werden ze geen grensbewoner van hun eigen kunnen.

In het verhaal van hun leven legden deze mensen de belangrijke aspecten van de eerstelijnszorg bloot. Voor Koen werd de eerste lijn een plaats om energie te tanken om zijn zoektocht verder te zetten. Voor moeder en dochter een rustpunt om hun eerder gezette en volgende stappen van de tocht te overzien. Voor ieder van hen was het een aanspreekpunt om vertrouwen te kweken om te blijven doen wat ze graag doen.

Deze en gelijkaardige verhalen gaven de zuurstof aan dit proefschrift. Het Fonds Daniël De Coninck van de Koning Boudewijnstichting zorgde op zijn beurt voor de nodige ademruimte. Door de inzet van het Fonds voor een toegankelijke, kwaliteitsvolle en humane eerste lijn, konden deze mensen gehoord worden. Dankzij het Fonds wordt ervoor gezorgd dat de gezondheid en levenskwaliteit van deze mensen en van mensen die in gelijkaardige omstandigheden leven verbetert en hulpverleners de nodige ondersteuning krijgen. Om dit mogelijk te maken investeert het Fonds in de Academie voor de Eerste Lijn. De Academie bundelt krachten, middelen en kennis van vier universiteiten en zes hogescholen voor de uitbouw van een sterke eerstelijnszorg in Vlaanderen. Dit proefschrift is hierin verankerd.

De investering in de Academie voor de Eerste Lijn maakt het mogelijk dat mensen de zoektocht naar zingeving in hun bestaan kunnen verderzetten. Zo kan de eerste lijn een plaats worden waar woorden tussen de regels verdwijnen en verhalen hun weg vinden.

Laat dit proefschrift een inspiratiebron zijn voor ieder die zichzelf geen grensbewoner wil noemen.

Dagje

Wandering in discovery

There was the mother and daughter who had found their home in two trailers. They were placed in front of each other so it looked like they could keep an eye on each other. The miniature carousal on their pantry displayed their life as fairgoers, travelling together. Mother and daughter stopped travelling and now spent their days knitting blankets for the children's hospital. There was also Koen* who approached me on his terrace with a homemade papier-mâché flower. There were also the many conversations with providers who give the best of themselves on a daily base to care for these people.

Despite their limitations, these people sought creative solutions to challenge themselves and find meaning in their lives, without becoming their own limiters.

In the story of their lives, these people exposed pillars of primary care. For Koen, primary care became a place to refuel his energy to continue his quest. For mother and daughter rather a resting point to ponder. Each of them found a point of contact to build confidence and to keep doing what they love. Their stories, along with others like them, brought life to the pages of this dissertation.

The King Baudouin Foundation's Daniel De Coninck Fund provided support to ensure their voices were heard, and committed to improving accessible, quality, and humane primary care. Thanks to the Fund, the health and quality of life of these people and those living in similar circumstances can be improved and providers can be given the needed support. To make this possible, the Fund invests in the Primary Care Academy. The Academy combines forces, resources, and knowledge of four universities and six universities of applied sciences to build strong primary care in Flanders. This dissertation is anchored in this Academy.

The investment in the Primary Care Academy makes it possible for people to continue the search for meaning in their lives. Primary care can become a place where words disappear between the lines and stories find their way.

Let this dissertation be a source of inspiration to all those who do not want to call themselves frontiersmen.

Dagje

TABLE of CONTENT

GENERAL INTRODUCTION

Judith is a middle-aged woman of 53 years who is living in a remote village on the outskirts of a bigger city. She moved to a small house in the shadow of a park after her partner passed away a few years ago. Judith has one daughter, Marie, who is studying abroad for the next three years. When Marie is in town, they are committed to spend as much time as possible together by going shopping, grabbing a coffee and cake, or catching up at the firepit in the garden. Judith thrives at those moments she can spend with her daughter. Judith and Marie are lookalikes, both warm-hearted women with a positive mindset who are determined to make the most out of life. Together they went through some hard times, and are trying to find their way back in life.

Besides her daily job as a social worker in the nursing home, Judith has been a long-time volunteer at the local community center; a true evergreen. During her spare weekends, she can often be found at the center making soup, organizing activities, or talking to the visitors. She is a beloved person who gets along with a lot of people. Despite it seems that Judith has her life on track, she is battling with various health-issues. In her late 40's Judith has been diagnosed with diabetes type 2 which has led to the introduction of insulin therapy and blood glucose monitoring. As if this was not enough, she was later diagnosed with hypertension, requiring additional medications to control her blood pressure. Alongside these challenges, Judith has also been battling osteoarthritis. The joint pain and decreased mobility caused by osteoarthritis affect her ability to carry out her work at the nursing home and community center to the fullest, adding an additional layer of challenges to her already complex medical journey. The combination of health issues places a considerable demand on her overall well-being.

To manage her diverse health issues, Judith relies on a dedicated team of care providers (family physician, physiotherapist, endocrinologist, cardiologist) each of them doing their best to offer the best treatment. However, despite her resilient spirit, Judith grapples with several difficulties resulting from her health issues. She find it difficult to keep track of various medications, dosages, and timing. Additionally, the lack of seamless communication and coordination among the multiple providers she relies on complicate her medical journey, the continuous management of her chronic conditions takes an emotional toll leading to feelings of stress and anxiety, and the dietary recommendations and exercise regimes prescribed by different providers to manage her diabetes and hypertension also impedes her daily routine. Furthermore, the burden of frequent medical appointments consume significant portion of her time, disrupting her work and personal life.

Above all, Judith is eager to find a way to effectively cope with her multiple conditions while continuing doing her work at the nursing home and community center. The fulfillment she derives from her job and volunteering work is what she finds most meaningful and rewarding in her daily life. Despite the challenges posed by her health, maintaining her active involvement in these roles remains her utmost desire. Unfortunately, the current approach she employs to manage her conditions falls short of enabling her to fully pursue her work at the nursing home and community center.

Judith's situation is not an isolated case. Many people face a situation where they are overwhelmed by a combination of (health) issues. It inhibits them in pursuing that what is meaningful for them. Often, this is thwarted by a system that is ingrained in the belief that care is focused on curing diseases while some benefit from prolonged follow-up and a more personalized approach. At the same time, questions could be raised about how we can ensure that care addresses that what matters most to patients.

To understand why it is important to focus on 'what matters most to patients', and thus understand the rationale of this dissertation, the general introduction outlines the 1) importance of primary health care, 2) the impact and burden of people with moderate complex care needs, 3) strategies to manage multimorbidity, and 4) the potential of goal-oriented care.

PRIMARY HEALTH CARE

Primary health care and primary care are both terms that are often used interchangeably. According to the World Health Organization (WHO), primary health care is a broader approach that comprises three main facets: 1) primary care and essential public health functions as a core of integrated health services, 2) multisectoral policy and action, and 3) empowered people and communities [1].

Primary care offers a first point of contact to health services for all, guarantees continuity of care by building prolonged relationships between people and providers, offers a broad range of services such as curative and preventive care, and coordinates services across levels of the care system[1]. It mostly refers to medical care as the service to support all people in conquering their challenges of everyday life [2].

In this dissertation, primary health care and primary care will both be used and refer to health as well as social services.

Judith's case

Judith has built a long-term relationship with her family physician who serves as a first contact point to effectively coordinate her health-issues. From keeping on track of her tests and referrals to managing medication prescriptions, her family physician plays a crucial role in ensuring seamless communication among all her providers.

Box 1 Judith's case

Before primary health care made its bones, a long history proceeded. What follows is an overview of primary health care history, its definitions and core values, and its importance for the health system.

Primary health care: history

Compared to other levels in the health and welfare, primary health care is a fairly new introduced service. It was Sir Bertrand Dawson who, in 1920, wrote the observation that "*organizations grapple with the growth of knowledge and the conviction that the best resources to maintain or cure diseases should be made available to all citizens*" [3]. In the Dawson report, named after him, he mentioned the importance of primary care centers as an answer to the failing system to bring care to people. Sir Dawson advocated for primary care centers that provide curative and preventive medicine, offer care in the patients' environment (including pharmacy, community doctors, and nurses), and can refer patients to secondary health centers. His observation and suggestions for system transformation gave rise to primary health care in the United Kingdom and laid the foundation for what is still regarded as the core values for primary health care today [3].

However, it was not until 1978 before primary health care was considered as a cornerstone of the health system. In 1978, 134 countries participated in the International Conference on Primary Health Care in Helsinki, Finland. They approved the Alma-Ata Declaration stating that primary health care is key to attaining health for all. At this conference, the ambitious goal was set to attain a level of health that would permit people over the world to lead a socially and economically productive life by the year 2000. By pursuing this objective, the Declaration of Alma-Ata set a new vision for primary health care. The same Alma-Ata Declaration also published the first definition of primary health care and became as such a landmark in the history of global health [4].

Later on, in 2005, a new definition of primary health care was proposed by Barbara Starfield. She was an American pediatrician and a strong advocate of primary health care. Her work stems from concerns that the United States was too focused on investing in specialists compared to primary care physicians. Throughout her entire life, professor Starfield found that primary health care had a pivotal role in lowering care costs, improving health to providing more accessible services, and reducing inequities in population health [5].

Thirty years after the Declaration of the Alma Ata, in 2008, the World Health Organization (WHO) published the report "Primary Health Care: Now more than ever". Whereas the Declaration of Alma-Ata was based on a conviction that primary health care was important, this report was grounded in scientific evidence and responded to trends and documentation that were not available before. Based on this evidence, the report noticed three main concerns that have to be taken into account when building the future of primary health care. First, despite a substantial progress in health in a large part of the world, a noticeable number of countries is limping behind. Second, the nature of problems have changed because of ageing, urbanization, and globalization that have increased the burden of chronic conditions. Third, health systems are influenced by the rapid changes and transformation worldwide as result of globalization. Not only does the report draw attention to these three concerns, it also criticizes that health systems fail to pursue the goals of health for all as articulated in the Declaration of Alma-Ata. By proposing four sets of reforms, the WHO hopes to respond to today's health challenges, values of equity, and the growing expectations of the population. These four sets consist of: universal coverage reforms to improve

health equity, service delivery reforms to make health-systems people-centered, leaderships reforms to make authorities more reliable, and public policy reforms to promote and protect the health of communities [6].

Another decade later, on the Declaration's fortieth birthday in 2018, a new Global Conference on Primary Health Care was held in Astana, Kazakhstan. This conference allowed to scrutinize the initial targets, as described in the Alma-Ata Declaration of 1978, and formulate lessons learned in the report 'From Alma Ata towards Universal Health Coverage and the Sustainable Development Goals' [7]. The baseline remained the same, but was adjusted to the evolving society. The revised declaration now highlights the progress that has been made over the four decades, considers challenges and opportunities, and proposes aims for the future of primary health care [7]. The central tenet remained that health is a right, not a privilege for those who can afford it. With the concluding remarks that *"primary health care must be seen as a launching pad for people, nations, and communities to thrive; as an investment, not a cost; and as a movement, not a moment*", the WHO accommodates the broader society needs [8].

Overview definitions primary health care

Vision primary health care Declaration of Alma-Ata
Primary health care is the first level of contact of individuals, the family, and community with the national health system, bringing health care as close as possible where people live and work.

Definition primary health care Declaration of Alma-Ata – WHO - 1978
Primary health care is an essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.

Definition primary health care by Barbara Starfield - 2005
Primary health care is the provision of first contact, person focused, ongoing care over time that meets the health-related needs of people, referring (to hospital) only those problems too uncommon to maintain competence and coordinates care when people receive services at other levels of care.

Definition primary health care – WHO - 2018
Primary health care is a whole-of-society approach to health that aims at ensuring the highest possible level of health and well-being and their equitable distribution by focusing on people's needs and as early as possible along the continuum from health promotion and disease prevention to treatment, rehabilitation, and palliative care, and as close as feasible to people's everyday environment.

Box 2 Overview definitions primary health care

Primary health care: core values

The various definitions of primary health care are underpinned by different core values. The most referred values are the ones articulated by Barbara Starfield in 1992; better known as the 4 C's of primary health care: providing first contact, continuity, comprehensiveness, and coordination [9].

1) Providing a first contact refers to the accessibility and use of health services that are directly reachable for patients [9]. This should not only be understood in terms of physical elements such as location, but also in terms of having interactions with primary care providers (e.g., by phone, patient visit).

2) Continuity implies individual use of primary health care or usual sources of care over time for most health care needs [9]. This also includes coordinating individual care across services through integrated care pathways across the care continuum. Of the four C's, continuity of care has the strongest evidence base as a number of studies already reported that it is associated with greater satisfaction with care, and lower undesirable utilization and costs of care [10].

3) Comprehensiveness means that primary health care should take care of all problems, with short-term referral if needed [9]. This includes a set of interventions across the care continuum, including health education and promotion, screening, disease prevention, diagnosis, management of acute and chronic conditions and multimorbidity, and palliative and end-of-life care.

4) Coordination consists of leading, organizing, and integrating patient care across different locations, specialties, and phases of care [9]. This also includes integrated care pathways that span over services and information sources.

After the "four C's" were presented in literature, other research has been conducted to either elaborate on the 4 C's or develop additional values [11-13]. Bodenheimer et al. described ten building blocks of primary care and thus expanded the original 4 C's with the importance of engaged leadership, data-driven improvement, team-based care, patient-team partnership, and population management [12]. Epperly et al., published 'the shared principles of primary care' that were co-created with multiple stakeholders (i.e., health providers, patients, purchasers). Besides reidentifying the four values as presented by Starfield, they added the values of person- and family-centered, team-based and collaborative, and high value (i.e., wisely considering costs to patients, payers, and the system) [13].

Primary health care: pivotal role

As already mentioned, primary health care plays a pivotal role in guaranteeing a qualitative health system. There is a body of knowledge showing that a strong primary health care contributes to better patient outcomes and population health [14, 15], reduces provider burden [15], can lower healthcare costs [16], and reduces inequity in health [17]. Hence, a strong primary health care system seems to contribute to the quintuple aim [18].

In 2009, Stange opened the debate about the contribution of primary health care to the health system in his publication "The paradox of primary care" [19]. This paradox comprises that, on the one hand, primary health care offers poorer quality of care than specialists when looking at the level of individual diseases. On the other hand, at the level of populations, primary health care can lower costs, and enhance quality of care and great equity. The same publication mentioned that primary health care is better suited to manage care for people with chronic conditions and multimorbidity. By presenting this paradox, Stange also started a discussion about quality of care [19].

Indeed, a vast number of research highlighted the pivotal role of primary health care in the light of chronic conditions and multimorbidity [20-22]. Hansen et al. questioned if in countries with stronger primary health care systems people with chronic conditions have better self-rated health, fewer limitations in activities of daily living, and suffer less from untreated conditions. They investigated this by combining country- and individual-level data for 27 countries of the European Union. They found that people with chronic conditions in a stronger primary health care system experience better care coordination, and more comprehensive packages of primary care services were more likely to be in good or very good health. Additionally they found that people with more than two chronic conditions benefited the most [23].

In summary, a robust primary health care system is crucial in ensuring high quality care for everyone. As such, it is essential to remain vigilant and continuously explore ways to strengthen primary health care, especially in the context of multimorbidity.

MODERATE COMPLEX CARE NEEDS

The evolution of primary health care was intensified by the changing demographic, epidemiological, political, economic, sociocultural, and technological contexts. Indeed, the global health landscape has changed much since the Declaration of Alma-Ata was signed forty years ago. Whereas healthcare was mainly focused on treating infectious diseases, this has shifted over the years to a focus on chronic conditions and multimorbidity as a result of an ageing population, lifestyle changes, and healthcare technology improvements [24]. At the same time, the definition of health became subject of discussion. Whereas a first definition stated a more static approach, this has more recently been evolved into a more dynamic approach as an answer to the changing epidemiological context [25, 26].

In the following paragraphs we will elaborate on those different topics. To start, we will provide an overview of the definitions relevant in this new context, continue by describing the prevalence and incidence of chronic conditions and multimorbidity, and address the related burden for patients, providers, and the system. To end, we will reflect on the concept of health.

Defining population

As mentioned before, primary health care acts as the first point of contact within the healthcare system, and consequently, engages with diverse population groups. However, with the given epidemiological evolution, primary health care is increasingly handling people with moderate complex care needs.

Moderate complex care needs refer to a broad range of health and other related issues. Iglesias et al. articulated six criteria of which people with moderate complex care needs meet at least one [27]:

1. Having one severe or two or more stable chronic conditions (i.e., comorbidity), or
2. Taking four or more types of medication, or
3. Having a temporarily higher care need after, for instance, hospitalization, or
4. Having a low socioeconomic status, or
5. Lacking health literacy and self-management skills, or
6. Showing the need for more care, according to at least one member of the primary care team

The criteria indicate that moderate complex care needs are concentrated across diverse domains. To address these issues, this population depend on primary care teams for care coordination, effective communication, and interprofessional collaboration. However, they do not necessitate continuous monitoring and supervision [27].

Given that moderate complex care needs can encompass various domains, it becomes challenging to define a specific study population in this dissertation. For research purpose, the population will be defined as 'having chronic conditions or multimorbidity'.

The most commonly adopted definition of **chronic conditions** is described by the WHO [28].

> 'Chronic' means that something is of long duration, slow in progression, and cannot be passed from person to person. 'Conditions' is often used as a synonym with "illness", "disease", and "disorder", but captures a more umbrella view on the state of health that interferes with daily activities or feeling of well-being .

As the context evolves, an increasing number of people will present multiple chronic conditions, known as **multimorbidity.** Multimorbidity is a more complex issue for which ambiguity exists [29]. The European General Practice Research Network (EGPRN) has identified more than hundred different definitions used for multimorbidity by academic research. To clarify ambiguity that might have occurred from this huge number, they performed a systematic review [30]. Based on this review they presented a definition of multimorbidity that reads as:

> "Multimorbidity is any combination of chronic disease with at least one other disease (acute or chronic) or bio-psychosocial factor (associated or not) or somatic risk factor. Any biopsychosocial factors, any somatic risk factor, the social network, the burden of diseases, the health care consumption, and the patients' coping strategies may function as modifiers (of the effects of multimorbidity). Multimorbidity may modify the health outcomes and lead to an increased disability or a decreased quality of life or frailty."

Although there is no international consensus on the exact cut-off value for defining multimorbidity, the most commonly used value is "having two or more chronic conditions". This cut-off value is frequently employed when assessing the prevalence and incidence of multimorbidity [31].

Chronic conditions and multimorbidity: prevalence and incidence

Worldwide, chronic conditions and multimorbidity are considered as the pandemic of the 21st century [32]. As many as 16-57% of adults in high-income countries suffer from multiple chronic conditions. Although large differences within and across countries are noticed. For example, the prevalence in the United Kingdom ranges from 16%-57%, the United States report a number of 25,5%, and China even 45%. These differences can mostly be attributed to the use of other methodological approaches (e.g., different list of chronic conditions) [32].

In Belgium, the prevalence of chronic conditions at the population level is measured by the Belgian Health Interview Survey (HIS). However, as the HIS relies on self-reported data, the results must be viewed with caution. To assess multimorbidity, people are considered to have at least two of the following six most common diseases or conditions: cardiovascular disease, chronic pulmonary

disease, diabetes, cancer, (osteo)arthritis, and hypertension. In the population aged 15 years and above, 60,5% report having none of these, 24,3% have one, 10,6% have two, and 4,6% have three or more condition(s). According to these criteria, multimorbidity occurs in 15,2% of the Belgian population. The percentage even increases to 37,9% among those 65 years and older [33].

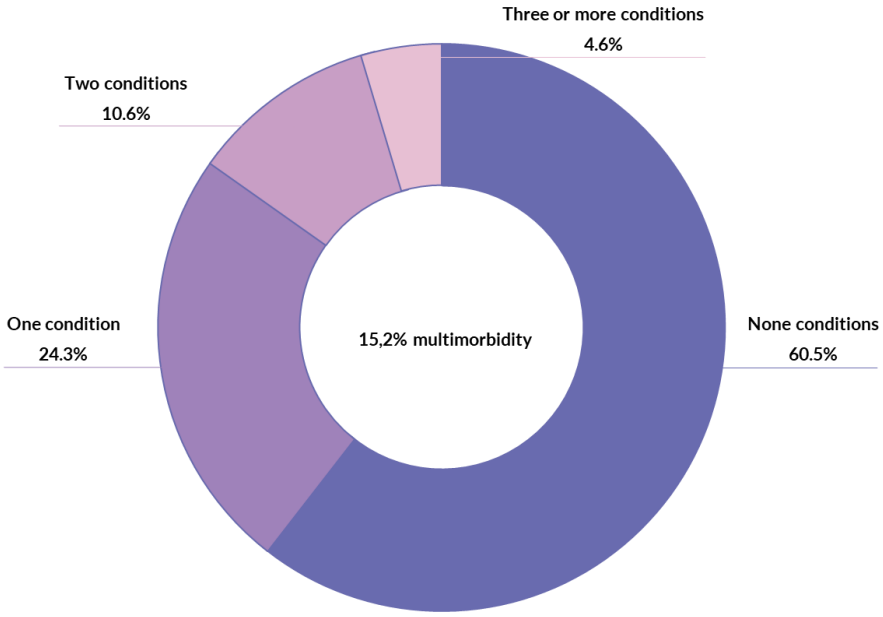

Figure 1 Prevalence chronic conditions in the Belgian population

Additionally, socioeconomic disparities are noted as with a percentage of 31,1%, multimorbidity is higher in people without a degree or only one of elementary school compared to the 10% of highly-educated people with multimorbidity. Finally, between 1997 and 2018 there was an increase from 8,9% to 15,2% primarily due to an ageing population. Because this number is only expected to increase in the coming years, it will be getting more imperative to think about strategies to best manage care for people with multimorbidity [33].

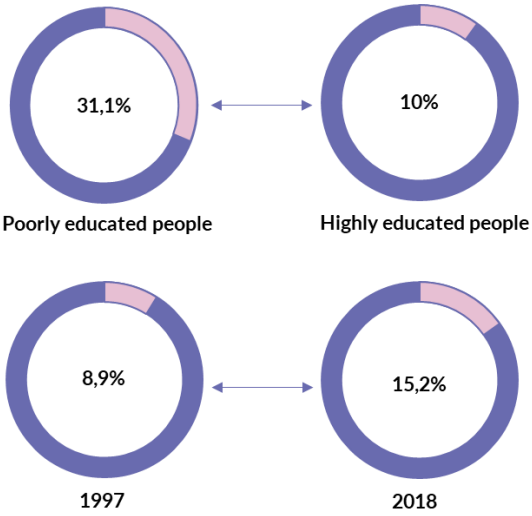

Figure 2 Differences in prevalence of chronic conditions

Chronic conditions and multimorbidity: burden

Chronic conditions and specifically multimorbidity come with a burden for patients, providers, and the health system.

Judith's case

Judith bears a heavy burden, grappling with the challenges that accompany her multiple chronic conditions. The complexity of managing her medication schedules, numerous medical appointments, and the lack of effective communication among her providers create a significant disruption in her daily life. Moreover, the emotional toll of dealing with her health issues, along with the necessary lifestyle changes, further impact her ability to fulfill her commitments at the nursing home and community center.

Box 3 Judith's case

For patients, living with multimorbidity is burdensome as it impacts their physical, mental, and social functions. In most cases, these consequences are intertwined and result in lower quality of life (QOL) [34, 35]. The WHO defines QOL as "*an individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*" [36]. Commonly, five domains are considered to be important in one's QOL: physical, psychological, social, economic, and spiritual [37]. Besides QOL, research often mention health-related quality of life (HRQOL) which consists only of the "*the individual's perceived physical and mental health over time*". Confusion among both concepts might occur as research often use them interchangeable [38]. Nonetheless, QOL and HRQOL are often used as a measure to evaluate outcomes for patients with chronic conditions [39].

A systematic review of 2004 specifically focusing on multimorbidity and QOL in primary care, showed that multimorbidity potentially affected all QOL domains. In particular, the physical domain is highly affected compared to social and psychological domains. However, the study noted that there is a decline in the latter domains when patients are diagnosed with three or more conditions [20]. Although, the findings might be considered outdated, they were confirmed in a more recent systematic review of 2021 [40]. One of the reasons that the psychological domain is likely to be less affected, might be that current measurements tools lack to capture the change on this domain. Therefore it is interesting to take a look at qualitative studies that might give a more thorough explanation of the experiences of patients living with chronic conditions or multimorbidity. A qualitative study on the patients' perspectives living with multimorbidity showed that chronic conditions lead to physical limitations and psychological distress which can result in adverse outcomes in daily life. The same study also reported that patients found it hard to maintain their work; which is indicated as an important activity to create a fulfilling life [41].

In addition to the impact on (HR)QOL, patients also face a high treatment burden due to the need to make lifestyle changes to cope, adhere to treatments, and scheduling an overload of appointments with providers [34, 42].

Primary care providers have a key role to play in managing chronic conditions and multimorbidity [22], especially as they often build a long-term therapeutic relationship with their patients [43]. However, whereas the burden for patients is extensively described, there is much less known about the burden related to managing multimorbidity for primary care providers. Moreover, research only focusses on primary care physicians and lacks perspectives of other providers in primary care (e.g., nurses, occupational therapists, psychologist).

A qualitative study conducted by family physicians in Switzerland showed that physicians have the feeling of being powerless, do not feel prepared to deal with patients' socio-economic situation, and experience conflicts between guidelines and the patients' reality. As a result, the physicians deal with an emotional strain for which they felt not well-prepared to cope with [44]. A systematic review and synthesis of qualitative research on primary care physicians also highlighted that they have a sense of professional isolation in managing multimorbidity [45]. More often than the personal burden, literature describes the challenges providers face when providing chronic care. Providers report a lack of appropriate guidelines to manage multimorbidity, fragmentation in the healthcare system, and their inability to deal with multimorbidity [46].

At the system level, the economic burden of chronic conditions and multimorbidity is high [47]. Costs increase with the number of conditions, and it has been shown that multimorbidity imposes a fivefold of costs compared to single chronic conditions [48]. This is mostly due to increased utilization of healthcare resources. An effect is found on primary care consultations, hospital out-patient visits, hospital admissions, and total health care costs [48]. Multimorbidity also entails a societal cost for example due to absenteeism at work. In addition, multimorbidity is associated with increased social care utilization compared to one or no chronic conditions to help patients with activities of daily living e.g., dressing, eating, and instrumental activities of daily living (e.g., communication, transport) [49].

Most of the burden at all these levels can be attributed to a system that is fragmented, resulting in poorly integrated and coordinated care among providers and organizations [50].

Health: evolving definition

The increasing number of people with chronic conditions and multimorbidity has also shifted the perception of the concept "health". As a result, its definitions has undergone multiple revisions.

The first definition of health, operationalized by the WHO in 1948, reads as *"health is a state of complete physical, mental, and social well-being, not merely the absence disease or infirmity"* [51]. The origin of this definition must however be understood in the context of the time. In the fifties, the main challenge for healthcare were mainly infectious diseases such as measles and tuberculosis. Additionally, chronic conditions as for example cardiovascular diseases were considered untreatable and may have resulted in a poor prognosis. Taking that context into account, it is not surprising that the WHO presented a more strict definition of health. However, the landscape has changed since then, as already described. Diseases with short life expectancy evolved to chronic conditions as result of the healthcare improvements and advancing knowledge

in medication research. In this new context, the WHO definition has been criticized to be too static, unrealistic, and too medically focused and not achievable for most of the people [26, 52]. As a result most of the people would be categorized unhealthy for most of the time. A more dynamic definition of health urges itself and would be a better fit with this changing context.

The first more dynamic definition of health was presented by Georges Canguilhem in his book "The Normal and the Pathological" in 1943 [25]. He saw health as the *"the ability to adapt to one's environment"* and, in this way, recognized that health includes the physical, mental, and social dimensions of human life [25]. This definition was decades later endorsed by The Lancet who published an editorial entitled 'What is health? The ability to adapt.' [53]. Also Dubos viewed health as *"being able to get the greatest in life"* [54] and emphasized that it is about finding meaning from the challenges life comes with and reaching one's full potential as a human being throughout the cycle of life [54]. More recently, Machteld Huber described that the health definitions stated by the WHO minimizes the role of human capacity to cope with physical, emotional, and social changes [26]. As a counter movement she proposed, in 2011, a new concept of health to address its broader characteristics. In her publication "How should we define health", she presented health as "*the ability to adapt and self-manage in the face of social, physical, and emotional challenges [26]."*

Judith

Judith would not be considered healthy based on the traditional, static approach because of her multiple chronic conditions. However, she does not concern herself with meeting the criteria of complete physical, mental, and social well-being. For Judith, health is intertwined with her ability to continue her commitments at the nursing home and community center. Only if her conditions hindered her from fulfilling these roles she would perceive herself as unhealthy.

Box 4 Judith's case

To conclude, the concept of health is not merely medical. It is now regarded as a more dynamic concept addressing different aspects of someone's life and acknowledging various life domains, while also recognizing that people might experience health differently [55]. This 'experience' refers to the 'illness experience' that includes the perceptions and belief of patients and their significant others regarding their physical, psychological, social, and emotional response to their disease, and their health or illness behavior [56]. It is imperative to acknowledge the unique illness experiences of each individual and tailor care accordingly [56].

Overview definitions "health"

World Health Organization – 'WHO Constitution' – 1948
Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Georges Canguilhem – 'The normal and the pathological' – 1943
Health as the ability to adapt to one's environment. Health is not a fixed entity. It varies from individual, depending on their circumstances. Health is not defined by the doctor, but by the person, according to his or her functional needs.

René Dubos – 'The mirage of health' – 1959
Health as the condition best suited for each individual to reach his or her personal and social goals.

Machteld Huber – 'How should we define health' – 2011
Health as the ability to adapt and self-manage in the face of social, physical, and emotional challenges.

Box 5 Overview definitions of health

MANAGING MULTIMORBIDITY

Multimorbidity imposes a burden that extends beyond the medical domain affecting patients, providers, and the system. At the same time, health is no longer limited to a strict medical perspective. With the increasing number of people with multimorbidity, finding appropriate strategies to manage multimorbidity becomes an urgent but complex task. Strategies are needed that take into account all those domains while prioritizing quality over quantity of life.

Before describing what such strategies might look like, we first start by building an understanding of the practice of evidence-based medicine (EBM) [57]. EBM is one of the most known and commonly used models to guide care that suggests, on the one hand, a disease-oriented paradigm and, on the other hand, patient-centered care. By making reflections on those two paradigms, we will illustrate what strategies for managing multimorbidity need to comprise.

Evidence-based medicine

It is David Sackett who started the movement from "the sins of expertness" to a "proposal of redemption" in which he presented EBM as a more mechanical approach of health compared to the system, that was back in time, rooted in the authority of doctors. EBM meant a turnaround in hierarchy and a focus on not only the clinical expertise of care providers, but also on the best scientific evidence, and the patients' values and preferences [57].

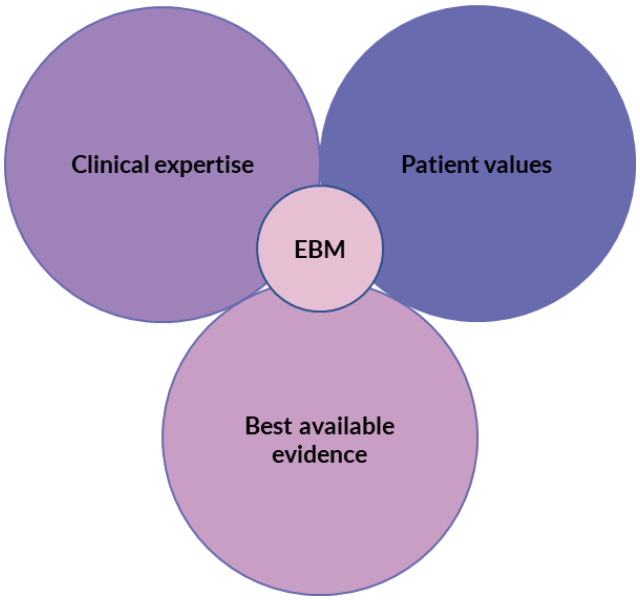

Figure 3 Evidence-based medicine

In EBM, Sacket prizes meta-analysis and Randomized Controlled Trials (RCTs) as the highest ranked and unfiltered data and thus as the best scientific evidence, resulting in disease-oriented guidelines[57]. However, it is important to mark that both methodologies come with some shortcomings. RCTs are particularly interesting for finding new treatment methods and developing disease-oriented guidelines, but unfortunately do not pay attention to the individual factors or comorbidities as they are pushed aside as confounding factors [58]. For this reason it is crucial to take into account the clinical expertise of providers. Based on their years of experience they are best placed to make a critical appraisal of what can be regarded as the best treatment approach for the patient. This is important as without clinical expertise, providers might be driven by research that might be inappropriate for the individual patient. However, inconsistency exists about what 'clinical expertise' defines as it is depending from the providers capacities [59].

Besides the clinical expertise on top of the scientific evidence, Sacket points to the patients' values and preferences as a third component to guide care delivery, and makes by this notice of patient-centered care. The addition of patients' values and preferences are needed to temper how the evidence is applied to the individual patient. However, providers lack guidance and evidence to adopt a focus on patients' values and preferences in making deliberate choices for care delivery [57]. As a result, patients' values and preferences are often lingered in the shadows and ignored by providers who rather focus on disease-oriented guidelines than on patients' values and preferences.

Disease-oriented paradigm

Disease-oriented guidelines underpin the disease-oriented paradigm. These guidelines are defined as *"statements that included recommendations, intended to optimize patient care, that are informed by systematic review of evidence, and an assessment of the benefits and harms of alternative care options* [60]." They provide formal and structured advice on what treatments providers should prescribe without taking the patients' perspectives into account. The disease-oriented paradigm is a more quantitative approach of care that assesses quality based on clinical outcomes (e.g., HbA1 level). However, there is a growing trend towards tailoring these guidelines to the individual patient, and giving weight to their personal risks and benefits rather than prescribing standardized treatments [61]. Sackett recommended to use the guidelines more as a set of rules instead of strict rules as this will potentially increase quality of care and reduce costs [57].

In the context of multimorbidity, disease-oriented guidelines have been criticized because the complexity and interactivity of multiple conditions make it challenging to adhere to them [62]. Guthrie et al. suggests that the accumulation of conditions is the primary reason why guidelines are becoming less suitable in the context of multimorbidity [63]. This might be a result of the fact that patients with multimorbidity are often excluded from many evidence-generating randomized, controlled trials making these study outcomes not always applicable for this population [64].

Attempting to adhere to disease-oriented guidelines in multimorbidity can come with negative consequences for patients [62]. A qualitative study conducted in Norway reported that family physicians felt obliged to implement multiple guidelines that most of the time were not suited to

their patients. Moreover, they experienced that applying multiple guidelines increased the risk for their patients of polypharmacy, excessive non-pharmacological recommendations, and reduction of quality of life [65]. A review also noted that disease-oriented guidelines, in multimorbidity, could drive polypharmacy which is an often reported consequence of following them [62, 63]. Even more, adhering to multiple guidelines at the same time, will likely result in fragmented care [66].

To conclude, it seems that a quantitative standardized approach such as the disease-oriented paradigm does not properly fit what is needed to manage care for people with multimorbidity. It seems that strategies should be more centered around the patient, integrate care, and be more qualitative in nature.

Patient-centered care

In its publication 'Crossing the quality chasm: a new health system for the 21st century', the Institute of Medicine defines patient-centered care (PCC) as *"providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions* [67]."

Moira Stewart divides PCC into four main components: (1) exploring health, disease, and the illness experience, (2) understanding the whole person, (3) finding common ground, and (4) enhancing the patient-doctor relationship[68]. The first component emphasizes the understanding of both perceptions of the patient and provider including the patients' understanding of being ill and how the conditions are affecting patients' functioning. The second component is about creating awareness on the multiple aspects of the patients' life (e.g., personality, developmental history, life cycle issues) and assessing the whole person. The third component is about finding a common ground between the patient and the provider and focus on the area of defining the problem, establishing treatment goals, and identifying each other roles. The fourth, and last, component highlights that each contact between the patient and the provider should be based on a relationship grounded in compassion, empathy, sharing of power, healing, and hope [68].

1. Exploring health, disease, and the illness experience
    - Unique perceptions and experience of health (meaning and aspirations)
    - History, physical, lab
    - Dimensions of the illness experience (feelings, ideas, effects on function and expectations)
2. Understanding the whole person
    - The person (e.g., life history, personal, and developmental issues)
    - The proximal context (e.g., family, employment, social support)
    - The distal context (e.g., culture, community, and ecosystem)
3. Finding common ground
    - Problems and priorities
    - Goals of treatment and/ or management
    - Roles of patient and doctor
4. Enhancing the patient-doctor relationship
    - Compassion and empathy
    - Power
    - Healing and hope
    - Self-awareness and practical wisdom
    - Transference and countertransference

Box 6 Components of patient-centered care

When PCC was first introduced in 1980, it was considered as a soft science in which the importance of patient-centered communication was not yet fully acknowledged. Nowadays, PCC is frequently described in literature as it enables providers to tailor care according to the patients' unique needs by presenting a more qualitative approach of care [69]. In particular because PCC is associated to improved satisfaction of care, enhanced physical and social well-being, and more positive treatment outcomes [69]. PCC is also often been described in literature on multimorbidity because it aims to understand the person as a whole on different domains in life, tries to find a common ground by active communication and collaboration between patients and providers, and take into account the patients' perspectives. In this way, PCC seems to meet the needs of people with multimorbidity and presents key components to consider in strategies to manage multimorbidity [70].

Chronic care model

The paradigms of disease-oriented care and patient-centered care are not limited to multimorbidity but instead provide overarching frameworks to direct care.

A well-known and most studied model that combines those two paradigms to manage chronic conditions, is the Chronic Care Model (CCM) [71]. The CCM was created by, first, a literature review to report successful practice and system changes to improve care of people with chronic conditions, and second, by expert feedback and consensus round. It is widely recognized by

multiple countries such as the United States and United Kingdom as a model for system improvement for people with chronic conditions [72].

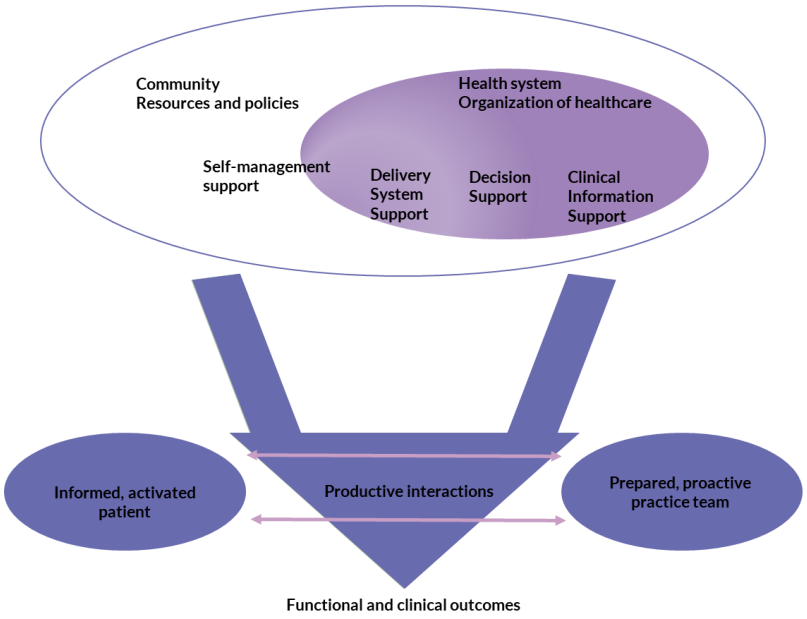

Figure 4 Chronic care model

The impetus for the development of this model arose from Wagners' clinical practice. Having observed that the traditional approach of educating patients to manage their chronic conditions was ineffective, he created the CCM. In the CCM he aimed to acknowledge the patients' sense of what they think solutions for their problems might be. By bringing that together with the evidence, he argued that this will end up in a plan that is consistent with the patients' perspective. In this way, he aimed to improve the functional and clinical outcomes for people with chronic conditions. With this model, Wagner also acknowledged that chronic care takes place in overlapping galaxies of the entire community, the health system, and the organizations [72]. To achieve these outcomes, the model presents a multidimensional solution of six interrelated elements: community resources and policies, health system organization of healthcare, self-management support, delivery system redesign, decision support, and clinical information support [72]. By addressing the productive interactions between patients and providers, educating patients to control their own health and their capacity to access health care, the CCM suggests PCC [73].

Towards a new strategy for managing multimorbidity

While the CCM acknowledged the importance of PCC, it is worth noting that the model is situated within a disease-oriented approach. This is evident in the model's emphasis on integrating disease-oriented guidelines into care delivery to ensure optimal care to people with chronic conditions [74]. In addition, most studies on CCM have primarily concentrated on single chronic conditions such as diabetes [75] or chronic pulmonary disease [76], within a problem-based approach to managing them, and self-management support emphasizing lifestyle changes. However, as already widely addressed, the landscape of chronic care has changed and multimorbidity became a new problem in the healthcare scene. It is therefore questionable if the CCM meets the emerging needs of people living with multimorbidity, especially because the model does not mention how to implement the six interrelated elements in this new context. It is therefore highly probable that the CCM needs reexamination to also address the needs of people with multimorbidity [74].

People with multimorbidity would benefit from adopting care approaches that recognize and address the interplay between their multiple care needs, situated in their socio-personal and biomedical context. This also implies that a 'one size fits all approach' will not be considered the best fit. Care approaches that places greater emphasis on the perspectives and preferences of people with multimorbidity throughout the entire continuum of care are required.

It is therefore important to keep working on finding appropriate strategies to manage multimorbidity by prioritizing the patients' perspectives, meeting patients' needs, fostering strong patient-provider relationships, and allowing better coordination of care [30]. This will include a shift from a quantitative approach of care, dominated by the disease-oriented paradigm, to a more qualitative approach of care, grounded in a PCC approach [77, 78].

What this means, is illustrated by Candy Cam in her Ted Talk "Towards at patient-centered care system: view from chronic illness."

Giving an A

Benjamin Zander, conductor of the Boston Philharmonic proposes a method called 'giving an A'. It all started when he walked into his music class at the start of the academic year and he says to his students "Guys, at the end of this year you're all going to be getting an A. That's right, the top grade. It sounds like a good deal, right. But, I want you to write a letter addressed to me imagining yourself in the position a year from now telling my why you deserved your A." That's what he did in that very first class. By doing this, Zander has allowed the students not to be defined by that singular letter grade and instead explore their passions and their motivations for why they wanted to take his music class in the first place and allowed that to carry them throughout the year. Translating this to a care setting, this would be asking patients what they want to achieve out of their health care. When doctors give patients an A, they choose to line up with the patient to combat their disease, rather than lining up with the standards against the patient. They're inviting them as colleagues rather than speaking to them from a position of power. Patients become than equally valid, wheelers of knowledge of their own health. They're seen as individuals rather than just an amalgamation of their health conditions. This simple act of giving an A will revolutionize centuries of provider and patients relationships.

Box 7 Ted Talk "giving an A"

The metaphor of giving an 'A' underlines the importance of shifting towards a more qualitative approach of care instead of the quantitative approach that the disease-oriented guidelines imply. In other words, a shift from 'what is the matter with the patient' to 'what matters to the patient' is the likely way forward for managing multimorbidity [78]. While this shift seems reasonable, the actual implementation of such approach into practice is rather challenging. Several related concepts and care approaches have already been proposed as a way to support this shift:

- The concept of **personalized care planning** recognizes that people with multimorbidity have a role in self-managing their health, despite the complexity of tasks involved. This approach allows providers to offer tailored care to the patients' individual needs and acknowledges the patients' concerns and aims to empower them to take an active role in managing their own health. It involves a series of conversations between a patient and provider, where they collaboratively establish goals and develop action plans for effectively managing the patients' health issues [79].

- **Narrative medicine** is introduced as a means to use narratives as a tool to collect and interpret information on the patient's illness experience [80]. It recognizes that illness and healthcare are not merely a biological phenomenon, but are also shaped by personal, cultural, and social factors. Through eliciting narratives, providers can better understand the impact of the illness on the patients' live and the individual meanings that patients attach to their health and well-being.

- **Collaborative goal-setting** is a process by which providers and patients agree on health-related goals that can be general (e.g., exercising more) or specific (e.g., walking for 15 minutes four times a week) [81]. It can be useful to adapt care plans to patients' goals, values, and resources [82, 83].

- **Advanced care planning** refers to a process "which enables individuals to define goals and preferences for future medical treatment and care, including end-of life, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate" [83, 84].

The concepts and care approaches mentioned in this brief, non-limitative list contribute to a continuum of care that aims to move beyond the disease-oriented approach. While further research is needed to explore similarities and differences among these concepts and approaches, they all seem to share the common ground of improving patients' experiences and outcomes by actively involving patients as partners in their care. The underlying mechanisms of each concept and care approach (e.g., target population, setting) will likely to be different.

Further along this continuum, there is also the increasing recognition that people with multimorbidity would benefit from a focus on their personal goals (e.g., 'Control of pain to perform an activity such as bowling [85]) instead of health-related goals (e.g., 'Inventory of disease-specific signs and symptoms [85]) to direct the process of care [86]. This idea raises from the fact that the burden in multimorbidity, as mentioned before, stems from the risk of fragmented care. A focus on patients' personal goals has the potential to establish a shared understanding between patients and providers, thereby facilitating better collaboration, and reducing the risk of fragmented care [87], Above all, a focus on patients' personal goals will allow to address that what is important and meaningful to patients at all domains in life [88].

Judith

For Judith, the ideal approach to her care would involve her providers organizing care plans in a way that allows her to continue her commitments at the nursing home and community center. By placing emphasis on these personal goals, care would become more meaningful to Judith, and would likely enhance her overall well-being.

Box 8 Judith's case

Nevertheless, there is a significant lack in understanding concepts and care approaches that direct care process based on patients' personal goals. However, there is a rising concept that deserves further exploration, namely **goal-oriented care [88].**

GOAL-ORIENTED CARE

Goal-oriented care: origin

One of the originators to advocate for goal-oriented care is dr. Jim Mold. Dr. Mold is an American geriatrician who experienced in his work as a clinician that the cumulation of diseases older patients come with, requires another approach of care then the well-known disease-oriented guidelines. Long before the concept of health has been described more dynamic, dr. Mold started proposing a shift that recognizes the patient as a person with individual experiences, values, and goals. In 1991, he send this idea into the world as 'goal-oriented care' in his publication 'Goal-oriented medical care'. In this publication, he argues that each individual should be encouraged to achieve the highest possible level of health as defined by the individual [88].

Later, in 2012, Reuben and Tinetti proposed a similar alternative approach for healthcare delivery what they called 'goal-oriented patient care'. Both researchers are American geriatricians, so as dr. Mold, and experienced from their own practice that care delivery following a disease-oriented approach should be reconsidered. For them, goal-oriented patient care encompasses two main characteristics. First, care would be focused on patients' individual health goals within a variety of dimensions (e.g., symptoms, physical functional status, including mobility, social and role functions), and second, determine how well these goals are being met [85].

When talking about goal-oriented care, one cannot ignore these three clinician researchers. They have introduced the concept in literature and gave the impetus for other researchers to work on this new approach of care.

Goal-oriented care: ambiguity

Numerous studies have been conducted in the recent years to further explore goal-oriented care. However, not always under the same name. Other terms such as 'goal-setting decision [89]', 'patient priority directed decision-making [90]', 'goals in care [91]' found their way into the literature. The variety of these terms might hamper a common vision and understanding on goal-oriented care, and in the end, an efficient implementation.

This lack of a common vision has already resulted in a knowledge gap on how to put goal-oriented care into practice. This is demonstrated by the number of approaches and interventions that have been developed and reported in the literature. Patient Priority Care (PPC) was created by Naik and colleagues to align patients' desired outcomes with healthcare goals of providers. PPC is a structured process that involves patients initially conversing with a facilitator to determine their preferred outcome goals based on their values (i.e., value-based outcome goals) and healthcare preferences. Providers then use this information to engage in discussions that align their clinical decisions with the priorities of the patients [92]. On the other hand, Bernsten and colleagues proposed a patient-centered integrated (PC-IC) cyclical process. This process starts by defining the care plan's scope based on the patient's priorities and proceeds to align the care plan with those goals, resulting in the evaluation of goal-attainment [93]. In yet another study, Salter and

colleagues have developed a goal-setting training model. In this model, patients are prepared and engaged before eliciting and legitimizing their goals. Their final stage of collaborative action planning entails patients and providers discussing SMART (i.e., specific, measurable, achievable, relevant, time bound) goals [94].

These examples of approaches and interventions to put goal-oriented care into practice show that a shared understanding of the concept is missing and ambiguity exists. Although goal-oriented care holds promise, there are still knowledge gaps that must be addressed before it can be presented as a viable strategy for managing multimorbidity.

Goal-oriented care: viable strategy

Goal-oriented care knows its origin in practice making it a strong foundation for further uptake. To present goal-oriented care as a viable strategy in primary health care, it is essential to enrich it with scientific input, supplementing the existing practice-based experiences.

For the integration of goal-oriented care in primary health care and present it as a strategy to manage multimorbidity, we must strive to establish a shared understanding and a common ground to provide guidance. Drawing inspiration from proven models like the Chronic Care Model, we understand that goal-oriented care requires productive interactions at various levels and active involvement of diverse primary care stakeholders is needed [72]. Therefore, working on such understanding requires a multi perspective lens that accounts for various layers within primary health care; patients, informal caregivers, providers, scholars, policy makers [95].

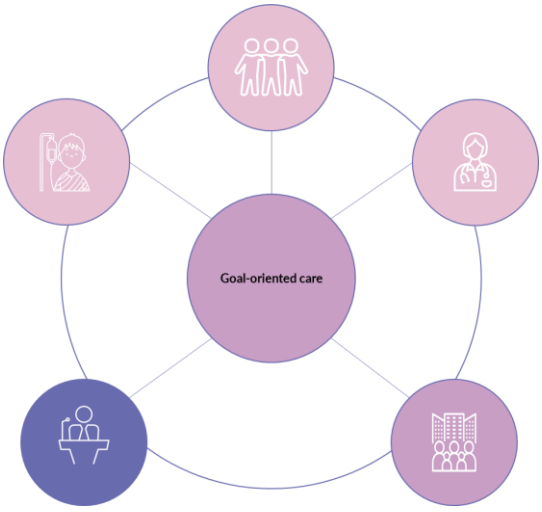

Figure 5 Multi perspective lens goal-oriented care

In conclusion, approaching goal-oriented care as a strategy to improve management of multimorbidity, is a complex task. It calls for integration of practice-based experiences and evidence-based scientific knowledge, along with the active engagement of primary care stakeholders.

RATIONALE

We ended by proposing goal-oriented care as a strategy for managing multimorbidity and overcoming the limitations of the disease-oriented paradigm in this context. Goal-oriented care seems to have the potential to address patients' personal goals across all domains of life, foster stronger patient-provider relationships, and improve integration of care by centering care around patients' personal goals. Goal-oriented care also appears to complement the core values of primary health care, making it a well-suited context for implementation. Given these advantages, it appears that goal-oriented care is a well-suited strategy for addressing the burdens that people with multimorbidity, providers, and healthcare systems often face.

Despite its potential, there still remain knowledge gaps. Gaps stem from a lack of a common understanding, which has resulted in the use of multiple terms to describe goal-oriented care, as well as varying approaches and interventions for implementation. To address these gaps, more insights are required on the theoretical underpinnings of goal-oriented care and how to translate it into primary health care. By identifying the building blocks of goal-oriented care, guidance can be offered to patients, providers, and primary health care to manage multimorbidity. Such intervention will be complex in nature because 1) multimorbidity affects multiple domains in life beyond the medical, 2) numerous stakeholders will need to be engaged in implementing goal-oriented care, and 3) an intervention cannot be limited to a "one size fits all approach". These reasons will make it challenging to translate goal-oriented care into a feasible strategy for primary health care.

With the title 'Goal-oriented care: bridging theory and practice; Towards building blocks for primary health care interventions', this dissertation aims to bridge many of the knowledge gaps in goal-oriented care by identifying the building blocks of goal-oriented care to inform interventions. It contributes to the body of knowledge on how to make the shift from 'what is the matter with the patient' to 'what matters most to the patient'.

REFERENCES

(1) Organization, W. H. Operational framework for primary health care: transforming vision into action. **2020**.
(2) Ahmed, A.; van den Muijsenbergh, M.; Vrijhoef, H. J. M. Person-centred care in primary care: What works for whom, how and in what circumstances? *Health Soc Care Community* **2022**, *30* (6), e3328-e3341. DOI: 10.1111/hsc.13913 From NLM.
(3) Dawson, B. Interim report on the future provision of medical and allied services. *Ministry of Health, Consultative Council on Medical and Allied Services. London* **1920**, *17*, 1083-1085.
(4) Organization, W. H. *Declaration of alma-ata*; World Health Organization. Regional Office for Europe, 1978.
(5) Starfield, B.; Shi, L.; Macinko, J. Contribution of primary care to health systems and health. *The milbank quarterly* **2005**, *83* (3), 457-502.
(6) Chan, M. Primary health care: now more than ever. *UN Chronicle* **2012**, *47* (2), 4-7.
(7) Organization, W. H. *Report of the Global conference on primary health care: from Alma-Ata towards universal health coverage and the Sustainable Development Goals*; World Health Organization, 2019.
(8) Organization, W. H. *A vision for primary health care in the 21st century: towards universal health coverage and the Sustainable Development Goals*; World Health Organization, 2018.
(9) Starfield, B. *Primary care: balancing health needs, services, and technology*; Religion in America, 1998.
(10) Lautamatti, E.; Sumanen, M.; Raivio, R.; Mattila, K. J. Continuity of care is associated with satisfaction with local health care services. *BMC Fam Pract* **2020**, *21* (1), 181. DOI: 10.1186/s12875-020-01251-5 From NLM.
(11) Bazemore, A.; Grunert, T. Sailing the 7C's: Starfield revisited as a foundation of family medicine residency redesign. *Family Medicine* **2021**, *53* (7), 506-515.
(12) Bodenheimer, T.; Ghorob, A.; Willard-Grace, R.; Grumbach, K. The 10 building blocks of high-performing primary care. *The Annals of Family Medicine* **2014**, *12* (2), 166-171.
(13) Epperly, T.; Bechtel, C.; Sweeney, R.; Greiner, A.; Grumbach, K.; Schilz, J.; Stream, G.; O'Connor, M. The shared principles of primary care: a multistakeholder initiative to find a common voice. *Family Medicine* **2019**, *51* (2), 179-184.
(14) Rao, M.; Pilot, E. The missing link--the role of primary care in global health. *Glob Health Action* **2014**, *7*, 23693. DOI: 10.3402/gha.v7.23693 From NLM.
(15) van Weel, C.; Kidd, M. R. Why strengthening primary health care is essential to achieving universal health coverage. *Cmaj* **2018**, *190* (15), E463-e466. DOI: 10.1503/cmaj.170784 From NLM.
(16) Sawicki, O. A.; Mueller, A.; Klaaßen-Mielke, R.; Glushan, A.; Gerlach, F. M.; Beyer, M.; Wensing, M.; Karimova, K. Strong and sustainable primary healthcare is associated with a lower risk of hospitalization in high risk patients. *Sci Rep* **2021**, *11* (1), 4349. DOI: 10.1038/s41598-021-83962-y From NLM.
(17) Detollenaere, J.; Desmarest, A.-S.; Boeckxstaens, P.; Willems, S. The link between income inequality and health in Europe, adding strength dimensions of primary care to the equation. *Social Science & Medicine* **2018**, *201*, 103-110.

(18) Itchhaporia, D. The Evolution of the Quintuple Aim: Health Equity, Health Outcomes, and the Economy. *J Am Coll Cardiol* **2021**, *78* (22), 2262-2264. DOI: 10.1016/j.jacc.2021.10.018 From NLM.
(19) Stange, K. C.; Ferrer, R. L. The paradox of primary care. Annals Family Med: 2009; Vol. 7, pp 293-299.
(20) Fortin, M.; Lapointe, L.; Hudon, C.; Vanasse, A.; Ntetu, A. L.; Maltais, D. Multimorbidity and quality of life in primary care: a systematic review. *Health and Quality of life Outcomes* **2004**, *2* (1), 1-12.
(21) McGlynn, E. A.; Asch, S. M.; Adams, J.; Keesey, J.; Hicks, J.; DeCristofaro, A.; Kerr, E. A. The quality of health care delivered to adults in the United States. *N Engl J Med* **2003**, *348* (26), 2635-2645. DOI: 10.1056/NEJMsa022615 From NLM.
(22) Wallace, E.; Salisbury, C.; Guthrie, B.; Lewis, C.; Fahey, T.; Smith, S. M. Managing patients with multimorbidity in primary care. *Bmj* **2015**, *350*.
(23) Hansen, J.; Groenewegen, P. P.; Boerma, W. G.; Kringos, D. S. Living in a country with a strong primary care system is beneficial to people with chronic conditions. *Health affairs* **2015**, *34* (9), 1531-1537.
(24) Koné Pefoyo, A. J.; Bronskill, S. E.; Gruneir, A.; Calzavara, A.; Thavorn, K.; Petrosyan, Y.; Maxwell, C. J.; Bai, Y.; Wodchis, W. P. The increasing burden and complexity of multimorbidity. *BMC public health* **2015**, *15* (1), 1-11.
(25) Canguilhem, G. *On the Normal and the Pathological*; Springer Science & Business Media, 2012.
(26) Huber, M.; Knottnerus, J. A.; Green, L.; Van Der Horst, H.; Jadad, A. R.; Kromhout, D.; Leonard, B.; Lorig, K.; Loureiro, M. I.; Van Der Meer, J. W. How should we define health? *Bmj* **2011**, *343*.
(27) Iglesias, F. H.; Celada, C. A.; Navarro, C. B.; Morales, L. P.; Visus, N. A.; Valverde, C. C.; Dorado, V. M.; Martínez Muñoz, M. L.; Pueyo, C. B.; Ramírez, E. L.; 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. DOI: 10.5334/ijic.3292 From NLM.
(28) Organization, W. H. *Global status report on noncommunicable diseases 2014*; World Health Organization, 2014. Emson, H. E. Health, disease and illness: matters for definition. *CMAJ: Canadian Medical Association Journal* **1987**, *136* (8), 811.
(29) Johnston, M. C.; Crilly, M.; Black, C.; Prescott, G. J.; Mercer, S. W. Defining and measuring multimorbidity: a systematic review of systematic reviews. *European journal of public health* **2019**, *29* (1), 182-189.
(30) Le Reste, J. Y.; Nabbe, P.; Lygidakis, C.; Doerr, C.; Lingner, H.; Czachowski, S.; Munoz, M.; Argyriadou, S.; Claveria, A.; Calvez, A. A research group from the European General Practice Research Network (EGPRN) explores the concept of multimorbidity for further research into long term care. *Journal of the American Medical Directors Association* **2013**, *14* (2), 132-133.
(31) Holzer, B. M.; Siebenhuener, K.; Bopp, M.; Minder, C. E. Overcoming cut-off restrictions in multimorbidity prevalence estimates. *BMC public health* **2014**, *14*, 1-6.
(32) Hajat, C.; Stein, E. The global burden of multiple chronic conditions: A narrative review. *Preventive medicine reports* **2018**, *12*, 284-293.

(33) Van Der Heyden, J.; Charafeddine, R. Chronische ziekten en aandoeningen. *Gezondheidsenquëte* **2018**, 37-38.
(34) Van Merode, T.; Van De Ven, K.; Van Den Akker, M. Patients with multimorbidity and their treatment burden in different daily life domains: a qualitative study in primary care in the Netherlands and Belgium. *Journal of comorbidity* **2018**, *8* (1), 9-15.
(35) Van Wilder, L.; Devleesschauwer, B.; Clays, E.; De Buyser, S.; Van der Heyden, J.; Charafeddine, R.; Boeckxstaens, P.; De Bacquer, D.; Vandepitte, S.; De Smedt, D. The impact of multimorbidity patterns on health-related quality of life in the general population: results of the Belgian Health Interview Survey. *Qual Life Res* **2022**, *31* (2), 551-565. DOI: 10.1007/s11136-021-02951-w From NLM.
(36) Group, W. The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social science & medicine* **1995**, *41* (10), 1403-1409.
(37) Arnold, R.; Ranchor, A.; Sanderman, R.; Kempen, G.; Ormel, J.; Suurmeijer, T. P. The relative contribution of domains of quality of life to overall quality of life for different chronic diseases. *Quality of life Research* **2004**, *13*, 883-896.
(38) Karimi, M.; Brazier, J. Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics* **2016**, *34*, 645-649.
(39) Megari, K. Quality of life in chronic disease patients. *Health psychology research* **2013**, *1* (3).
(40) Zhou, T.; Guan, H.; Wang, L.; Zhang, Y.; Rui, M.; Ma, A. Health-related quality of life in patients with different diseases measured with the EQ-5D-5L: a systematic review. *Frontiers in Public Health* **2021**, *9*, 675523.
(41) Duguay, C.; Gallagher, F.; Fortin, M. The experience of adults with multimorbidity: a qualitative study. *Journal of comorbidity* **2014**, *4* (1), 11-21.
(42) Rosbach, M.; Andersen, J. S. Patient-experienced burden of treatment in patients with multimorbidity–a systematic review of qualitative data. *PloS one* **2017**, *12* (6), e0179916.
(43) Savoy, M.; Hazlett-O'Brien, C.; Rapacciuolo, J. The Role of Primary Care Physicians in Managing Chronic Disease. *Dela J Public Health* **2017**, *3* (1), 86-93. DOI: 10.32481/djph.2017.03.012 From NLM.
(44) Braillard, O.; Slama-Chaudhry, A.; Joly, C.; Perone, N.; Beran, D. The impact of chronic disease management on primary care doctors in Switzerland: a qualitative study. *BMC family practice* **2018**, *19*, 1-9.
(45) 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.
(46) Bower, P.; Macdonald, W.; Harkness, E.; Gask, L.; Kendrick, T.; Valderas, J. M.; Dickens, C.; Blakeman, T.; Sibbald, B. Multimorbidity, service organization and clinical decision making in primary care: a qualitative study. *Family practice* **2011**, *28* (5), 579-587.
(47) Lehnert, T.; Heider, D.; Leicht, H.; Heinrich, S.; Corrieri, S.; Luppa, M.; Riedel-Heller, S.; König, H.-H. Health care utilization and costs of elderly persons with multiple chronic conditions. *Medical Care Research and Review* **2011**, *68* (4), 387-420.

(48) Glynn, L. G.; Valderas, J. M.; Healy, P.; Burke, E.; Newell, J.; Gillespie, P.; Murphy, A. W. The prevalence of multimorbidity in primary care and its effect on health care utilization and cost. *Family practice* **2011**, *28* (5), 516-523.
(49) Picco, L.; Achilla, E.; Abdin, E.; Chong, S. A.; Vaingankar, J. A.; McCrone, P.; Chua, H. C.; Heng, D.; Magadi, H.; Ng, L. L. Economic burden of multimorbidity among older adults: impact on healthcare and societal costs. *BMC health services research* **2016**, *16*, 1-12.
(50) Joo, J. Y. Fragmented care and chronic illness patient outcomes: A systematic review. *Nurs Open* **2023**. DOI: 10.1002/nop2.1607 From NLM.
(51) Organization, W. H. Definition of health. *http://www. who. int/suggestions/faq/zh/index. html* **1948**.
(52) Card, A. J. Moving beyond the WHO definition of health: a new perspective for an aging world and the emerging era of value-based care. *World Medical & Health Policy* **2017**, *9* (1), 127-137.
(53) What is health? The ability to adapt. *Lancet* **2009**, *373* (9666), 781. DOI: 10.1016/s0140-6736(09)60456-6 From NLM.
(54) Dubos, R. J. *Mirage of health: utopias, progress and biological change*; Rutgers University Press, 1987.
(55) Pierret, J. The illness experience: state of knowledge and perspectives for research. *Sociology of health & illness* **2003**, *25* (3), 4-22.
(56) Larsen, P. D. The illness experience. *Lubkin's Chronic Illness: Impact and Intervention* **2014**, 21-43.
(57) Sackett, D. L. Evidence-based medicine. In *Seminars in perinatology*, 1997; Elsevier: Vol. 21, pp 3-5.
(58) Masic, I.; Miokovic, M.; Muhamedagic, B. Evidence based medicine-new approaches and challenges. *Acta informatica medica: AIM: journal of the Society for Medical Informatics of Bosnia & Herzegovina: casopis Drustva za medicinsku informatiku BiH* **2008**, *16* (4), 219-225.
(59) Haynes, R. B.; Devereaux, P. J.; Guyatt, G. H. Clinical expertise in the era of evidence-based medicine and patient choice. *BMJ Evidence-Based Medicine* **2002**, *7* (2), 36-38.
(60) Steinberg, E.; Greenfield, S.; Wolman, D. M.; Mancher, M.; Graham, R. *Clinical practice guidelines we can trust*; national academies press, 2011.
(61) Eddy, D. M.; Adler, J.; Patterson, B.; Lucas, D.; Smith, K. A.; Morris, M. Individualized guidelines: the potential for increasing quality and reducing costs. *Annals of Internal Medicine* **2011**, *154* (9), 627-634.
(62) Hughes, L. D.; McMurdo, M. E.; Guthrie, B. Guidelines for people not for diseases: the challenges of applying UK clinical guidelines to people with multimorbidity. *Age Ageing* **2013**, *42* (1), 62-69. DOI: 10.1093/ageing/afs100 From NLM.
(63) Guthrie, B.; Payne, K.; Alderson, P.; McMurdo, M. E.; Mercer, S. W. Adapting clinical guidelines to take account of multimorbidity. *Bmj* **2012**, *345*, e6341.
(64) Weiss, C. O.; Varadhan, R.; Puhan, M. A.; Vickers, A.; Bandeen-Roche, K.; Boyd, C. M.; Kent, D. M. Multimorbidity and evidence generation. *Journal of general internal medicine* **2014**, *29*, 653-660.
(65) Austad, B.; Hetlevik, I.; Mjølstad, B. P.; Helvik, A.-S. Applying clinical guidelines in general practice: a qualitative study of potential complications. *BMC family practice* **2016**, *17*, 1-8.

(66) Stange, K. C. The problem of fragmentation and the need for integrative solutions. *Ann Fam Med* **2009**, *7* (2), 100-103. DOI: 10.1370/afm.971 From NLM.
(67) Baker, A. *Crossing the quality chasm: a new health system for the 21st century*; British Medical Journal Publishing Group, 2001.
(68) Stewart, M.; Brown, J. B.; Weston, W.; McWhinney, I. R.; McWilliam, C. L.; Freeman, T. *Patient-centered medicine: transforming the clinical method*; CRC press, 2013.
(69) Kuipers, S. J.; Cramm, J. M.; Nieboer, A. P. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Serv Res* **2019**, *19* (1), 13. DOI: 10.1186/s12913-018-3818-y From NLM.
(70) Poitras, M.-E.; Maltais, M.-E.; Bestard-Denommé, L.; Stewart, M.; Fortin, M. What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC health services research* **2018**, *18*, 1-9.
(71) Grover, A.; Joshi, A. An overview of chronic disease models: a systematic literature review. *Glob J Health Sci* **2014**, *7* (2), 210-227. DOI: 10.5539/gjhs.v7n2p210 From NLM.
(72) Wagner, E. H.; Bennett, S. M.; Austin, B. T.; Greene, S. M.; Schaefer, J. K.; Vonkorff, M. Finding common ground: patient-centeredness and evidence-based chronic illness care. *J Altern Complement Med* **2005**, *11 Suppl 1*, S7-15. DOI: 10.1089/acm.2005.11.s-7 From NLM.
(73) Battersby, M.; Von Korff, M.; Schaefer, J.; Davis, C.; Ludman, E.; Greene, S. M.; Parkerton, M.; Wagner, E. H. Twelve evidence-based principles for implementing self-management support in primary care. *Jt Comm J Qual Patient Saf* **2010**, *36* (12), 561-570. DOI: 10.1016/s1553-7250(10)36084-3 From NLM.
(74) Boehmer, K. R.; Abu Dabrh, A. M.; Gionfriddo, M. R.; Erwin, P.; Montori, V. M. Does the chronic care model meet the emerging needs of people living with multimorbidity? A systematic review and thematic synthesis. *PLoS One* **2018**, *13* (2), e0190852. DOI: 10.1371/journal.pone.0190852 From NLM.
(75) Stellefson, M.; Dipnarine, K.; Stopka, C. The chronic care model and diabetes management in US primary care settings: a systematic review. *Prev Chronic Dis* **2013**, *10*, E26. DOI: 10.5888/pcd10.120180 From NLM.
(76) Adams, S. G.; Smith, P. K.; Allan, P. F.; Anzueto, A.; Pugh, J. A.; Cornell, J. E. Systematic review of the chronic care model in chronic obstructive pulmonary disease prevention and management. *Arch Intern Med* **2007**, *167* (6), 551-561. DOI: 10.1001/archinte.167.6.551 From NLM.
(77) Kuluski, K.; Reid, R. J.; Baker, G. R. Applying the principles of adaptive leadership to person-centred care for people with complex care needs: Considerations for care providers, patients, caregivers and organizations. *Health Expect* **2021**, *24* (2), 175-181. DOI: 10.1111/hex.13174 From NLM.
(78) Oksavik, J. D.; Aarseth, T.; Solbjør, M.; Kirchhoff, R. 'What matters to you?' Normative integration of an intervention to promote participation of older patients with multi-morbidity - a qualitative case study. *BMC Health Serv Res* **2021**, *21* (1), 117. DOI: 10.1186/s12913-021-06106-y From NLM.

(79) Coulter, A.; Entwistle, V. A.; Eccles, A.; Ryan, S.; Shepperd, S.; Perera, R. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database Syst Rev* **2015**, *2015* (3), Cd010523. DOI: 10.1002/14651858.CD010523.pub2 From NLM.
(80) Fioretti, C.; Mazzocco, K.; Riva, S.; Oliveri, S.; Masiero, M.; Pravettoni, G. Research studies on patients' illness experience using the Narrative Medicine approach: a systematic review. *BMJ Open* **2016**, *6* (7), e011220. DOI: 10.1136/bmjopen-2016-011220 From NLM.
(81) Bodenheimer, T.; Handley, M. A. Goal-setting for behavior change in primary care: an exploration and status report. *Patient Educ Couns* **2009**, *76* (2), 174-180. DOI: 10.1016/j.pec.2009.06.001 From NLM.
(82) Vermunt, N.; Harmsen, M.; Westert, G. P.; Olde Rikkert, M. G. M.; Faber, M. J. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC Geriatr* **2017**, *17* (1), 167. DOI: 10.1186/s12877-017-0534-0 From NLM.
(83) Sudore, R. L.; Lum, H. D.; You, J. J.; Hanson, L. C.; Meier, D. E.; Pantilat, S. Z.; Matlock, D. D.; Rietjens, J. A. C.; Korfage, I. J.; Ritchie, C. S.; et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage* **2017**, *53* (5), 821-832.e821. DOI: 10.1016/j.jpainsymman.2016.12.331 From NLM.
(84) Rietjens, J. A. C.; Sudore, R. L.; Connolly, M.; van Delden, J. J.; Drickamer, M. A.; Droger, M.; van der Heide, A.; Heyland, D. K.; Houttekier, D.; Janssen, D. J. A.; et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* **2017**, *18* (9), e543-e551. DOI: 10.1016/s1470-2045(17)30582-x From NLM.
(85) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* **2012**, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM.
(86) Kernick, D.; Chew-Graham, C. A.; O'Flynn, N. Clinical assessment and management of multimorbidity: NICE guideline. *Br J Gen Pract* **2017**, *67* (658), 235-236. DOI: 10.3399/bjgp17X690857 From NLM.
(87) Steele Gray, C.; Grudniewicz, A.; Armas, A.; Mold, J.; Im, J.; Boeckxstaens, P. Goal-Oriented Care: A Catalyst for Person-Centred System Integration. *Int J Integr Care* **2020**, *20* (4), 8. DOI: 10.5334/ijic.5520 From NLM.
(88) Mold, J. W.; Blake, G. H.; Becker, L. A. Goal-oriented medical care. *Fam Med* **1991**, *23* (1), 46-51. From NLM.
(89) Yu, C. H.; Ivers, N. M.; Stacey, D.; Rezmovitz, J.; Telner, D.; Thorpe, K.; Hall, S.; Settino, M.; Kaplan, D. M.; Coons, M.; et al. Impact of an interprofessional shared decision-making and goal-setting decision aid for patients with diabetes on decisional conflict--study protocol for a randomized controlled trial. *Trials* **2015**, *16*, 286. DOI: 10.1186/s13063-015-0797-8 From NLM.
(90) Tinetti, M. E.; Esterson, J.; Ferris, R.; Posner, P.; Blaum, C. S. Patient Priority-Directed Decision Making and Care for Older Adults with Multiple Chronic Conditions. *Clin Geriatr Med* **2016**, *32* (2), 261-275. DOI: 10.1016/j.cger.2016.01.012 From NLM.
(91) Secunda, K.; Wirpsa, M. J.; Neely, K. J.; Szmuilowicz, E.; Wood, G. J.; Panozzo, E.; McGrath, J.; Levenson, A.; Peterson, J.; Gordon, E. J.; et al. Use and Meaning of "Goals of Care" in the Healthcare Literature: a Systematic Review and Qualitative Discourse Analysis. *J Gen Intern Med* **2020**, *35* (5), 1559-1566. DOI: 10.1007/s11606-019-05446-0 From NLM.

(92) Naik, A. D.; Dindo, L. N.; Van Liew, J. R.; Hundt, N. E.; Vo, L.; Hernandez-Bigos, K.; Esterson, J.; Geda, M.; Rosen, J.; Blaum, C. S.; et al. Development of a Clinically Feasible Process for Identifying Individual Health Priorities. *J Am Geriatr Soc* **2018**, *66* (10), 1872-1879. DOI: 10.1111/jgs.15437 From NLM.
(93) Berntsen, G. K.; Gammon, D.; Steinsbekk, A.; Salamonsen, A.; Foss, N.; Ruland, C.; Fønnebø, V. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care. *BMJ Open* **2015**, *5* (12), e009403. DOI: 10.1136/bmjopen-2015-009403 From NLM.
(94) Salter, C.; Shiner, A.; Lenaghan, E.; Murdoch, J.; Ford, J. A.; Winterburn, S.; Steel, N. Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations. *British Journal of General Practice* **2019**, *69* (684), e479-e488.
(95) Huybrechts, I.; Declercq, A.; Verté, E.; Boeckxstaens, P.; Raeymaeckers, P.; Anthierens, S. Will the implementation process for goal-oriented primary care succeed? A qualitative study investigating five perceived attributes of goal-oriented care. *Soc Sci Med* **2023**, *331*, 116048. DOI: 10.1016/j.socscimed.2023.116048 From NLM.

AIMS and OUTLINE

Research aim

This dissertation aims to identify the building blocks of goal-oriented care interventions for primary health care accordingly to the development phase of the Medical Research Council (MRC) Framework.

Medical Research Council Framework

The Medical Research Council Framework (MRC), developed by the UK Medical Research Council in 2000, is used as a guiding framework to underline the outline of the studies. The framework offers guidance for developing and evaluating complex interventions, and can as such offer guidance in identifying the building blocks of goal-oriented care. Complex interventions are defined as *"interventions with several interacting components, difficulty of behaviors required by delivering the intervention, number of groups targeted by the intervention, variability of outcomes, and degree of flexibility of the intervention permitted*[1]*."*

The framework has been continuously revised to address key questions about complex interventions [2], but the four main phases remained the same over the years: 1) intervention development, 2) feasibility and piloting the intervention model, 3) evaluation, and 4) implementation [1]. This dissertation focusses on the development phase that includes three steps: 1) identifying the evidence base, 2) identifying and developing the theory, and 3) modelling process and outcomes.

Intervention development is an iterative process that involves stakeholders, reviewing published research evidence, undertaking primary data collection in the real world [3]. Therefore, to identify the building blocks of goal-oriented care interventions, multiple viewpoints (i.e., patients, informal caregivers, primary care providers, scholars, and policy makers) are continuously captured over the different studies by a combination of foremost qualitative research approaches. This allowed us to stay close to the context wherein goal-oriented should be implemented.

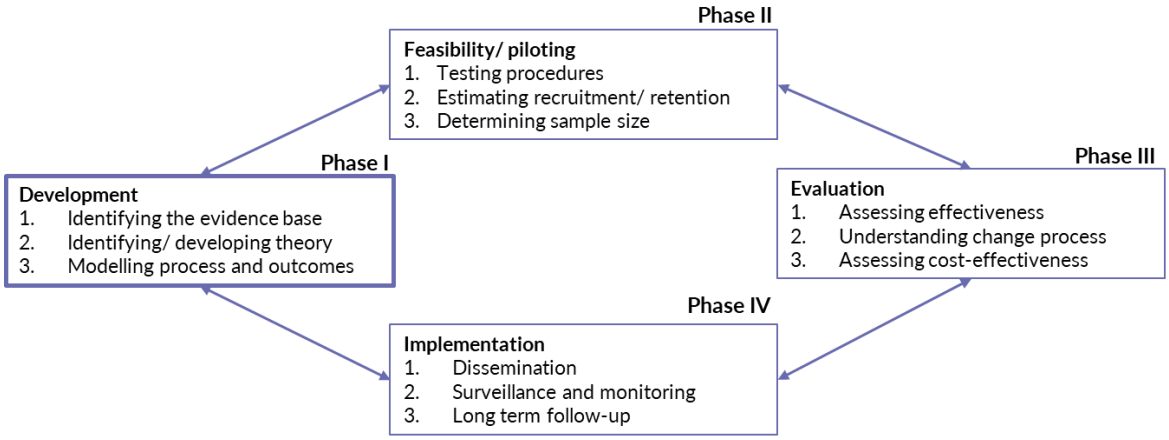

Figure 6 Medical Research Council Framework

Research methodologies

Various research methodologies, mainly grounded in a qualitative design, are used to identify the building blocks of goal-oriented care interventions. Qualitative research is a research approach that focuses on understanding and interpreting social phenomena through collection and analysis of non-numerical data. It aims to explore the complexities, meanings, and subjective experiences of individuals or groups in their natural setting [4]. In this dissertation, a qualitative lens was used to identify the building blocks of a goal-oriented care intervention.

Four different approaches have been applied: phenomenological-hermeneutics, descriptive phenomenology, normalization process theory, and a concept analysis.

Phenomenology

Two approaches within the broader field of phenomenology have been applied: phenomenological-hermeneutical method and descriptive phenomenology.

Phenomenological-hermeneutics

A phenomenological-hermeneutical method, as introduced by Lindseth and Norberg, draws from the tradition of phenomenology as well from the tradition of hermeneutics to research lived experiences. Lived experiences can be understood as *'experiences we simply have without concluding anything from it. It is more felt than known. Only when we express it, through word or deed, we realize what it is about.'* [5].

Phenomenology originated from the work of philosopher Edmund Husserl and has been further developed by other successors. It offers a philosophical and methodological framework that focuses on the subjective experience and meaning of phenomena as they are perceived and lived by individuals. Phenomenology explores the lived experience of individuals and aims to uncover the underlying structures and essences of these experiences [6].

Hermeneutics was introduced by Heidegger and is the study of interpretation. This assumes the idea that there is no such thing as pure description; every communicative act involves interpretation [6].

Lindseth and Norberg combines those two philosophies and developed a phenomenological-hermeneutical method for interpreting narrative texts, such as interview transcripts. Their method was inspired by Paul Ricoeur who presented the hermeneutic circle to emphasize the process of understanding and interpreting the world. This circle consists of three phases that are reiterated by Lindseth and Norberg. The first phase is getting familiarity with a text; in this case interview transcripts. Together with the researcher's preunderstanding, a first idea of what the text is about is generated. In the second phase, the transcripts are more closely looked at to find out how parts are related to the whole and form a structure of meaning. Lastly, the third phase is aimed at returning back to the whole and form a comprehensive understanding [5].

In this dissertation, the phenomenological-hermeneutical method is applied in both one-on-one interviews with people living with chronic conditions and their informal caregivers (study 1), and in focus groups with primary care stakeholders (study 2).

The use of this method in focus groups seems at odds and one might argue that they are not compatible. However, other studies have already demonstrated that individual, lived experiences can be preserved within a focus group setting [7]. These settings can stimulate discussions and open new perspectives. Nevertheless, more than in one-on-one interviews, it is important to remain critical and keep in mind the phenomenon under investigation [8] .

Descriptive phenomenology

Sundler et al. present a guiding framework for conducting thematic analysis grounded in descriptive phenomenology [9]. This approach, inspired by Husserl's writings, provides a valuable tool to analyze lived experiences. The aim of this analysis is to unravel patterns of meaning derived from interview transcripts, leading to the formulation of themes that capture the richness and significance of these experiences. Sundler et al. prescribes three steps: 1) achieve familiarity with the data through open-minded reading, 2) search for meanings and themes, and 3) organizing themes into a meaningful wholeness[9]. Compared to the phenomenological-hermeneutical method, descriptive phenomenology places less emphasis on interpretation and contextual understanding.

Normalization process theory

To bridge the gap between research and implementation, the Normalization Process Theory (NPT) offers valuable insights into successful implementation and integration of interventions into routine work [10]. NPT explores how interventions become routine practices through four key constructs: coherence (or sense-making), cognitive participation (or engagement), collective action (or work done to enable the intervention to happen), and reflexive monitoring (or formal and informal appraisal of the benefits and costs of the intervention) [11]. These constructs interact dynamically with each other and the broader intervention context. By exploring these dynamics, crucial insights into the reception and normalization of goal-oriented care as a normalized practice is gained which offers a starting point to assess if further investment goal-oriented care is worthwhile.

Concept analysis

The method of Walker and Avant is used to conduct a concept analysis, which serves as a systematic approach for the clarification of the attributes, antecedents, and consequences of a specific concept, namely goal-oriented care. The purpose of a concept analysis is to provide precise insights into goal-oriented care, thereby enhancing its theoretical and practical understanding within primary health care. The methodology prescribed by Walker and Avant entails a structured eight-step approach: identifying the concept, determining its purpose and scope, conducting a literature review, defining the attributes, identifying the antecedents and consequences, illustrating with cases, and providing empirical referents for measurement [12].

Outline

The described methodologies are applied in six studies to identify the building blocks for goal-oriented care interventions; three for identifying the evidence base, one for identifying/ developing theory, and two for modelling process and outcomes. Of those six studies, five are published in peer-reviewed A1 journals, and one is under review.

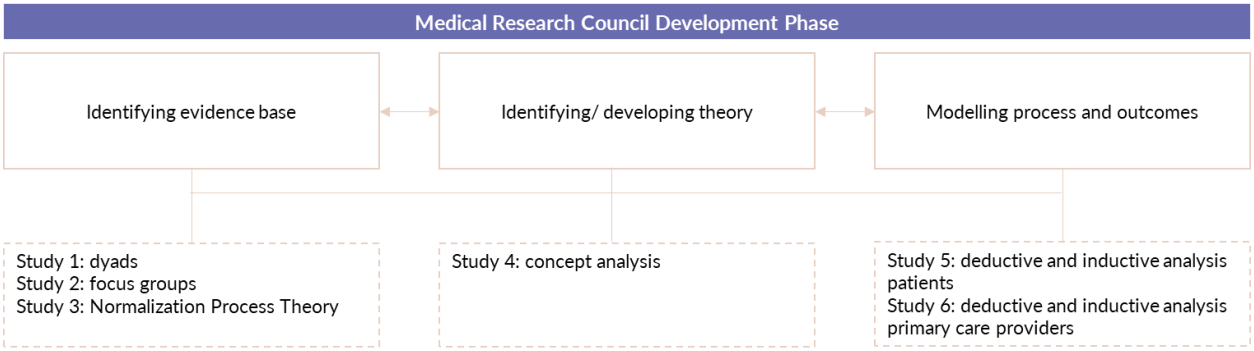

Figure 7 Overview of the studies

Identifying the evidence base

The first three studies aim to identify the evidence base for goal-oriented care. The first study describes how people living with chronic conditions and their informal caregivers (i.e., PCDs) experience primary care and what is needed to improve quality of care. This study allows us to determine if and how PCDs reflect upon their need for goal-oriented care. The second study provides insights into how primary care stakeholders (i.e., scholars, policy makers, and primary care providers) introduce patients' personal goals into care. It gives a first glimpse on how patients' personal goals are addressed, strategies that are used, and challenges encountered in putting patients' personal goals first. Drawing from the stakeholders' experiences, it is possible to create an initial understanding of the actions that should be taken to direct care by patients' personal goals. By looking at goal-oriented care through a theoretical implementation lens, the third study gives a first idea on how goal-oriented care would be received as a new intervention in primary care. In this way, this study explores the potential for implementing goal-oriented care and additionally identifies focal points for a goal-oriented care intervention.

Paper	Research question	Design
How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study	How do people living with chronic conditions and their informal caregivers experience primary healthcare in Flanders?	A qualitative, phenomenological-hermeneutical research design, in-depth interviews with 32 individuals (i.e., 16 patients and informal caregiver dyads).

Creating space to talk about patients' personal goals: experiences from primary care stakeholders	What are the experiences, strategies, and challenges of primary care stakeholders with putting patients' personal goals first during care delivery?	A qualitative, phenomenological-hermeneutical research design, six focus groups in four waves with 41 participants.
Exploring readiness for implementing goal-oriented care in primary care using Normalization Process Theory	What is the potential for implementing goal-oriented care in primary care in Flanders?	A quantitative study using the Normalization Process Theory with 131 primary care providers who have followed a two-hour introduction on goal-oriented care.

Identifying/ developing theory

The fourth study identifies and develops a theory on goal-oriented care. By means of a concept analysis, this study describes the attributes (i.e., main characteristics), antecedents, and consequences of goal-oriented care. This allowed us to generate a comprehensive understanding, grounded in literature, of goal-oriented care.

Paper	Research question	Design
Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: a scoping review and concept analysis	What are the antecedents, attributes, and consequences of goal-oriented care?	A concept analysis using the method of Walker and Avant based on 37 research articles.

Modelling process and outcomes

The fifth and sixth study aim to model the goal-oriented process of care that was developed in the fourth study. The fifth study models this process by adding the perspectives of people living with chronic conditions and multimorbidity. The sixth study takes the point of view of primary care providers. In this way, the theory on goal-oriented care is further modelled by integrating a top down approach from literature, and bottom-up approach based on practice-based experiences.

Paper	Research question	Design
Goal-oriented care: building an understanding through the experiences of people living with chronic conditions	How do people living with chronic conditions experience goal-oriented care during primary care encounters?	A qualitative deductive and inductive, thematic analysis based on a descriptive phenomenology on 50 interviews with people living with chronic conditions.
Goal-oriented care: from the theoretical concept to a descriptive understanding of how primary care stakeholders put this into practice	How do primary care providers and leaders put goal-oriented care into practice?	A qualitative deductive and inductive, thematic analysis on 48 in-depth interviews with primary care providers of three different sites (Ghent, Ottawa, and Vermont).

REFERENCES

(1) 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*, a1655. DOI: 10.1136/bmj.a1655 From NLM.
(2) Bleijenberg, N.; de Man-van Ginkel, J. M.; Trappenburg, J. C. A.; Ettema, R. G. A.; Sino, C. G.; Heim, N.; Hafsteindóttir, T. B.; Richards, D. A.; Schuurmans, M. J. Increasing value and reducing waste by optimizing the development of complex interventions: Enriching the development phase of the Medical Research Council (MRC) Framework. *Int J Nurs Stud* **2018**, *79*, 86-93. DOI: 10.1016/j.ijnurstu.2017.12.001 From NLM. Skivington, K.; Matthews, L.; Simpson, S. A.; Craig, P.; Baird, J.; Blazeby, J. M.; Boyd, K. A.; Craig, N.; French, D. P.; McIntosh, E.; et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *Bmj* **2021**, *374*, n2061. DOI: 10.1136/bmj.n2061 From NLM.
(3) O'Cathain, A.; Croot, L.; Duncan, E.; Rousseau, N.; Sworn, K.; Turner, K. M.; Yardley, L.; Hoddinott, P. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open* **2019**, *9* (8), e029954. DOI: 10.1136/bmjopen-2019-029954 From NLM.
(4) Jackson, R. L.; Drummond, D. K.; Camara, S. What is qualitative research? *Qualitative research reports in communication* **2007**, *8* (1), 21-28.
(5) Lindseth, A.; Norberg, A. Elucidating the meaning of life world phenomena. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* **2022**, *36* (3), 883-890. DOI: 10.1111/scs.13039 From NLM. Lindseth, A.; Norberg, A. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* **2004**, *18* (2), 145-153. DOI: 10.1111/j.1471-6712.2004.00258.x From NLM.
(6) Patton, M. Q. *Qualitative research & evaluation methods: Integrating theory and practice*; Sage publications, 2014.
(7) Tomkins, L.; Eatough, V. Reflecting on the use of IPA with focus groups: Pitfalls and potentials. *Qualitative Research in Psychology* **2010**, *7* (3), 244-262. Palmer, M.; Larkin, M.; De Visser, R.; Fadden, G. Developing an interpretative phenomenological approach to focus group data. *Qualitative research in psychology* **2010**, *7* (2), 99-121.
(8) Bradbury-Jones, C.; Sambrook, S.; Irvine, F. The phenomenological focus group: an oxymoron? *J Adv Nurs* **2009**, *65* (3), 663-671. DOI: 10.1111/j.1365-2648.2008.04922.x From NLM.
(9) Sundler, A. J.; Lindberg, E.; Nilsson, C.; Palmér, L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open* **2019**, *6* (3), 733-739. DOI: 10.1002/nop2.275 From NLM.
(10) May, C. R.; Cummings, A.; Girling, M.; Bracher, M.; Mair, F. S.; May, C. M.; Murray, E.; Myall, M.; Rapley, T.; Finch, T. Using normalization process theory in feasibility studies and process evaluations of complex healthcare interventions: a systematic review. *Implementation science* **2018**, *13* (1), 1-27.
(11) Murray, E.; Treweek, S.; Pope, C.; MacFarlane, A.; Ballini, L.; Dowrick, C.; Finch, T.; Kennedy, A.; Mair, F.; O'Donnell, C.; et al. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC Med* **2010**, *8*, 63. DOI: 10.1186/1741-7015-8-63 From NLM.
(12) Walker, L. O.; Avant, K. C. *Strategies for theory construction in nursing*; Pearson/Prentice Hall Upper Saddle River, NJ, 2005.

RESULTS

RESULTS

Paper 1

Dagje Boeykens*, Muhammed Mustafa Sirimsi*, Lotte Timmermans*, Maja Lopez Hartmann, Dominique Van de Velde^, Patricia De Vriendt^ & on behalf of the Primary Care Academy. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. Journal of Clinical Nursing, doi: 10.1111/jocn.16243

A1, Q1, IF=4,42

Paper 2

Dagje Boeykens*, Reini Haverals*, Muhammed Mustafa Sirimsi, Lotte Timmermans, Dominique Van de Velde, Patricia De Vriendt^, Pauline Boeckxstaens^ & on behalf of the Primary Care Academy. Creating space to talk about patients' personal goals: experiences from primary care stakeholders. BMC Primary Care, doi.org/10.1186/s12875-022-01956-9

A1, Q2, IF=2,63

Paper 3

Ine Huybrechts*, Dagje Boeykens*, Agnes Grudniewicz, Carolyn Steele Gray, An De Sutter, Peter Pype, Dominique Van de Velde, Pauline Boeckxstaens^, Sibyl Anthierens^ & on behalf of the Primary Care Academy. Exploring readiness for implementing goal-oriented care in primary care using Normalization Process Theory. Primary Health Care Research and Development, doi.org/10.1017/s1436423622000767

A1, Q4, IF=1,79

Paper 4

Dagje Boeykens*, Pauline Boeckxstaens*, An De Sutter, Lies Lahousse, Peter Pype, Patricia De Vriendt^&, Dominique Van de Velde^ & on behalf of the Primary Care Academy. Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: a scoping review and concept analysis. PlosOne, doi: 10.1371/journal.pone.0262843

A1, Q2, IF=3,75

Paper 5

Dagje Boeykens, Lara Decoster, Dorine Lenoir, An De Sutter, Reini Haverals, Lies Lahousse, Peter Pype, Dominique Van de Velde, Pauline Boeckxstaens*, Patricia De Vriendt* & on behalf of the Primary Care Academy. Building an understanding of goal-oriented care through the experiences of people living with chronic conditions. Patient Education and Counseling. doi: 10.1016/j.pec.2022.11.009

A1, Q2, IF= 3,47

Paper 6

Dagje Boeykens, Patricia De Vriendt, An De Sutter, Agnes Grudniewicz, Lies Lahousse, Peter Pype, Carolyn Steele Gray, Dominique Van de Velde & Pauline Boeckxstaens. Goal-oriented care: from the theoretical concept to a descriptive understanding based on experiences of primary care providers.

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

Dagje Boeykens*, Muhammed Mustafa Sirimsi*, Lotte Timmermans*, Maja Lopez Hartmann, Dominique Van de Velde^, Patricia De Vriendt^ & on behalf of the Primary Care Academy

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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: primary care, chronic illness, qualitative study, lived experiences, phenomenological-hermeneutical, nursing practice

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?

METHODOLOGY

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 1. 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’.

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	

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 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 people with chronic conditions 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." (P - 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." (IC - 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 people with chronic conditions and their informal caregivers. The performance of meaningful activities confronted PCDs with the deterioration of the person with chronic conditions since the extent of disabilities played an important role in how these activities were done. Therefore, PCDs 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 it in one time… 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." (P – 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 people with chronic conditions; 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' (P - 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". I used to be working or helping at home. Now this is no longer possible." (P – P6)

Others experienced feelings of dejection, losing interest in activities and expressed that they *"had nothing to strive for anymore" (P- P5).* These people with chronic conditions 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…" (P– 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 people with chronic conditions 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 ones who they cared for by taking them out and going on excursions together. For these reasons, informal caregivers were described as *"key figures" (P - P2)*.

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

Although informal caregivers "*did their utmost" (IC - 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 people with chronic conditions 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, people with chronic conditions 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 people with chronic conditions 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 owner 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." (P – 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."(P - 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…" (P – 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 it with my mother…when I will be alone later that I would like to have someone to support me in cooking…" (P – P7)

The social environment had a positive impact on the situation of the people with chronic conditions but some PCDs also faced a decrease in social contacts as the 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 (IC - P13)"* hampering the management of meaningful and essential activities.

6. **Combination of emotional support and practical skills to fulfill the needs of people with chronic conditions**

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 person with chronic conditions …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." (IC – 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 "*intuit the needs of people with chronic conditions" (P- P14)",* to *"discover their unexpressed needs" (P - P14)*, and to adapt their treatment approach to the personality of the person with chronic conditions. When PCDs experienced a lack of empathy they tended to change to another formal caregiver.

7. **Dialogue between people with chronic conditions and providers to achieve open communication**

"Communication goes both ways (IC - P15)" reflects the need for a dialogue between the PCDs and their formal caregivers. People with chronic conditions experienced that they want to share their story; formal caregivers in turn must provide the right context for them 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." (P – 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 person with chronic conditions 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." (P – 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'**

People with chronic conditions expressed the wish to be involved in their care processes, for example by participating in the search for the best treatment. Involvement gave them 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." (P – 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." (P – 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 (IC - P8)*".

Coordination was also mentioned as essential to ensure care continuity. This included communication among (in)formal caregivers and people with chronic conditions. 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 (IC - 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 person with chronic conditions would be supported by a network of caregivers." (P – 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 someone was discharged. People living with chronic conditions desired better follow-up, especially from their family doctor, who should be aware of recent events that they 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 [P] 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 take 2-3 weeks." (IC - P3)

In addition to better follow-up, PCDs needed structure and certainty from their formal caregivers. In the case of home nurses, people with chronic conditions 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…" (P – 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 (IC - P15)*". If support was provided, PCDs could focus on activities that give purpose to life.

COMPREHENSIVE UNDERSTANDING

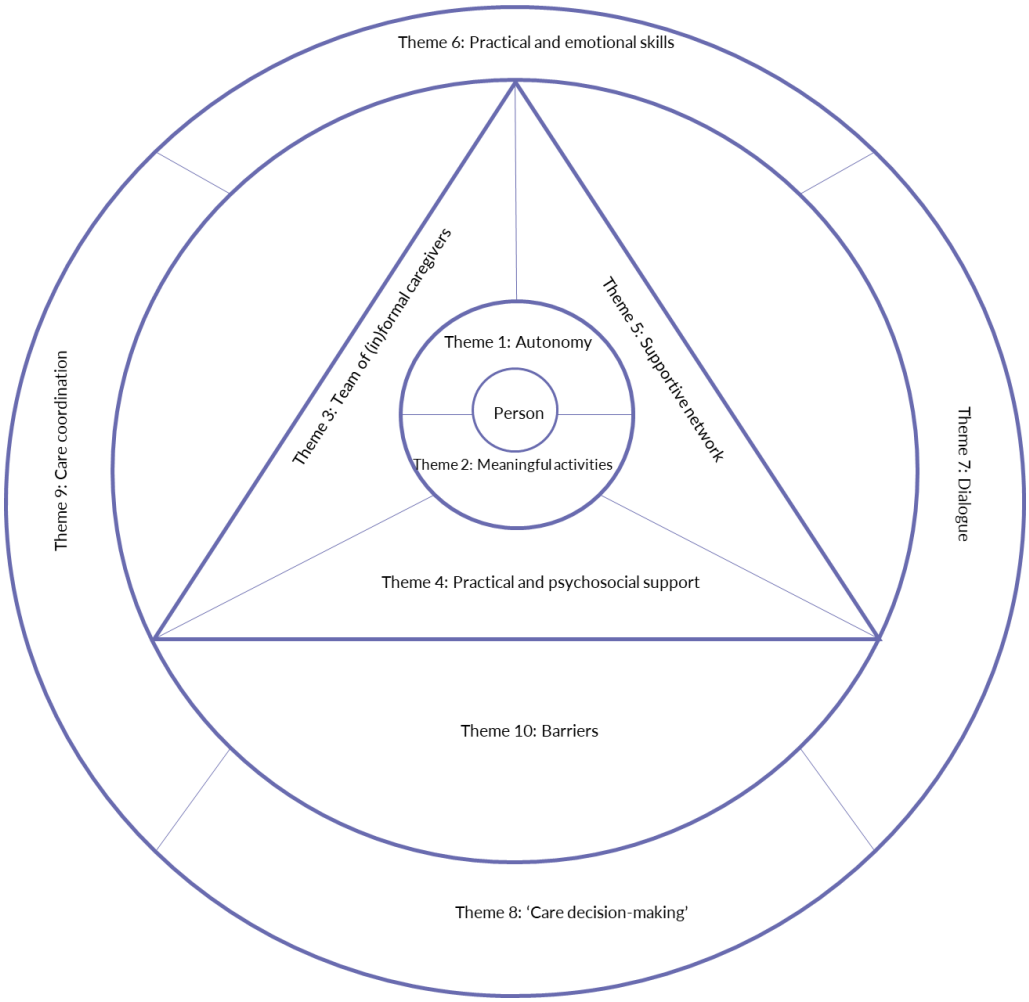
The naïve understanding and the identified themes from the structural analysis were re-read as a whole to see how they interrelated and to formulate a comprehensive understanding. By doing so, patterns between the themes and thus the lived experiences of people living with chronic conditions regarding 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, 29, 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.

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Conflict of interest

The authors declare that they have no conflicting interests.

Author contributions

The manuscript has been read and approved by all the authors. DB, MMS, LOT, MLH, DVdV and PDV contributed to the conceptualisation and the methodology of this study. DB, MMS and LT acquired the data and conducted the interviews. DB, MMS and LT analysed the data and wrote the manuscript. MLH, DVdV and PDV contributed to the interpretation of the data and critically revised the manuscript several times.

Ethics approval

Approval was obtained from the Ethical Committee of University of Antwerp (B300201942302).

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.

(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).

Creating space to talk about patients' personal goals: experiences from primary care stakeholders

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ABSTRACT

Background: To address the many challenges health systems and communities face, primary care is constantly searching for new strategies to improve quality of care. One of the strategies is to focus on patients' personal goals to direct the care process. To adopt an explicit focus on patients' personal goals, actions at different levels are required. As a first step in this process, this study aims to explore the experiences of primary care stakeholders (i.e., scholars, primary care providers, and policy makers) and develop a comprehensive understanding on the idea 'putting patients' goals first'. This will help to formulate suggestions about what these actions should include.

Method: In this study, 41 primary care stakeholders participating in six focus groups between January 2020 and September 2020, were recruited via maximal variation purposive sampling. Data collection was done through an open-ended semi-structured interview guide. Focus groups were audio-recorded, transcribed verbatim, and analyzed following a phenomenological-hermeneutical philosophy of Lindseth and Norberg.

Results: All participants expressed a strong fundamental belief for putting patients' personal goals first. The primary care providers shared that they created space for patients' personal goals by letting them talk about their values and stories. They reported to integrate their medical expertise with patients' personal goals in order to develop a balanced relationship. In this context, they also talked about the importance of taking into account the perspectives of patients' significant others. Primary care providers also talked about how they used patients' personal goals as a guide in interprofessional collaboration. Scholars denoted that (future) care providers need more training to acquire competencies to discuss patients' personal goals. The providers and policy makers talked about organizational limitations in terms of time restrictions and the lack of registration systems to support a workflow oriented towards patients' personal goals.

Conclusions: This study can be used to support the coherence of the development of different actions and strategies to get primary care stakeholders fully on board to support the adoption of patients' personal goals in care delivery at different levels. However, models of practice and policy plans are needed to work towards a person-centered integrated system.

Keywords: patients' goals, patient preferences, chronic care, chronic conditions, multimorbidity, primary care stakeholders, primary care, patients' goals, qualitative research

INTRODUCTION

Primary care is defined as "an integrated, accessible system by health and welfare providers who deal with a large majority of personal health care needs, developing sustained partnership with patients, and practicing in the context of family and community" [1]. In the context of the increasing number of people living chronic and complex care needs (i.e., "patients") the importance of a primary care system cannot be understated [1]. Primary care is the place where care for these patients mostly takes place, and care plans are developed. These care plans, often including an overload of medication prescriptions, referrals, etc. can make the patients feeling overwhelmed and result in fragmented care. [2]. The treatment burden reported by these patients raises the question on how primary care should be best transformed to better meet their needs and improve their quality of care and life [3].

To do so, the World Health Organization (WHO) recommends a shift towards person-centered integrated care (PC-IC) with a focus on patients' personal goals [4, 5]. A person-centered health system on the one hand builds on empowering people to participate in their care process, tailoring care delivery to their needs, and valuing the input and support of informal caregivers [6]. Integrated health services, on the other hand, "manage and deliver care in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, etc. at the different levels and institutions of care within the health system, and according to their needs throughout their life course"[4].

Following these WHO global recommendations, the Flemish primary care system (Dutch-speaking part of Belgium) is transforming to better support primary care practices, and foster intersectoral and interprofessional collaboration. One of the core strategies in this primary care reform is to explicitly direct care on the patients' personal goals [7]. To support this transformation, different organizations are established to link policy and practice, to translate governmental objectives into actions, and set up new partnerships among all primary care stakeholders. An example of such governmental organization, is the Flemish Institute of Primary Care (FIPC) that develops policy plans and strategies for local primary care settings [8]. Besides this example, other projects were established through public financial support such as the Primary Care Academy, funded by the King Baudouin Foundation. The Primary Care Academy focusses on primary care research and its implementation in education. [9]. More locally, practice-based projects have emerged to strive for better coordination and cooperation between individual primary care stakeholders and organizations and promote a focus on the patients' personal goals [7]. The common ground of all these initiatives is the aim to develop strategies or interventions to pursue a focus on patients' personal goals [3].

A focus on patients' personal goals is hypothesized as a catalyst for developing a person-centered and integrated health system [10]. It might also be worthwhile to direct care on patients' personal goals as it seemed to improve the social well-being, physical well-being, and satisfaction of people with chronic conditions and from those who deliver care, and thus improve their quality of care [6, 11]. Despite the relevance and potential of putting patients' personal goals first, there is still a knowledge gap about the actions needed to facilitate this transition in primary care [12]. These

actions could be situated in the field of research, practice, and policy and should result in well-designed models of practice or interventions and policy plans [3]. As a first step in this process, it is important to incorporate viewpoints of all primary care stakeholders (scholars, primary care providers, and policy makers) into a comprehensive understanding of the idea "putting patients' goals first". Therefore this study aims to explore the experiences of scholars, primary care providers, and policy makers to formulate suggestions about what these actions should include.

METHOD

RESEARCH TEAM

This study was conducted by an interprofessional research team embedded in the Primary Care Academy. This study has been performed by a team of occupational therapists, pharmacists, general practitioner and gerontologist. This interprofessional approach ensures a diverse and broad perspective when analyzing the data of primary care stakeholders.

DESIGN

This study used a qualitative, phenomenological-hermeneutical method of Lindseth and Norberg [13]. This approach is suited to enable a greater understanding on the (lived) experiences of primary care stakeholders (scholars, primary care providers, and policy makers) regarding the phenomenon under investigation: experiences of putting patients' goals first, the strategies they use, and the challenges they encounter [14]. To collect data, a focus group methodology was used. These focus groups were organized in four waves characterizing an iterative process; the new questions that arose from each wave preceding another, guided the interview guide of the consecutive focus groups until data saturation was obtained.

The entire method of this study is checked with the Consolidated criteria for Reporting Qualitative research (COREQ) (see Supplementary File 1) [15].

PARTICIPANTS AND SAMPLING

The participants represented a broad variation of scholars, primary care providers, and policy makers with experience and expertise in primary care; named as the primary care stakeholders. They were contacted via the network of the Primary Care Academy (phone and mail) using a maximum variation sampling strategy following the principles of Patton 2014 [16].

Focus groups were conducted in four waves. The first wave comprised one pilot focus group with scholars and members of the Primary Care Academy consortium. The second wave included three parallel focus groups with primary care providers who, based on their patient contact, could discuss how they put patients' goals first during their patient encounters. In a third wave, one focus group with a selection of participants of wave two took place to validate or invalidate the results of the previous waves. For this focus group, the selection of participants was based on professions and their contribution and engagement during the focus groups of wave two. In the final and fourth wave, scholars and policy makers were selected when they adopted patients' personal goals in their research, development of tools, or taking it as a leading principle in their work.

Contributing to the focus groups was completely voluntary and participants did not receive any form of renumeration.

DATA COLLECTION

The focus groups (January 2020-September 2020) were coordinated by a moderator (DB, MMS, or LT) trained in qualitative research techniques.

For each wave, a semi-structured interview guide with open-ended questions was tailored based on the results of the previous waves. Topics relating to the phenomenon under investigation were discussed in depth. The first wave aimed to explore the topic broadly allowing adaptations to the interview guide for the following waves. The second wave allowed more in-depth information about their experiences regarding patients' personal goals, how they enabled patients to manage their conditions, and how they fostered collaboration. Specific topics for this second wave were '*understanding on putting patients' personal goals first, 'adoption of patients' personal goals', 'implementation of patients' personal goals'* in their practice. For the third wave, the preliminary results were presented to broaden insights on specific topics (e.g., *'tension that providers might experience when putting patients' goals first'*). For the fourth wave, results of the previous focus groups were presented and deepened the data until no new information emerged and thus saturation was achieved. If necessary, additional questions or probes were used in all focus groups to encourage the participants to clarify and elaborate on their answers. The moderator was supported by an assistant who wrote down the non-verbal observations, kept an eye on the time, passed on additional questions, or opened the floor to someone. Focus groups took place at the university or online due to the Covid19 measures.

DATA ANALYSIS

The focus groups were audio-taped and transcribed verbatim. The phenomenological-hermeneutical approach described by Lindseth and Norberg was used [13]. This method consists of three steps: 1) naïve understanding, 2) structural analysis, and 3) comprehensive understanding. The analyzing process from writing down the naïve understanding to the comprehensive understanding is characterized by an iterative process. Throughout this process, specific attention was given to distinct between the participants' different backgrounds and illuminate their lived experiences. This was done by allocating meaningful units and quotations to the corresponding participant and referring to their specific input while analyzing towards to the different themes.

The naïve understanding is *'a first conjecture of the analysis and has to be validated or invalidated by the more extensive structural analysis' [13].* The initial naïve understanding was formulated after intensive reading of the transcripts from the first two waves and was written in such way that the text speaks for itself. This initial naïve understanding was written by the first authors (DB, RH), consistently discussed with the team, and finally rewritten by the research team (DB, RH, DVdV, PDV, PB). In the structural analysis meaning units, condensations, sub themes, and themes were identified and described as condensed descriptions to illuminate lived experiences [13]. In a first phase of this structural analysis, the first two focus groups were analyzed to elicit preliminary themes. These preliminary results were then presented and discussed in the interdisciplinary context of the researchers (occupational therapists, pharmacists, general practitioner, and gerontologist). Additionally they were presented to externals with the aim to validate the results and identify remaining questions. In a second phase of the structural analysis, the four remaining focus groups were analyzed with the preliminary themes kept in mind to generate new themes.

Saturation was reached as no new themes arose. In a third phase of the structural analysis, the themes were revisited again until consensus by all co-authors was achieved before they were written down in the final themes. Finally, the comprehensive understanding was created with the aim to critically reflect on the relation between the themes, the research question, the study context, and finally formulate the participants' lived experiences as a whole. For this, the transcripts were read again with the naïve understanding and structural analysis in mind. This stepwise approach allowed to become more familiar with the data and gain in-depth knowledge in the lived experiences of primary care stakeholders regarding the research aim.

ETHICAL APPROVAL

Ethical approval was obtained from the Ethical Committee of University of Antwerp (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. They all gave written informed consent. No incentives were given to the participants.

RESULTS

A total of 41 primary care stakeholders participated in six focus groups. An overview of the participants is given in Table 1. They presented a broad range of disciplines working in primary care ensuring a multidisciplinary character of the focus groups. The focus groups lasted between 68 minutes and 150 minutes.

Given that the sample represent a diversity of primary care stakeholders, distinctions between their different professional backgrounds have been described in the results to illuminate their different lived experiences.

Table 1 Overview of the participants

Focus group	Code	Discipline	Job description
Wave 1 (123min)	P1	Gerontologist & speech therapist	Policy worker (PM)
	P2	Nurse	Professor (S)
	P3	Pharmacist	Professor (S)
	P4	Physiotherapist	Teaching assistant (S)
	P5	Occupational therapist	Professor (S)
Wave 2a (68min)	P1	Social worker	Care coordinator (PM)
	P2	Psychologist	Lecturer (S)
	P3	Nurse & Diabetes educator	Project worker (PM)
	P4	Nurse	Diabetes nurse (P)
	P5	Pharmacist	Pharmacist (P)
	P6	Social worker	Director of patient organization (PM)

	P7	Pharmacist	Pharmacist (P)
Wave 2b (90min)	P1	Social worker	Social worker (P)
	P2	Pharmacist	Pharmacist (P)
	P3	General practitioner	General practitioner (P)
	P4	Sociology & Healthcare management	Policy worker patient organization (PM)
	P5	Pharmacist	Pharmacist (P)
	P6	Pharmacist	Pharmacist (P)
	P7	Psychologist	Psychologist (P)
	P8	Pharmacist	Pharmacist (P)
Wave 2c (119min)	P1	Occupational therapist	Occupational therapist (P)
	P2	Occupational therapist	Expert vulnerable populations (P)
	P3	Social worker	Social worker (P)
	P4	Nurse	Home nurse (P)
	P5	Nurse	Care coordinator (PM)
	P6	General practitioner	General practitioner (P)
	P7	Occupational therapy	Lecturer (S)
	P8	Social worker	Manager non-residential care (PM)
Wave 3 (107min)	P1	Psychologist	Psychologist (P)
	P2	Nurse & Diabetes educator	Project worker (PM)
	P3	General practitioner	General practitioner (P)
	P4	Sociology & healthcare management	Policy worker patient organization (PM)
	P5	Social worker	Social worker (P)
	P6	Social worker	Manager non-residential care (PM)
Wave 4 (86min)	P1	Psychologist	Consultant (PM)
	P2	Biomedical sciences	Project leader (PM)
	P3	Social worker	Policy worker (PM)
	P4	Social pedagogy	Director home care organization (PM)
	P5	Nurse	Lecturer (S)
	P6	General practitioner	Professor (S)
	P7	Gerontologist & speech therapist	Policy worker patient organization (PM)

Abbreviations: (S) scholars, (P) primary care providers, (PM) policy makers

NAÏVE UNDERSTANDING

The initial reading of the transcripts revealed that all participants have a strong belief that it is worthwhile to focus on patients' personal goals. The primary care providers put patients' personal goals first by talking about things that matter most to them and addressing their personal goals and values. They experienced a better understanding of the patients' situation during their encounters by doing so. If they were aware of the patients' personal goals, they felt they were better placed to inform the patients about treatment options allowing them to make well-considered decisions regarding their goals. In this context, all participants talked about the importance of taking into account the goals of patients' significant others. All participants also talked about how they used patients' personal goals as a guide in interprofessional collaboration. They reflected that this supported the alignment of different care plans of care providers into a shared vision. Despite their overall support towards putting patients' goals first, participants reported about challenges. The scholars stressed the importance of acquiring competencies by training and education to discuss patients' personal goals and step aside from thinking in terms of solutions to patients' problems. The providers and policy makers also talked about organizational limitations in terms of time restrictions and the lack of a registration system to support a workflow oriented towards patients' personal goals.

STRUCTURAL ANALYSIS

After selecting and condensing the meaning units, and further analysis, six themes could be elicited from the transcripts (Table 2). Table 3 provides an excerpt from the structural analysis.

Table 2 Overview of the themes

Awareness of the necessity to create time and space to elicit patients' personal values and stories
Experiencing a balanced relationship through combining own expertise and patients' personal goals
Taking into account the perspectives of significant others
Feeling connected with other team members through the patients' personal goals
The challenge to become competent in discussing patients' personal goals
Experienced organizational limitations

Table 3 Example of structural analysis of a meaning unit

Meaning unit	Condensation	Themes
"I think if patients can make an informed choice and say 'I don't want to do this', we as a provider, have to respect that. We have goals we set and patients have their goals. If they don't agree after they are well-informed about their options, then we have to agree with that. *(P3 -wave 3)*	You have to respect the informed choices the patients make. We can set goals, but if patients do not agree with them, it's ok.	Experiencing a balanced relationship through combining own expertise and patients' personal goals

1. **Awareness of the necessity to create time and space to elicit patients' personal values and stories**

All participants expressed a strong fundamental belief that putting patients' goals first was a promising strategy for doing good for patients. According to the primary care providers (e.g., wave 2 and 3), putting patients' goals first felt as their "natural" attitude. They said that they tried to "create space" to let patients articulate their personal values and stories. During conversations with their patients, participants experienced that they were able to identify things that mattered most to the patients, could gain insight into their needs, and into that what is valuable for experiencing a good life. The scholars and policy makers (e.g., wave 1 and 4) also reflected that it is the intrinsic nature of care providers to put patients' goals first. They acknowledged that it was important to have openness to talk about what matters most to patients.

"When you let people talk about what matters to them, what's important to them, that creates an open door to what matters to them... to values and emotions for what those people find relevant to live a good life, what matters to them, then I feel healthy." (P3, wave 1)

The primary care providers reported that these values gave rise to formulating patients' personal goals. Besides eliciting goals throughout patients' stories, they also shared that they explicitly asked questions as "*What do you want to achieve?" (P5 - wave 3)* to elucidate goals. By focusing on patients' personal goals, participants experienced that they gained more insight into the patients' lives aside their disease. It gave them the feeling of contributing to the patients' quality of life.

2. **Experiencing a balanced relationship through combining own expertise and patients' personal goals**

The primary care providers, reported that they informed patients about different treatment options. They mentioned that it was important for them that their patients were well informed

about how procedures could contribute to their quality of life. This was also pinpointed by the policy makers who reported that treatments should be regarded in the light of pursuing quality of life as defined by the patients. By informing patients, they hoped that patients were given the opportunity to make well-considered decisions regarding the goals they wanted to strive for.

"The goals can help to review and look together at the pros and cons of each treatment and see how that matches up with the life and quality of life that the patient sees for himself." (P1, wave 1)

Primary care providers experienced that, by informing patients, they could bring in their own medical expertise into the conversations with their patients, which seemed important to them. They shared that they tried to combine their medical goals with patients' personal goals into one shared care plan while still respecting patients' personal goals throughout this process. By equally integrating each perspective, these participants got the feeling of contributing to a balanced relationship.

3. Taking into account the perspectives of significant others

The primary care providers felt the need to involve patients' significant others (e.g., informal caregivers, family, and friends) during consultations as it allowed them to gain more insight into the patients' living situation. The policy makers (e.g., director, care coordinator) denoted that it was important to acknowledge each individual expertise (e.g., care provider, patient, significant other) as equal because they all had a contributing and supporting role in the care process.

"For me, the core is the equality of everyone involved in the process and from there, going on a journey, each from their own expertise. The physician has his own expertise, the patient has his own expertise, the informal caregivers as well. To identify that equality and bring it together." (P4 – wave 4)

By exploring the goals of patients' significant others, all participants experienced that they could unravel their unexpressed frustrations or concerns ("*My father wants to drive his car despite his Parkinson's disease" (*P4, wave 1)). Especially in the event that patients set goals that were conflicting with the goals of their significant others, participants expressed that it was important to generate discussion about everyone's goals. This resulted, based on the participants' experiences, in less misunderstanding between patients and their significant others. If succeeding in aligning conflicting goals, the primary care providers felt more connected with their patients and their significant others.

"If you then also start to determine the goals of the people surrounding the patient, then suddenly a new world opens up because then you start to see why the daughter is so panicked or asking to have her mother fixated, why her mother becomes so aggressive... And if you then have identified both goals, then you can start to connect and make a compromise of which in the best case they say 'Ah yes, that's why', that's what brings people closer." (P7, wave 2c)

4. Feeling connected with other team members through the patients' personal goals

All participants shared that patients' personal goals could be used as potential guidance to organize interprofessional collaboration. The primary care providers shared that they used patients' personal goals as a way to find connection and to guide team collaboration. The policy makers, reported that they proposed a focus on patients' personal goals to their teams as a strategy to better collaborate and allocate team members who could best support the patients to work towards those goals.

"...Maybe it can start from the patient, the patient's perspective and then it gives an opportunity for care providers to align with that and then look at it like 'Okay, what expertise can I add to this?'." (P1-wave 1)

The primary care providers experienced that this focus helped them to get everyone on the same page. The participants shared that they used different ways to integrate patients' personal goals during interprofessional collaboration. In some cases, goals were discussed in a one-on-one conversation between one provider and the patient prior to interprofessional meetings and were then represented by that provider. In other cases, depending on the organizational structure, patients attended interprofessional meetings and could share their goals in person.

5. The challenge to become competent in discussing patients' personal goals

All participants experienced that for discussing patients' personal goals specific competencies needed to be acquired. Participants working in education, observed that most (future) care providers still have the desire to provide strategies and solutions for the patients' problems instead of focusing on their goals. These participants recognized that competencies need to be acquired during education to be able to shift from a coaching role to a focus on patients' personal goals.

"Last year on the exam, I played a patient with cancer and tiredness. I strongly felt and observed that students adopted a coaching role and relied on their theoretical knowledge instead of integrating all what they have learned to approach me as a person. You have to know when to apply what and to which patient. That requires competencies." (P5 – wave 4)

In addition, the primary care providers experienced that it is hard to always focus on patients' personal goals. Particularly in cases where the patient did no longer had any goals it felt counterintuitive for them to focus on their goals. In these cases, they shared that they tried to put themselves in place of their patients and wonder if they would be happy with the way how care was delivered.

"I think it's a mind shift for everyone. We as care providers have been way too much of rescuers. All disciplines, always solving things for people, going to rescue them, figuring things out for them, and that's an attitude where that we, we need to step away from that." (P2 -Wave 2c)

6. Experiences organizational limitations

The participants were positive towards putting patients' goals first but all shared they encountered organizational limitations for doing so. The main concern primary care providers and policy makers shared was the lack of time to fit discussions on patients' personal goals into their daily practice. They denoted that, however their organization acknowledged the benefits of a focus on patients' personal goals, the current structure did not allow them to adopt this focus. However, participants experienced that a focus on patients' personal goals could save time on the long term as care was, in their opinion, better aligned among the team members and patients were feeling more satisfied.

"...that health care providers don't have the time to fill that out with the patient... Because actually all that time that is put into life goals is seen as kind of lost time. Actually that's free, working for free in that moment. But we do agree that when we look at the greater goal and when we constantly look at the same goal from that focus from different care providers, we're going to obtain a better outcome." (P4-wave 2b)

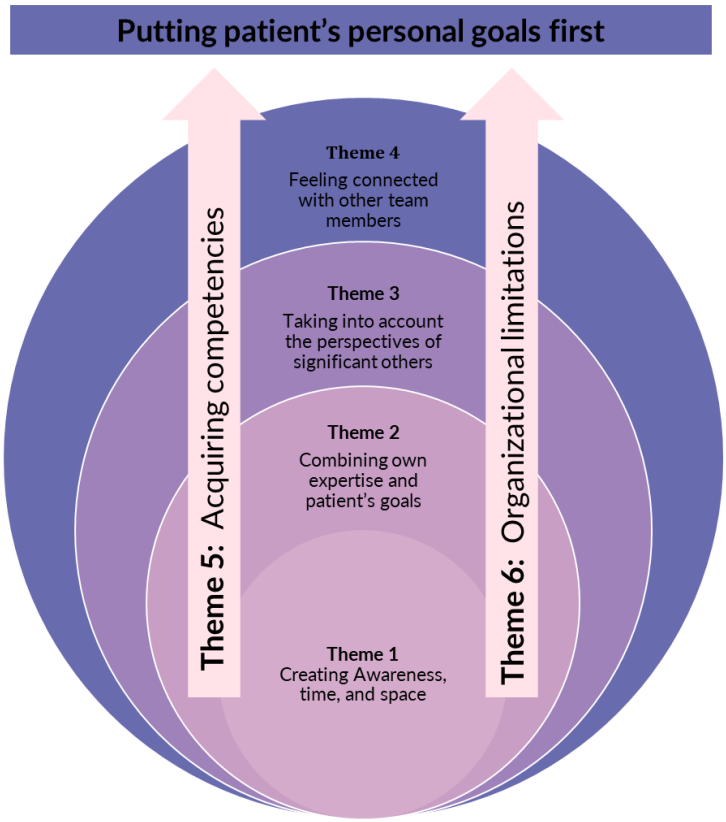
The primary care providers and policy makers talked about the need for a workflow and registration system that supports providers to start the care process from the patients' perspectives. One of the suggestions made by, was to acknowledge a goal-setting consultation as an intervention. They stated that also the financing system is still too much focused on pay for performance and number of interventions instead of patients' personal goals. Changes to this system could support them to reorient their focus. For them, a first step in pursuing a focus on patients' personal goals is to train and educate management and make them familiar with the potential of this care approach.

COMPREHENSIVE UNDERSTANDING

To formulate the comprehensive understanding, the naïve understanding and the themes were re-read, critically reflected on, linked to each other, and considered as an overarching whole to make the patterns between these parts visible (Fig. 1).

It seemed to be an intrinsic attitude to leave room to explore the patients' values and stories and at the same time to integrate the medical perspective by sharing treatment options. In essence it is important to bridge between the lived experiences of patients and the expertise of providers and translate the patients' goals into a feasible care plan. The gap that therefore has to be tackled is nourished by the participants' needs for more competencies to discuss patients' personal goals first and the organizational challenges they are experiencing in doing so. The need for balance between what is important for the patient and for the provider can be further extended to the level of involving the patients' informal and formal network to generate a care plan tailored to the patients' personal goals. In general and at all these levels, patients' personal goals were used as a guidance to create a common understanding on how care delivery should be organized.

Figure 1 Illustration of the comprehensive understanding



DISCUSSION

This study examined the experiences of primary care stakeholders towards putting patients' personal goals first, the strategies they use, and the challenges they encounter when doing so. The structural analysis resulted in six themes of which four of them described main strategies. First, the participants reported that they intrinsically created space towards their patients to explore what is meaningful for them. Second, they informed patients about the treatment options to combine their own medical expertise to patients' personal goals and strive for the best quality of life as defined by the patient. Third, they listened to the patients' significant others to elicit their goals and value everyone's role during the care process. Fourth, they integrated patients' personal goals during interprofessional collaboration. However, to engage patients in sharing their goals and being able to put the patients' goals first, the participants encountered two main challenges. In the field of education, focus should be put on equipping (future) providers with the needed competencies to discuss patients' personal goals. In the field of policy, organizational transformations have to occur prior to sustainable putting patients' goals first.

Our interview data showed that primary care providers had an intrinsic attitude to put patients' personal goals first by exploring their values and that what is meaningful for them. However it is not straightforward to inherently align care plans with patients' personal goals [17, 18]. Weir et al. for

instance interviewed general practitioners (GPs) about their perspectives on discussing patients' personal goals and preferences in regard to medicine management [17]. They found different patterns in GPs practices ranging from 'considering goals as a low priority' to 'goals are central', indicating that not every GP puts this high on his agenda [17]. Looking further into the literature, Ospina et al. observed how patients' agendas were elicited during clinical encounters [18]. They reported, contrasting with our findings, that only in half of the primary care encounters the patients' agenda was elicited and in the other half the providers interrupted their patients too early in their story [18]. As the providers' experiences contrast with observable results, it can be discussed if providers indeed intrinsically focus on patients' personal goals or just have the feeling they do.

Reflecting further on the finding that the participants implicitly focused on the patients' personal goals, it can be questioned if there is indeed a focus on the patients' personal goals (e.g., 'I want to visit my overseas friends') instead of a direct focus on the treatment decision, named in the literature as health-related goals (e.g., 'I don't want to take my medication because they make me tired'). The literature bears this doubt and describes that providers tend to go more along with the patient's health-related goals instead of their personal goals [19]. Whether there is a focus on personal or health-related goals, our findings and the literature describe that goals should be placed in the context of the patients' values and primarily focus on improving the patients' quality of life [20, 21]. Therefore, patient-provider dialogue is important to integrate those both perspectives and formulate questions as 'How will these test results help achieve the patients' goals of care?' [20, 21]. Raising awareness of primary care stakeholders about these differences is important as a focus on personal goals illustrates the shift away from the traditional, disease-oriented paradigm [22, 23].

Another aspect that was mentioned by the primary care stakeholders, was the importance of involving the patients' significant others in developing the care plan. Based on the literature, this social environment could play a crucial role in supporting patients to better deal with their complex situation resulting in better prognoses, stress relieve, etc. [24]. We would have expected that by discussing everyone's goals and roles conflicts could arise, but neither our results or the literature points to that. So described Kaldjian that a shared understanding could be formulated when goals are explained or negotiated [21]. Despite the benefits of involving significant others such as the informal caregiver, it is unclear how that should be organized [25]. This unclarity was also shown in our results as there seemed to be no uniform way to do so. However, when the roles of patients and informal caregivers are recognized within a team setting, it helps the providers to better understand the perspectives of patients and informal caregivers [25]. It might also make the patients feel more supported and satisfied [26].

Despite the eagerness and willingness of the primary care stakeholders to put patients' goals first, they reported the need to develop competencies to do so. A recent scoping review explored the needed knowledge, skills, and attitudes primary care providers must have to deliver person-centered and integrated care. They concluded that the current literature is lacking information about what competencies are needed and how they should be acquired [27]. In any case, primary care providers should be better equipped to make the shift from medical oriented goals towards the patients' personal goals [28]. To succeed, other concepts in which patients' personal goals are

one of their central pillars might be inspiring. A concept wherein patients' personal goals get a prominent position is goal-oriented care. In goal-oriented care, care is organized around the patients' personal goals [23]. It is a promising concept to explore further in regard to the role of patients' personal goals in care delivery [23]. Also narrative-based medicine might be inspiring as providers try to bridge the gap between the patients' story and their own story by exploring fears, feelings, and emotions to develop a deeper understanding on their patients [29]. But again, it is not clear which competencies should be developed to deliver goal-oriented care or narrative-based medicine [30]. All findings considered, there can be concluded that more attention has to be given to identifying and developing the needed competencies to integrate patients' personal goals into care delivery. This should already be addressed in higher education, but once more the knowledge of how to integrate this into existing programs is lacking [27]. Fortunately, the future looks bright as several initiatives are being taken to strengthen primary care such as the capacity building of primary care research (e.g., Primary Care Academy).

These initiatives – in practice and in education – are important as one of the major barriers is situated at the policy level. Therefore, the policy makers are important stakeholders to get on board to support the adoption of putting patients' goals first [28]. One of the recommendations the participants made, is to acknowledge goal-setting as a full-scale intervention so primary care providers will be rewarded for their time investment. Only in this way, the needed models of practice and policy plans could be developed to work towards a person-centered integrated care system [3].

Strengths and limitations

Some strengths and limitations go along with the choice for a focus group methodology. First, we have chosen for a phenomenological-hermeneutical design which could seem odd for analyzing focus groups as it aims to deepen lived experiences of individuals which is more related to in-depth interviews. Though, Bradbury et al. described that it is a well-suited design for focus groups as individual lived experiences could also be captured within a group context and it is even beneficial to stimulate discussion and open new perspectives [14]. Nevertheless, it was quiet a challenge to capture the lived experiences of the different participants which could have led to a more abstract description of the themes rather than a description of their lived experiences. However, we have tried to nuance between the different participants' professional backgrounds and their lived experiences in the description. Second, the participants in our study represented a broad range of primary care stakeholders going from primary care providers to scholars. These different views were an added value to enrich the discussions and gain a representative sample of all people involved in primary care. Moreover, this broad range helped to generate a common understanding on the idea of 'putting patients' personal goals first. Third, the different waves not only allowed to deepen the results, but also increased credibility among them and assured data saturation which was achieved in the fourth wave as no new information emerged. In this way the results of any previous wave were also validated. Fourth, this study was conducted by a team of researchers with different backgrounds (occupational therapists, general practitioner, pharmacists, and gerontologist) which reduced the risk of interpretation bias as personal opinions and previous knowledge could not prevail. A reflective attitude was the pillar of the analysis.

Suggestions for future research

This study adds knowledge on how patients' personal goals are put first in primary care in Flanders and provides important information to take into account when outlining future research. Future research should focus on identifying the needed competencies to put patients' personal goals first and translate these competencies into guidance or training packages. The premise of this guidance should be that primary care stakeholders learn how to make the shift from the disease-oriented paradigm to a focus on patients' personal goals. Besides this education oriented research, research should also focus on integrating the patients' perspectives into an understanding on how their goals are addressed during consultations. Therefore, it would be interesting to bring all stakeholders including patients, primary care providers, policy makers, and scholars together to generate a shared understanding on putting patients' personal goals first by means of a participatory action research.

Conclusion

The six focus groups with primary care stakeholders provided an answer on what their experiences are regarding putting patients' goals first, the strategies they therefore use, and the challenges they encounter. The results showed that they all expressed a strong belief for putting patients' goals first. They experienced that it is not only a valuable approach during one-on-one consultations, but that it might also be beneficial to reduce misunderstanding among patients and their significant others. Patients' personal goals seemed also to be used as a guide in interprofessional collaboration as it might have the potential to integrate different care plans with each other. However, the participants mentioned the need to acquire competencies to discuss patients' personal goals by for example training, and argue for changes at the policy level. Those latter points of attention could nourish future research.

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REFERENCES

(1) Institute of Medicine Committee on the Future of Primary, C. In *Defining Primary Care: An Interim Report*, Donaldson, M., Yordy, K., Vanselow, N. Eds.; National Academies Press (US)

Copyright 1994 by the National Academy of Sciences., 1994.

(2) 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. Goodwin, N. Understanding integrated care. *Int J Integr Care* 2016, *16* (4).

(3) 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.

(4) Organization, W. H. *WHO global strategy on people-centred and integrated health services: interim report*; World Health Organization, 2015.

(5) Kringos, D. S.; Boerma, W. G.; Hutchinson, A.; Saltman, R. B.; Organization, W. H. *Building primary care in a changing Europe*; World Health Organization. Regional Office for Europe, 2015.

(6) Morgan, S.; Yoder, L. H. A concept analysis of person-centered care. *Journal of holistic nursing* 2012, *30* (1), 6-15.

(7) en Gezondheid, A. Z. Een geïntegreerde zorgverlening in de eerste lijn. Brussel: Agentschap Zorg en Gezondheid: 2017.

(8) *Over VIVEL*. 2021. https://www.vivel.be/nl/ (accessed 2021 22 November).

(9) *Academie Voor De Eerste Lijn*. https://academievoordeeerstelijn.be/ (accessed 2021 22 November).

(10) Steele Gray, C.; Grudniewicz, A.; Armas, A.; Mold, J.; Im, J.; Boeckxstaens, P. Goal-Oriented Care: A Catalyst for Person-Centred System Integration. *Int J Integr Care* 2020, *20* (4), 8. DOI: 10.5334/ijic.5520 From NLM.

(11) 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. 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. Kuipers, S. J.; Cramm, J. M.; Nieboer, A. P. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Serv Res* 2019, *19* (1), 1-9.

(12) Murdoch, J.; Salter, C.; Ford, J.; Lenaghan, E.; Shiner, A.; Steel, N. The "unknown territory" of goal-setting: Negotiating a novel interactional activity within primary care doctor-patient

consultations for patients with multiple chronic conditions. *Soc Sci Med* 2020, *256*, 113040. DOI: 10.1016/j.socscimed.2020.113040 From NLM.

(13) 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.

(14) Bradbury-Jones, C.; Sambrook, S.; Irvine, F. The phenomenological focus group: an oxymoron? *Journal of advanced nursing* 2009, *65* (3), 663-671. DOI: 10.1111/j.1365-2648.2008.04922.x From NLM.

(15) 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.

(16) Patton, M. Q. *Qualitative research & evaluation methods: Integrating theory and practice*; Sage publications, 2014.

(17) Weir, K. R.; Naganathan, V.; Carter, S. M.; Tam, C. W. M.; McCaffery, K.; Bonner, C.; Rigby, D.; McLachlan, A. J.; Jansen, J. The role of older patients' goals in GP decision-making about medicines: a qualitative study. *BMC family practice* 2021, *22* (1), 13. DOI: 10.1186/s12875-020-01347-y From NLM.

(18) Singh Ospina, N.; Phillips, K. A.; Rodriguez-Gutierrez, R.; Castaneda-Guarderas, A.; Gionfriddo, M. R.; Branda, M. E.; Montori, V. M. Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters. *J Gen Intern Med* 2019, *34* (1), 36-40. DOI: 10.1007/s11606-018-4540-5 From NLM.

(19) Berntsen, G. K.; Gammon, D.; Steinsbekk, A.; Salamonsen, A.; Foss, N.; Ruland, C.; Fønnebø, V. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care. *BMJ Open* 2015, *5* (12), e009403. DOI: 10.1136/bmjopen-2015-009403 From NLM. Vermunt, N.; Harmsen, M.; Westert, G. P.; Olde Rikkert, M. G. M.; Faber, M. J. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC geriatrics* 2017, *17* (1), 167. DOI: 10.1186/s12877-017-0534-0 From NLM. Kuluski, K.; Gill, A.; Naganathan, G.; Upshur, R.; Jaakkimainen, R. L.; Wodchis, W. P. A qualitative descriptive study on the alignment of care goals between older persons with multi-morbidities, their family physicians and informal caregivers. *BMC Family Practice* 2013, *14* (1), 1-10.

(20) Secunda, K.; Wirpsa, M. J.; Neely, K. J.; Szmuilowicz, E.; Wood, G. J.; Panozzo, E.; McGrath, J.; Levenson, A.; Peterson, J.; Gordon, E. J.; et al. Use and Meaning of "Goals of Care" in the Healthcare Literature: a Systematic Review and Qualitative Discourse Analysis. *J Gen Intern Med* 2020, *35* (5), 1559-1566. DOI: 10.1007/s11606-019-05446-0 From NLM.

(21) Kaldjian, L. C. Teaching practical wisdom in medicine through clinical judgement, goals of care, and ethical reasoning. *J Med Ethics* 2010, *36* (9), 558-562. DOI: 10.1136/jme.2009.035295 From NLM.

(22) Mold, J. W.; Blake, G. H.; Becker, L. A. Goal-oriented medical care. *Family medicine* 1991, *23* (1), 46-51. From NLM.

(23) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* 2012, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM.

(24) Blazer, D. G.; Hernandez, L. M. Genes, behavior, and the social environment: Moving beyond the nature/nurture debate. 2006.

(25) Doekhie, K. D.; Strating, M. M. H.; Buljac-Samardzic, M.; van de Bovenkamp, H. M.; Paauwe, J. The different perspectives of patients, informal caregivers and professionals on patient involvement in primary care teams. A qualitative study. *Health Expect* 2018, *21* (6), 1171-1182. DOI: 10.1111/hex.12824 From NLM.

(26) Haslam, D. "You're an expert in me": the role of the generalist doctor in the management of patients with multimorbidity. *J Comorb* 2015, *5*, 132-134. DOI: 10.15256/joc.2015.5.65 From NLM. Coulter, A. Partnerships with patients: the pros and cons of shared clinical decision-making. *Journal of health services research & policy* 1997, *2* (2), 112-121.

(27) Michielsen, L.; Bischoff, E. W. M. A.; Schermer, T.; Laurant, M. Primary Healthcare Competencies Needed in the Management of Integrated and Person-centred Care for Chronic Illness and Multimorbidity. Research Square: 2022.

(28) Yardley, S.; Cottrell, E.; Rees, E.; Protheroe, J. Modelling successful primary care for multimorbidity: a realist synthesis of successes and failures in concurrent learning and healthcare delivery. *BMC family practice* 2015, *16*, 23. DOI: 10.1186/s12875-015-0234-9 From NLM.

(29) Zaharias, G. What is narrative-based medicine? Narrative-based medicine 1. *Can Fam Physician* 2018, *64* (3), 176-180. From NLM.

(30) Reuben, D. B.; Jennings, L. A. Putting Goal-Oriented Patient Care Into Practice. *J Am Geriatr Soc* 2019, *67* (7), 1342-1344.

Exploring readiness for implementing goal-oriented care in primary care using Normalization Process Theory

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ABSTRACT

Aim: To use Normalization Process Theory to build a strategy for the implementation of goal-oriented care (GOC) in primary care in Flanders, Belgium.

Background: GOC is a possible approach to more coordinated and integrated care and tailors care to patients' personal life goals. The concept has gained interest among policy makers and researchers but the main drivers for successful implementation are the Primary Care Professionals (PHCPs) who need to see added value of GOC in order to embed it into their daily practice. Normalization Process Theory (NPT), developed to understand the processes of implementing new ways of organizing care, offers a useful lens to understand adoption of GOC in primary care practice.

Method: PHCPs (n=131) who participated in a 2-hour community meeting on GOC were asked to complete the Normalization MeAsure Development survey (NoMAD) survey. This 23-item survey is based on NPT and describes participants' views about how an intervention would impact their work, their expectations about it, and whether it could become a routine part of their work.

Findings: The NPT-constructs coherence (sense-making work) and cognitive participation (relational work) showed positive tendency towards implementation of GOC. The participants had an initial understanding on GOC and there was much interest in supporting and start working with this approach. The other constructs collective action (operational work) and reflexive monitoring (appraisal work) will need further efforts to trigger implementation. A common ground is needed to integrate GOC as a common practice which can be achieved by intensive interprofessional collaboration.

Keywords: goal-oriented care, normalization process theory, implementation, primary care

INTRODUCTION

Primary healthcare providers (PHCPs) around the world often care for patients with numerous health and social needs. The increasingly complex combinations of diseases and social problems make it challenging to provide optimal care [1]. Patients with multiple problems require care across divers organizations and healthcare professionals leading to a risk of fragmented care [2]. Additionally, caring for patients with multiple problems can be burdensome and may not be centered around the patients' personal needs. Consequently, the care provided to these patients can be at odds with what is actually needed: an integrated and patient-centered approach [2-5]. One of the possible strategies to more integrated, patient-centered care for patients is goal-oriented care (GOC), which tailors care to the patient's personal life goals instead of to disease and problem-oriented targets [4, 6]. If professionals explicitly focus on the patient's personal life goals, care could potentially be better aligned with what is most important to patients and lead to better integration of the care provided across the system [7, 8].

While GOC is gaining interest in research and policy as a potential catalyst for integrated care [5, 8, 9], it remains unclear how primary healthcare professionals (PHCPs) in the field feel about GOC and whether they would be willing and able to implement and embed – or normalize - GOC in their daily practice. Gaining insights in the perceptions of PHCPs about GOC is important to work towards successful implementation of this approach in the long term.

Normalization Process Theory (NPT) has been specifically developed to help understand and explain the processes of implementation and normalization of complex interventions, such as GOC [10, 11]. NPT suggests that four constructs or mechanisms play a central role in embedding new processes of care: 1) coherence (whether the intervention makes sense to PHCPs), 2) cognitive participation (how PHCPs engage with it), 3) collective action (how they enact it), and 4) reflexive monitoring (how they appraise the ways that a new set of practices affect them and others around them) (Supplementary Table 1. NPT Core Constructs [10]). Studies that use NPT can identify which elements need the most effort and resources for the intervention to be successful from the development phase to the implementation phase. For example, NPT has been previously used as a theory to better understand implementation efforts for the implementation of person-centred care [12], for a complex intervention targeted at compassionate care [13], and for the implementation of integrated care [14].

NPT states that practices become routinely embedded – or normalized – as the result of people working, individually and collectively, to enact them. NPT emphasizes the contribution and roles of individuals and groups in the implementation of new ways of organizing care. As the theory focuses on action rather than more intentions or attitudes [15], it can provide insight into how GOC is interpreted individually and collectively by PHCPs and how this is reflected in their routine practices.

This study aims to explore the potential for the implementation of GOC in primary care in Flanders, Belgium through an NPT lens. NPT allows to look into the mechanisms of change that are at stake when planning a local initiative to support the implementation of GOC in primary care. This study will capture how these limited implementation efforts will affect the four different constructs of

NPT. What mechanisms are already triggered for GOC to be embedded in routine practices and what mechanisms still need further incitement when developing a sustainable implementation plan for GOC?

METHODS

CONTEXT

In Flanders, Belgium primary care is characterized by many self-employed PHCPs (such as family physicians, nurses, and physiotherapists), as well as attached PHCPs working in different organizations (community health centers, group practices), who are all organized and financed at different levels (local, regional, federal). As part of primary care reform efforts, in 2010, the Flemish government introduced local multidisciplinary networks to support PHCPs in implementing chronic disease management programs. As of December 2018, the local multidisciplinary network and clinician-researchers at Ghent University worked together to organize two-hours interprofessional meetings about GOC. These meetings (all similar) contained two parts: 1) an introduction on the concept of GOC relating to the disease-oriented paradigm, and 2) a workshop using cases and role plays to complement the theoretical knowledge with practice-based examples and tools. It should be emphasized that these meetings were not considered as an intensive training on GOC, but they did offer a first impression on the topic which could have triggered participants to apply GOC in their practice. Attendance at these meetings was completely voluntary.

SAMPLE

For this study, purposive sampling was used; PHCPs working in Ghent were recruited at the end of the interprofessional community meeting on GOC. These PHCPs had limited experience or knowledge about GOC, but showed interest in GOC as an innovative approach. Given this context and the intent of the survey described in the next section, these PHCPs were well-suited to reflect on the items of the NoMAD-survey.

DATA COLLECTION

The survey was introduced in three local community meetings in 2019. Immediately after the PHCPs attended one of the meetings, they were asked to complete the NoMAD survey on paper before they left the meeting [16]. The NoMAD survey has been developed to assess the perspective of PHCPs who need to embed a new practice into their daily work through an NPT lens. The instrument is used to describe participants' views about how a new practice would impact their work, their expectations about whether it could become a routine part of their work, and how it would influence collaboration within and outside of their organization [16].

Firstly, demographic data were collected, including the participants' profession, gender, and age. Place of employment was not asked to assure anonymity. Secondly, three general statements on GOC were assessed and 22 items of the NoMAD were completed. These 22 items reflected the four NPT constructs: coherence (4 items), cognitive participation (4 items), collective action (9 items), and reflexive monitoring (5 items) (see Table 1). Two questions were added on top of the original NoMAD survey (collective action) to make it more applicable for the context of this study. These items were assessed by a 5-point Likert-scale. Participants indicated an item as 'not

applicable' when it was not relevant to their role, at this stage in their career, or for the intervention.

A validated Dutch version of the NoMAD survey was used [17]. The survey has been established as highly reliable (20 items, α = 0.89), with a construct validity for coherence (4 items, α = 0.71), collective action (7 items, α =0.78), cognitive participation (4 items, α = 0,81), and reflexive monitoring (5 items, α = 0.65) [18].

Table 1 Normalization Process Theory Constructs

Core Construct	Definition	Components
Coherence	Sense-making work done individually and collectively during operationalization of a set of practices	Differentiation Communal specification Individual specification Internalization
Cognitive Participation	Relational work done to build and sustain a community of practice around a new practice	Initiation Enrolment Legitimation Activation
Collective Action	Operational work done to enact of new set of practices	Interactional workability Relational integration Skill set workability Contextual integration
Reflexive Monitoring	Appraisal work done to assess and understand the effects of new practices on themselves and others around them	Systematization Communal appraisal Individual appraisal Reconfiguration

Finch T, Girling M, May C, Mair F, Murray E, Treweek S, et al. NoMAD: implementation measure based on Normalization Process Theory.[Measurement instrument]. Retrieved from Retrieved from http://www normalizationprocess org. 2015

DATA ANALYSIS

The answers on the three general NoMAD items scored with the VAS-scale were converted to the 5-point Likert scale (categories 0 and 1 were integrated, as well as categories 2 and 3, 4 to 6, 7 and 8, and 9 and 10). Applicable for the 22 questions of the NoMAD, positive answers (agree or strongly agree) were compared to negative answers (disagree or strongly disagree) as depicted in Table 3. This approach eventually contributed to a better understanding of the results and is consistent with how the tool is meant to be scored [16].

The results are presented using frequencies. Based on these frequencies data was interpreted allowing the broadest insights of the participants on the items of the NoMAD survey. Scores ranging from 75% and above were considered high (or scores below 25%, for those items that were asked negatively). Scores ranging from 55% to 75% were considered to represent a mildly positive result. Scores below 55% were considered to have a low result, meaning that these items represent a shortcoming or barrier for implementation. When more than half of the items within

an NPT construct showed positive results, we argue that this construct is already "triggered" which means that this will be beneficial towards GOC becoming a routinized and embedded practice. When several items within a construct showed more mixed or negative results, this means that the construct should still be triggered by further implementation efforts in order to normalize GOC as an approach. No further statistical analyses were conducted.

ETHICS

Approval of the ethical committee of Ghent University was obtained (approval number 2018/1489) and written informed consent of all participants was given before the start of the survey.

RESULTS

DEMOGRAPHICS

In total, 131 PHCPs participated in one of the three community meetings that were selected for this study as they felt in the timeline. After the meeting, 104 participants completed the survey (response rate = 79%). Table 2 gives an overview of the participants' demographics.

Table 2 Demographics of participants (n=104)

Characteristics	**n (% of valid responses*)**
Profession (n=104)	
Nurse	18 (17.3)
Physiotherapist	18 (17.3)
General practitioner	15 (14.4)
Social worker	15 (14.4)
Pharmacist	9 (8.7)
Dietician	9 (8.7)
Certified nursing assistants	8 (7.7)
Other**	12 (11.5)
Gender (n=104)	
Female	85 (81.7)
Male	19 (18.3)
Age group (n = 101, 3 missing)	
≤ 35	43 (42.6)
36-50	35 (34.7)
≥ 51	23 (22.7)

* % of responses excluding missing

** 2 occupational therapists, 2 midwives, 2 psychologists, 2 community centre coordinators, 2 policy staff members, 1 community police officer, 1 expert by experience in poverty

Initial experience and views on GOC

The questions and results for how PHCPs experience and evaluate GOC are presented in Table 3. Although the participants had limited knowledge on GOC as a concept, they often seem to recognize this way of working as an intrinsic part of their work: 53% of the participants reported feeling comfortable and familiar in using GOC and 59% felt that GOC is currently a normal part of their work. A majority of participants (90%) were optimistic that GOC will become a normal part of their work.

In what follows, the results of the four main constructs of the NPT (coherence, cognitive participation, collective action, and reflexive monitoring) are linked to the participants' GOC experiences and views [10], as depicted in Figure 2.

Coherence

Coherence is *"the sense-making work that people do individually and collectively when they are faced with the problem of operationalizing some set of practices* [16]*".* It tells whether PHCPs adequately understand the nature of the intervention and how it fits into their current practices. Fig. 1 illustrates that most participants felt they have a good idea about what GOC encompasses and how it can become an intrinsic part of their work. Most of them could clearly *differentiate* between a GOC approach and a traditional approach, with 86% of the participants reported that they recognize how GOC differs from usual ways of working. The large majority *internalized* the aims of GOC very well: 91% saw the potential value of GOC for their work. *Individual specification* (sense-making on the individual level [16]) was slightly lower: 72% of participants understood how GOC affects the nature of their own work. It appears that *communal specification* (collective sense-making [16]) is somewhat lower: 61% of participants believed that their network has a shared understanding of the purpose of GOC.

Cognitive participation

Cognitive participation is about "*the relational work that people do to build and sustain a community of practice around a new technology or complex intervention* [16]." This sample of participants showed a high engagement for adopting a GOC approach. Almost all PHCPs (96%) believed that participating in GOC is a *legitimate* part of their role. In terms of further *enrolment* or implementation of GOC, as well as the effects of GOC on team interactions, 93% reported to be open to working with colleagues in new ways to use GOC. Ninety-two percent of participants were willing to continue to support GOC, which is beneficial for further *activation* of GOC as an innovative practice. Somewhat more uncertainty is noticeable when it comes to the presence of key people who drive GOC forward and get others involved: 76% believed such key people are present in their working environment. According to the NPT methodology, key people are essential for *initiation* of such an intervention.

Collective action

Collective action is *"the operational work that people do to enact a set of practices, whether these represent a new technology or complex healthcare intervention* [16]." Seventy-eight percent of the participants reported they can easily integrate GOC into their existing work, meaning that *interactional workability* is rather high. When it comes to *relational integration* participants did not

believe GOC disrupts working relationships with colleagues (84%) or patients (86%). Furthermore, 76% of the participants had confidence in other people's ability to use GOC. *Skill set workability,* allocating the work to those who are most fit for the given task [16], is more questionable. Only 46% of participants believed that work is assigned to those with skills appropriate to GOC. Moreover, only 16% of the participants reported that there is sufficient training provided to enable PHCPs to implement GOC. Around half of the participants (42% and 44%) neither agreed nor disagreed with these statements.

There was most uncertainty on the *contextual integration*, which is about resources and the presence or absence of a supporting policy and/or management context. Only 16% of participants was convinced that sufficient resources are available to support GOC. 51% of participants neither agreed nor disagreed. Only 15% of participants believed that the policy context adequately supports GOC and 43% believed that management adequately supports GOC.

Reflexive monitoring

Reflexive monitoring is *"the appraisal work that people do to assess and understand the ways that a new set of practices affect them and others around them [16]."* This is an important measure for *systemization,* the work of collecting information to be able to assess the effectiveness and usefulness of GOC as an innovation. Only 8% was aware of reports on the effects of GOC [16]. However, current evidence on the effectiveness of GOC is limited, which makes this measure rather irrelevant at this point. *Individual appraisal* gives a more positive image, with 69% of participants valuing the effect that GOC has had on their work. This is fairly similar to *communal appraisal,* with 66% of participants estimating that colleagues agree that GOC is worthwhile. According to how participants reported on the item representing *reconfiguration*, there seems to be openness when it comes to feedback about a GOC approach: 67% of participants believed that feedback about how GOC will be incorporated into daily practice can be used to improve it in the future. Moreover, 80% indicated that they will be able to modify how to work with GOC based on such feedback.

Figure 1 General NoMAD statements on goal-oriented care

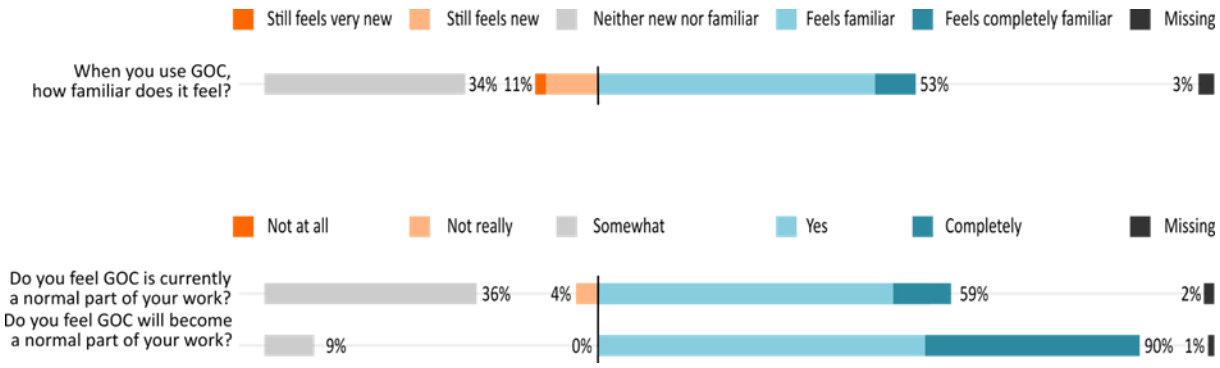
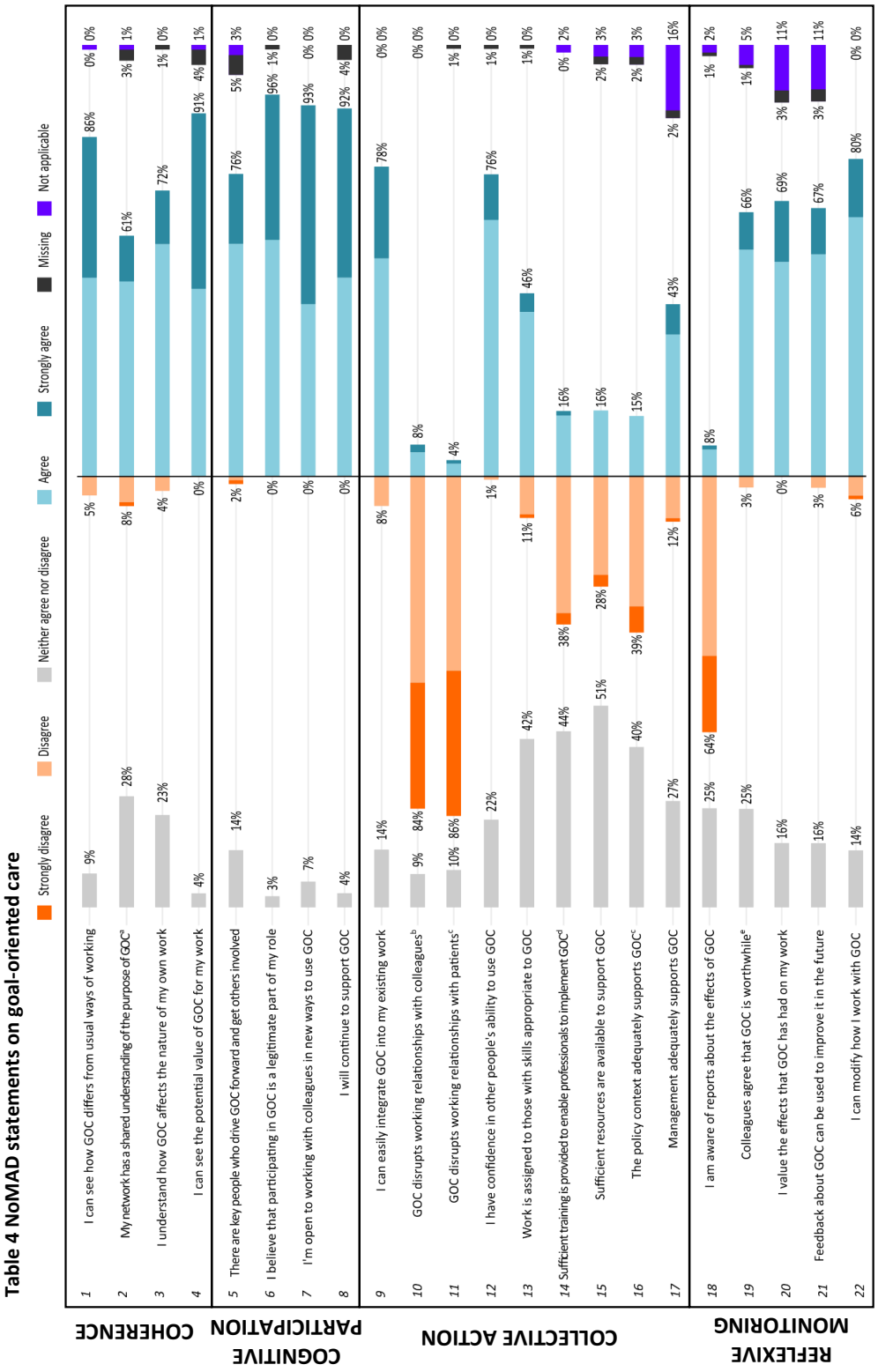


Figure 2 NoMAD statements on goal-oriented care



[a] question modified: 'staff in this organization' is adapted to 'my network'.
[b] question modified: 'with colleagues' is added.
[c] question added.
[d] question modified: 'staff' is replaced by 'professionals'.
[e] question modified: 'staff' is replaced by 'colleagues'.

DISCUSSION

This study aimed to describe the potential for implementation of GOC in primary care in Flanders, Belgium using the NoMAD survey based on the NPT. The results of this study demonstrate that the multidisciplinary PHCPs in our sample showed understanding of and openness to implementing a GOC approach. First, coherence was rather high, as participants indicated that they have an initial understanding of GOC and recognize its potential value for their way of working. Second, cognitive participation was promising, as there was much interest coming from the PHCPs to support and start working with a GOC approach. Third, relating to collective action, PHCPs in the sample believed that GOC can easily be integrated into existing work without disrupting any working relationships with colleagues or patients. However, the resources needed to integrate GOC in their practices were rather unclear. Fourth, reflexive monitoring will be an area that needs consideration in a sustainable implementation plan, as participants scored it rather low. PHCPs should be encouraged to reflect and share experiences about how to use GOC in their daily practices. In short, the constructs collective action and reflexive monitoring presented mixed results, which suggests that these mechanisms should still be strengthened in implementation efforts to facilitate GOC in primary care.

The *general questions of the NoMAD-survey* showed that more than half of the participants felt that GOC was already a normal part of their work. Looking at the literature, we learn that PHCPs often self-assess their practices as being in line with GOC, while they are in fact still focusing on health-related goals of their patients instead of life goals [19]. For our study, we did not collect data on how the participants would apply GOC in their practice. Future work should assess whether GOC was implemented after these meetings, and whether, with time, the collective action and reflexive monitoring mechanisms are important to that implementation. In our view, it is not surprising that coherence and cognitive participation are more likely to be triggered in an earlier stage (even pre-implementation), while collective action and reflexive monitoring are triggered in a later stage of implementation. First, the sense-making and relation work is needed to grasp a full understanding of the concept before concrete actions and monitoring can take place. This was also found in similar NPT studies [12].

The construct of *coherence* showed that most of the participants saw the potential of GOC, but reported that a shared understanding on the concept could be improved. Further growth in understanding could be facilitated through interprofessional collaboration. As in the construct of *cognitive participation* participants were open to working with colleagues to implement GOC, this interprofessional collaboration could be a step forward towards increasing understanding [20]. One of the benefits of interprofessional collaboration is the fact that PHCPs with more knowledge on GOC could be appointed as champions to initiate and disseminate GOC in their practice and thus enhance *cognitive participation.* From our expectations, greater understanding or adoption of GOC as a common philosophy within an interprofessional context could also be beneficial to strengthening relational integration, leading to more *collective action.* Other studies confirm that GOC could enhance collaboration in an interprofessional context and help PHCPs in their decision-making [4, 21]. To further enhance *collective action*, policy and management activities must support PHCPs in implementing GOC in their work. As the participants did not perceive having this

supportive context, it is important to make this one of the focal points for the future to make the implementation of GOC successful.

An interprofessional context could facilitate learning from each other as a means. To enable *reflexive monitoring* it is key to initiate formal or informal moments where PHCPs can reflect upon GOC after they have been given the chance to integrate the approach in their practices [22]. This could provide opportunities to share experiences about cases in which they intentionally applied GOC and how this was assessed. In this way, PHCPs could see the value of GOC from others and incorporate feedback from others into their practice.

We recognize the importance of interprofessional collaboration throughout the findings of all four constructs. NPT allowed us to identify the gaps to promote integration and embedding of GOC in primary care, but did not propose guidance on how to overcome those gaps. Therefore, we suggest to develop interprofessional training so PHCPs can learn from and with each other and to build-up a common ground on GOC which enhances collective action and reflexive monitoring. While there is overall recognition that interprofessional training is needed, there is no consensus in how this training should be organized and what content it should include. Disagreement exists about the population that should be targeted by the training, the duration of the training, and the methods that need to be used [23, 24]. There is also disagreement about the exact skills that need to be taught, although the development of certain personal skills (e.g., communication skills for active listening) is probably one of the cornerstones [23, 25]. It is also recommended that GOC be translated into a more concrete intervention with specific guidelines to enable deeper understanding of the concept along with tools to provide GOC.

Strengths and limitations

This study captures how GOC is accepted and interpreted by PHCPs who have been introduced to the approach in a local interprofessional community meeting. A strength of this study is the diversity of the sample of professions, which captures the interprofessional nature of primary care settings in which GOC is introduced. However, no statistical comparison between professions was executed as the sample sizes were too small.

For this study, it is possible that participants might have shown more affinity or openness towards GOC as they voluntarily participated in this meeting. The study should be described as an exploratory study with PHCPs interested in GOC, which can contribute to determining and targeting further implementation strategies. However, as the survey was launched immediately after the community meeting, PHCPs did not have the opportunity to apply GOC in their daily practice. It was therefore too early to measure several of the NPT constructs, especially reflexive monitoring. However, it is remarkable that coherence and cognitive participation were already triggered after following one single interprofessional meeting on GOC. At the same time it is not surprising that there is a lack of collective action and reflexive monitoring given such limitation of implementation effort. This is powerful given GOC represents a paradigm shift in how care is to be delivered and perhaps could be the most significant hurdle.

Future research should focus on the follow-up with the participants after these meetings to see what sticks and what has dropped to guide the research outlines.

Conclusion

This study is a first step toward exploring the implementation gaps of GOC. It helps to define a strategy for implementing a GOC intervention and states the importance of developing interprofessional training. Initial results on how GOC is perceived by PHCPs are promising. Participants of the interprofessional community meeting recognized the value of GOC and showed willingness to apply the approach in their practices. This suggests that there is a foundation for further implementation efforts to successfully establish GOC as a normalized approach for patients with chronic conditions in primary care. To further enable GOC to become routine practice, several mechanisms of the NPT still require attention. Development of a concrete intervention will enable PHCPs to have a deeper understanding in how to get started with GOC.

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Competing interests
None declared.

REFERENCES

(1) Loeb, D. F.; Bayliss, E. A.; Candrian, C.; deGruy, F. V.; Binswanger, I. A. Primary care providers' experiences caring for complex patients in primary care: a qualitative study. *BMC Fam Pract* 2016, *17*, 34. DOI: 10.1186/s12875-016-0433-z. Starfield, B. Challenges to primary care from co-and multi-morbidity. *Primary health care research & development* 2011, *12* (1), 1-2.

(2) Boult, C.; Wieland, G. D. Comprehensive primary care for older patients with multiple chronic conditions: "Nobody rushes you through". *JAMA* 2010, *304* (17), 1936-1943. DOI: 10.1001/jama.2010.1623.

(3) Kodner, D. L.; Spreeuwenberg, C. Integrated care: meaning, logic, applications, and implications–a discussion paper. *International journal of integrated care* 2002, *2*.

(4) Mold, J. W.; Blake, G. H.; Becker, L. A. Goal-oriented medical care. *Fam Med* 1991, *23* (1), 46-51.

(5) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *The New England journal of medicine* 2012, *366* (9), 777.

(6) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* 2012, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM. Boeckxstaens, P.; Willems, S.; Lanssens, M.; Decuypere, C.; Brusselle, G.; Kuhlein, T.; De Maeseneer, J.; De Sutter, A. A qualitative interpretation of challenges associated with helping patients with multiple chronic diseases identify their goals. *Journal of comorbidity* 2016, *6* (2), 120-126. DOI: 10.15256/joc.2016.6.64. Schellinger, S. E.; Anderson, E. W.; Frazer, M. S.; Cain, C. L. Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness. *Am J Hosp Palliat Care* 2018, *35* (1), 159-165. DOI: 10.1177/1049909117699600.

(7) Mold, J. Goal-Directed Health Care: Redefining Health and Health Care in the Era of Value-Based Care. *Cureus* 2017, *9* (2), e1043. DOI: 10.7759/cureus.1043.

(8) Gray, C. S.; Grudniewicz, A.; Armas, A.; Mold, J.; Im, J.; Boeckxstaens, P. Goal-oriented care: a catalyst for person-centred system integration. *International Journal of Integrated Care* 2020, *20* (4).

(9) World Health Organization. A vision for primary health care in the 21st century: towards universal health coverage and the Sustainable Development Goals: World Health Organization. 2018. Charette, S. L.; Garcia, M. B.; Reuben, D. B. Goal-oriented care. In *Psychology and Geriatrics*, Elsevier, 2015; pp 1-19. Mold, J. Goal-directed health care: redefining health and health care in the era of value-based care. *Cureus* 2017, *9* (2).

(10) May, C.; Finch, T. Implementing, embedding, and integrating practices: an outline of normalization process theory. *Sociology* 2009, *43* (3), 535-554.

(11) May, C. Towards a general theory of implementation. *Implementation Science* 2013, *8* (1), 1-14. May, C. R.; Cummings, A.; Girling, M.; Bracher, M.; Mair, F. S.; May, C. M.; Murray, E.; Myall, M.; Rapley, T.; Finch, T. Using normalization process theory in feasibility studies and process

evaluations of complex healthcare interventions: a systematic review. *Implementation Science* 2018, *13* (1), 1-27. McEvoy, R.; Ballini, L.; Maltoni, S.; O'Donnell, C. A.; Mair, F. S.; MacFarlane, A. A qualitative systematic review of studies using the normalization process theory to research implementation processes. *Implementation Science* 2014, *9* (1), 1-13. Murray, E.; Treweek, S.; Pope, C.; MacFarlane, A.; Ballini, L.; Dowrick, C.; Finch, T.; Kennedy, A.; Mair, F.; O'Donnell, C. Normalisation process theory: a framework for developing, evaluating and implementing complex interventions. *BMC medicine* 2010, *8* (1), 1-11. De Brún, T.; O'Reilly-de Brún, M.; O'Donnell, C. A.; MacFarlane, A. Learning from doing: the case for combining normalisation process theory and participatory learning and action research methodology for primary healthcare implementation research. *BMC health services research* 2016, *16* (1), 1-12.

(12) Alharbi, T. S.; Carlström, E.; Ekman, I.; Olsson, L.-E. Implementation of person-centred care: management perspective. *J Hosp Adm* 2014, *3* (3), 107-120.

(13) Bridges, J.; May, C.; Fuller, A.; Griffiths, P.; Wigley, W.; Gould, L.; Barker, H.; Libberton, P. Optimising impact and sustainability: a qualitative process evaluation of a complex intervention targeted at compassionate care. *BMJ Quality & Safety* 2017, *26* (12), 970-977.

(14) Ling, T.; Brereton, L.; Conklin, A.; Newbould, J.; Roland, M. Barriers and facilitators to integrating care: experiences from the English Integrated Care Pilots. *International journal of integrated care* 2012, *12*.

(15) May, C. Applying normalization process theory to the implementation of complex interventions. In *Complex interventions in health*, Routledge, 2015; pp 319-325.

(16) Finch, T.; Girling, M.; May, C.; Mair, F.; Murray, E.; Treweek, S.; Rapley, T. NoMAD: implementation measure based on Normalization Process Theory.[Measurement instrument]. *Retrieved from Retrieved from http://www. normalizationprocess. org* 2015.

(17) Vis, C.; Ruwaard, J.; Finch, T.; Rapley, T.; de Beurs, D.; van Stel, H.; van Lettow, B.; Mol, M.; Kleiboer, A.; Riper, H.; et al. Toward an Objective Assessment of Implementation Processes for Innovations in Health Care: Psychometric Evaluation of the Normalization Measure Development (NoMAD) Questionnaire Among Mental Health Care Professionals. *J Med Internet Res* 2019, *21* (2), e12376. DOI: 10.2196/12376.

(18) Finch, T. L.; Girling, M.; May, C. R.; Mair, F. S.; Murray, E.; Treweek, S.; McColl, E.; Steen, I. N.; Cook, C.; Vernazza, C. R.; et al. Improving the normalization of complex interventions: part 2 - validation of the NoMAD instrument for assessing implementation work based on normalization process theory (NPT). *BMC Med Res Methodol* 2018, *18* (1), 135. DOI: 10.1186/s12874-018-0591-x From NLM.

(19) Purkaple, B. A.; Nagykaldi, Z. J.; Allahyar, A.; Todd, R.; Mold, J. W. Physicians' Response to Patients' Quality-of-Life Goals. *J Am Board Fam Med* 2020, *33* (1), 71-79. DOI: 10.3122/jabfm.2020.01.190169 From NLM. Berntsen, G. K.; Gammon, D.; Steinsbekk, A.; Salamonsen, A.; Foss, N.; Ruland, C.; Fønnebø, V. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research

papers on goals for care. *BMJ Open* 2015, *5* (12), e009403. DOI: 10.1136/bmjopen-2015-009403 From NLM.

(20) Bookey-Bassett, S.; Markle-Reid, M.; Mckey, C. A.; 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, *73* (1), 71-84.

(21) Mangin, D.; Stephen, G.; Bismah, V.; Risdon, C. Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. *BMJ open* 2016, *6* (6).

(22) van Dongen, J. J.; Lenzen, S. A.; van Bokhoven, M. A.; Daniels, R.; van der Weijden, T.; Beurskens, A. Interprofessional collaboration regarding patients' care plans in primary care: a focus group study into influential factors. *BMC family practice* 2016, *17*, 58. DOI: 10.1186/s12875-016-0456-5.

(23) Reuben, D. B.; Jennings, L. A. Putting goal-oriented patient care into practice. *Journal of the American Geriatrics Society* 2019, *67* (7), 1342-1344.

(24) Lusk, J. M.; Fater, K. A concept analysis of patient-centered care. In *Nursing forum*, 2013; Wiley Online Library: Vol. 48, pp 89-98.

(25) 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. *International journal of integrated care* 2019, *19* (3). Vermunt, N. P.; Harmsen, M.; Westert, G. P.; Rikkert, M. G. O.; Faber, M. J. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC geriatrics* 2017, *17* (1), 1-12. Poitras, M.-E.; Maltais, M.-E.; Bestard-Denommé, L.; Stewart, M.; Fortin, M. What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC health services research* 2018, *18* (1), 1-9.

Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: a scoping review and concept analysis

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ABSTRACT

Background: The healthcare system is faced by an ageing population, increase in chronic conditions and multimorbidity. Multimorbid patients are faced with multiple parallel care processes leading to a risk of fragmented care. These problems relate to the disease-oriented paradigm. In this paradigm the treatment goals can be in contrast with what patients value.

The concept of goal-oriented care is proposed as an alternative way of providing care as meeting patients' goals could have potential benefits. Though, there is a need to translate this concept into tangible knowledge so providers can better understand and use the concept in clinical practice. The aim of this study is to address this need by means of a concept analysis.

Method: This concept analysis using the method of Walker and Avant is based on a literature search in PubMed, Embase, Cochrane Library, PsychInfo, CINAHL, OTSeeker and Web of Science. The method provides eight iterative steps: select a concept, determine purpose, determine defining attributes, identify model case, identify additional case, identify antecedents and consequences and define empirical referents.

Results: The analysis of 37 articles revealed that goal-oriented care is a dynamic and iterative process of three stages: goal-elicitation, goal-setting, and goal-evaluation. The process is underpinned by the patient's context and values. Provider and patient preparedness are required to provide goal-oriented care. Goal-oriented care has the potential to improve patients' experiences and providers' well-being, to reduce costs, and improve the overall population health. The challenge is to identify empirical referents to evaluate the process of goal-oriented care.

Conclusion: A common understanding of goal-oriented care is presented. Further research should focus on how and what goals are set by the patient, how this knowledge could be translated into a tangible workflow and should support the development of a strategy to evaluate the goal-oriented process of care.

Keywords: goal-oriented care, goal-setting, patient-centeredness, chronic conditions, multimorbidity, review, concept analysis

INTRODUCTION

The healthcare system is faced by an ageing population and an increase in chronic conditions and multimorbidity [1]. More and more people are forced to live with the consequences of these demographic changes and require ongoing (chronic) care on top of acute care [2]. At the same time, patient autonomy is gaining importance and patients are considered as an active and important partner in their care [3, 4]. Patients with chronic conditions are often consulting multiple health care providers [3] leading to a higher rate of encounters. They also receive a larger amount of prescriptions [5] and they are asked to complete a diverse set of self-monitoring tasks such as managing, exacerbations or monitoring biomedical targets [3]. Since patients with (multiple) chronic conditions are faced with multiple parallel care processes for their different conditions, there is a considerable risk of fragmented care. Especially when healthcare providers focus on disease control, patients can experience lack of care continuity and issues with communication as patients themselves focus on the meaning of care and more on personal wellbeing [6, 7]. As a result, treatment goals can be in contrast with what patients value in their personal lives [3].

The healthcare system is oriented towards a disease-oriented paradigm to which many of these problems relate [8-10]. In this paradigm, care is mainly organized according to disease-oriented guidelines [10]. This may work well for patients with a single disease, but becomes inappropriate for patients with multiple problems. The focus on single disease guidelines might distract providers from what really matters to the patient [10]. A possible way to overcome many of the challenges is to shift care back from 'what's the matter with the patient' to 'what matters to the patient'. It creates healthcare processes in which patients' needs are actively sought and met [9]. Meeting those patients' needs and tailoring care more to what patients want in a co-creation process could result in better social well-being, physical well-being, and satisfaction for patients and healthcare providers [11].

One of the possible strategies is to actively engage patients in identifying their personal goals and aligning care to those goals, which could be achieved by goal-oriented care [12]. The concept of goal-oriented care was conceived for the first time in 1991 by Mold who proposed the concept as an alternative way of providing care [13]. Later on, in 2012, Reuben and Tinetti took the concept of goal-oriented care a step forward by stating that care "must above all consider patients' preferred outcomes" [10]. The focus on setting goals based on the patients' needs and preferences rather than on health-related outcomes became one of the main novelties in chronic disease management [4]. Not only could goal-oriented care be proposed as an important paradigm to overcome some of the new challenges for chronic patients [9], it might also corresponded to the original concept of evidence based medicine (EBM) [14]. EBM was described by Sackett in 1996 who presented three key components: 1. best external evidence, 2. individual clinical expertise, and 3. patients' values and expectations [14]. Since the first description of EBM, multiple approaches and paradigms has been developed to compromise between those three components [15]. For example, patient-centered care (PCC), which is already a well-known and widely used concept, is defined as "providing care that is respectful of, and responsive to individual patient preferences, needs, and values and ensuring that patients values guide all clinical decisions" [15]. Shared-decision making, on the other hand, also strives to share evidence and engage patients in care as it is "an approach

where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, and to achieve informed preferences" [16]. Goal-oriented care is proposed as a promising healthcare paradigm and approach to operationalize EBM and return to where it all started [10]. However, in contrast to the other approaches and paradigms, goal-oriented care is ill defined. Developing a common understanding on the concept could potentially contribute to the clarification and in-depth comparison between the related concepts and eventually lead to better use in clinical practice. However, some healthcare providers might already assume that they practice goal-oriented care spontaneously, but there still is a lack of underpinning knowledge and guidance on how to provide goal-oriented care to patients. The main pitfall in most of these goal-setting activities is that the goals are not necessarily related to the patients' needs and preferences while in goal-oriented care these patients' needs and preferences are put on the forefront and are not necessarily health-related. [17, 18]. From this perspective, goal-setting and goal-oriented care should be taken together and focus on the patients' needs and preferences.

As a first step in exploring the potential of goal-oriented care in chronic care, it is important to gain in-depth knowledge on what goal-oriented care is about and how it can be generally described.

Goal-oriented care could be well-suited in primary care, as this context is often the linchpin for patients with chronic conditions, this is the focus of this study [19]. This study aimed to describe a structured approach to deepen the concept of goal-oriented care for patients with chronic conditions or multimorbidity in the primary care context.

METHOD

This concept analysis aims to present an overview and synthesis of the existing literature regarding goal-oriented care for chronically ill patients in primary care. This will be performed by analyzing the concept into antecedents, attributes, and consequences following the method of Walker and Avant [20]. This method provides a framework of eight iterative steps: 1. select a concept, 2. determine the aims or purposes of analysis, 3. identify all concept definitions and select the literature, 4. determine different attributes, 5. identify a model case, 6. identify an additional case, 7. identify antecedents and consequences, and 8. define empirical referents [20]. In this concept analysis the attributes are the heart and will present the characteristics of goal-oriented care and allow the broadest insight into the concept [20].

STEP 1: SELECT A CONCEPT

Goal-oriented care has been defined as an underpinning strategy for primary care reform in Flanders, Belgium. The concept is presented as one of the main topics of 'The Primary Care Academy' (PCA). The PCA is a consortium consisting of four universities (Ghent University, University of Antwerp, Catholic university of Leuven, Vrije Universiteit of Brussels), six universities of applied sciences (UAC VIVES, UAC Artevelde, UAC Ghent, UAC Leuven-Limburg, UAC Karel de Grote, UAC Thomas More), and important stakeholders (Flemish Patient Platform and White-Yellow Cross; a home care organization) in Belgium with the aim to strengthen the organization and delivery of primary care. The PCA includes experts in primary care from a variety of healthcare

and welfare disciplines. Discussions in the research group working on goal-oriented care created a necessity to clarify the concept.

STEP 2: DETERMINE THE AIMS AND PURPOSES OF THE ANALYSIS

The aim of this concept analysis is to build a common understanding to eliminate ambiguity between the concepts related to goal-oriented care. Specifically, the scope of the concept analysis is to define goal-oriented care for people with chronic conditions at the level of primary care.

STEP 3: SELECT THE LITERATURE

The literature was searched between January 2020 and April 2020. As the method of a concept analysis does not specify how the literature search has to be performed, this search was based on the method of a scoping review described by Levac (2010) [21]. A preliminary combination of search terms was identified: 'goal-oriented care', 'chronic care', and 'primary care'. Based on these keywords a first search was performed to identify adjacent terms in the literature. The search strategy was revised in consultation with the librarian of the university and the senior researchers. The definitive keywords were: 'goal-oriented care', 'goal-oriented medical care', 'person-centered goal-setting', 'patient-centered goal-setting', 'goal-oriented patient care', and 'patient priorities', emphasized goal-oriented care and it synonyms. Related concepts such as patient-centered care, value-based care, etc. were not included as the method of concept analysis prescribes to deepen all the attributes of one concept. In a first phase, the keywords were entered into PubMed, Embase, and Cochrane Library (Table 1). In a second phase, CINAHL, OTSeeker, PsycINFO, and Web of Science were consulted and confirmed the first results as no new studies were identified.

Table 1. Overview of the search strings.

PubMed

(goal-directed care[MeSH Terms]) OR goal-oriented care [Title/abstract]) OR goal-oriented medical care [Title/abstract]) OR person-centered goal-setting [Title/abstract]) OR patient centered goal-setting [Title/abstract]) OR goal-oriented patient care[Title/abstract]) OR patient priorities [Title/abstract])

Embase

'goal-oriented care':ab,ti OR '**goal-oriented medical care'**:ab,ti OR '**person-centered goal-setting'**:ab,ti OR '**patient centered goal-setting'**:ab,ti OR **'goal-oriented patient care'**: ab,ti OR '**patient priorities'**:ab,ti

Cochrane

goal-oriented care in Title Abstract Keyword OR goal-oriented medical care in Title Abstract Keyword OR person-centered goal-setting in Title Abstract Keyword OR patient-centered goal-setting in Title Abstract Keyword OR goal-oriented patient care OR patient priorities in Title Abstract Keyword - (Word variations have been searched)

Articles resulting from this search were put into Rayyan [22] to administer the data. A first selection based on title and abstract was performed with regard to the predefined in- and exclusion criteria. Inclusion criteria: (a) goal-oriented care as a health-related concept, (b) mentioning goal-setting, goal-oriented care or related concept (e.g. person-centered integrated care), and (c) focusing on patients with one or more chronic conditions. Exclusion criteria: (a) focusing on single-disease management, (b) goals regarding disease-specific outcomes (e.g. cancer or diabetes), (c) focusing on goal-oriented care in a specific context (e.g. rehabilitation center), and (d) specifically mentioning patient-centered care, shared-decision making, etc. as they will hamper the understanding of specifically goal-oriented care. Articles resulting from this first search were subjected to a full text screening based on the initial criteria and: (a) full text available, (b) written in English, (c) referring to goal-oriented care or related concepts as a concept, and (d) containing information of a theoretical building of a definition. There was no restriction by study design to gain as much insight in goal-oriented care from different data sources.

STEP 4: DEFINING THE ATTRIBUTES

The determination of the attributes started with a discussion of four key articles [1, 6, 23, 24] selected by the first author based on the divers approaches of goal-oriented care and presented to the research group. Similar to a qualitative, thematic analysis, the key articles were analyzed based on an open coding and then grouped into codes (Table 2 – example of data analysis). These codes were then presented to and discussed with the co-authors. In these discussion rounds, codes were translated into attributes. In a second phase, new articles were added and analyzed based on the same method as the key articles until all relevant literature (based on the inclusion criteria) was included. The different codes were put into NVIVO12 to synthesize the data and to initiate further discussion with the research group. This resulted in the final attributes (Table 4). The method starting from reading the first article to defining the attributes was characterized by an iterative process in which the attributes were reformulated until consensus with the research group was reached.

Table 2. Example of analysis process of the study of Bernsten et al. 2018.

Extract form article	Code	Attribute
…A professional and a personal goal clashes in a decision process regarding the discontinuation of a medication the informant had been using for years…	Negotiation goals between professionals and patients.	Goal-setting – patient-provider interaction
… However "What matters to you?" gave a richer and more immediate insight into areas threatened by health issues…	Patient centeredness	Tailoring to patients' needs and preferences
…Goal evaluation serves as feedback to all contributors in the seamless care process… The result should be documented and linked back to goal adjustment and learning for the next cycle…	Feedback to the care process	Goal-evaluation

STEP 5: IDENTIFY A MODEL CASE, A CONTRARY CASE, AND A BORDERLINE CASE

A model case is presented as a narrative of how goal-oriented care could be conceptualized and illustrates all defined attributes of goal-oriented care [20]. A contrary and borderline case differ from this model case and do not include all of the attributes and/or differ in one of them.

STEP 6: IDENTIFY ANTECEDENTS AND CONSEQUENCES

Antecedents are events or incidents that precede the process of applying goal-oriented care. Consequences are those events or incidents as a result of applying goal-oriented care [20].

The antecedents and consequences were searched simultaneously with the attributes (step 4). Results have been discussed by the entire research group until consensus was reached.

STEP 7: DEFINE EMPIRICAL REFERENTS

Empirical referents provide an overview of the identified assessment tools related to the attributes aiming to make the concept, goal-oriented care, measurable. These assessment tools may be seen as the underpinning needs and characteristics when developing an evaluation method of goal-oriented care.

RESULTS

STEP 1-3

A first search based on the predefined terms (Table 1) resulted in 590 articles; 82 from Cochrane Library, 188 from Embase, and 313 from PubMed. After removing the duplicates, 366 articles were screened by title and abstract yielding 68 articles. A full text screening of these 68 articles led to 15 articles that fitted the predefined in- and exclusion criteria (step 3). Based on the snowballing method of adding new articles based on references, citations, and similar articles 22 additional articles were added. This resulted in a total of 37 articles (Fig. 1 and Table 3) that were selected for the full text analysis. These articles represented a broad range of study types: 4 systematic reviews, 4 experimental studies (e.g. randomized controlled trial), 13 qualitative studies, 3 survey studies, 1 concept analysis, 1 methodology paper, 4 reviews, 2 position papers, 1 background paper, 1 status report, 1 commentary, 1 opinion paper, and 1 perspective.

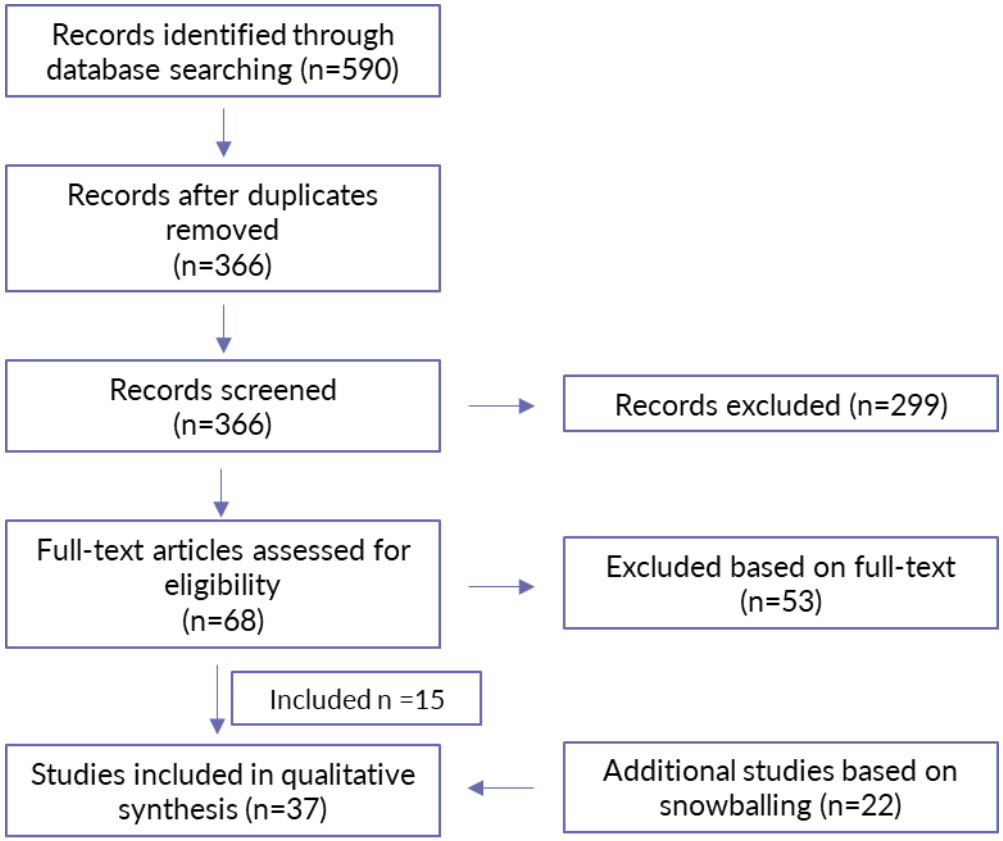


Figure 1 Flow Chart

Table 3. Overview of the included articles.

Papers identified based on full text screening				
No.	Year	Authors	Title	Study design + method
1	1991	Mold, Blake, Lorne, Becker [13]	Goal-oriented medical care.	Position paper
2	2011	De Maeseneer, Boeckxstaens [25]	Care for non-communicable diseases (NCD's): time for a paradigm-shift.	Opinion paper
3	2012	Reuben, Tinetti [10]	Goal-oriented patient care- an alternative health outcomes paradigm.	Perspective
4	2014	Bayliss, Bonds, Boyd, Davis, Finke, Fox, Stange [26]	Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters.	Forty-five experts met to critically consider four aspects of incorporating context into research on multiple chronic conditions.
5	2014	Kramer, Bauer, Dicker, Durusu-Tranriover, Ferreira, Rigby, van Hulsteijn [8]	The changing face of internal medicine: patient- centered care.	Position paper
6	2015	Bernsten, Gammon, Steinsbekk, Salamonsen, Foss, Ruland, Fonnebo [27]	How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care.	Document content analysis of seventy health service research papers on the topic of 'goals of care'.

7	2016	Blom, Elzen, Houwelingen, Heijmans, Stijnen, Van Den Hout, Gussekloo [28]	Effectiveness and cost-effectiveness of a proactive, goal-oriented, integrated care model in general practice for older people. A cluster randomized controlled trial: integrated systematic care for older people-the ISCOPE study.	Cluster randomized controlled trial –intervention group: general practitioners made an integrated care plan using functional geriatric approach; control group: care as usual; 59 general practices were included (30 intervention, 29 control); outcome measures on quality of life, activities of daily living, satisfaction with delivered healthcare, and cost-effectiveness of the intervention 1-year follow-up.
8	2016	Boeckxstaens, Willems, Lanssens, Decuypere, Brusselle, Kühlein, Sutter [29]	A qualitative interpretation of challenges associated with helping patients with multiple chronic diseases identify their goals.	Qualitative research – qualitative interviews with nineteen patients diagnosed with chronic, obstructive pulmonary disease and comorbidities to explore goal-setting in patients with multimorbidity.
9	2016	Mangin, Stephen, Bismah, Risdon [30]	Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity.	Systematic review – data sources: Medline, Embase, Cochrane databases; citations were included if they reported a tool to use a record patient priorities or preferences for treatment, and quantitative or qualitative results following administration of the tool.
10	2016	Schimdt, Babac, Pauer, Damm, von der Schulenberg [31]	Measuring patients priorities using the Analytic hierarchy process in comparison with best-worst scaling and rating cards: methodological aspects and ranking tasks.	Analysis of the results of non-standardized Analytic Hierarchy Process (AHP)for different consistency ration threshold, aggregation methods, and sensitivity analysis; comparison of rakings criteria of AHP with best-worst-scaling and ranking cards results by Kendall's tau b.

11	2016	Tinetti, Esterson, Ferris, Posner, Blaum [1]	Patient priority-directed decision making and care for older adults with multiple chronic conditions.	Review
12	2018	Bernsten, Hoyem, Lettrem, Rul, Rumpsfeld, Gammon [6]	A person-centered integrated care quality framework, based on qualitative study of patient's evaluation of care in light of chronic care ideals.	Qualitative evaluative review of the individual patient pathways experiences of nineteen strategically chosen persons with multimorbidity.
13	2019	Feder, Kiwak, Costello, Dindo, Hern, Bigos, Naik [3]	Perspective of patients in identifying their values-based health priorities.	Qualitative study using in-depth semi structured telephone and in-person interviews; open-ended questions about patient perceptions of the patient health priorities identification process, perceived benefits of the process, enables and barriers to PHPI, and recommendation for process enhancement.
14	2019	Franklin, Lewis, Willis, Roger, Venville, Smith [32]	Controlled, constrained or flexible? How self-management goals are shaped by patient-provider interactions.	Conversation analysis; observations of consultations for chronic care management between patients and their health professionals.
15	2019	Tinetti, Dindo, Smith, Blaum, Costello, Ouellet, Naik [33]	Challenges and strategies in patient's health priorities-aligned decision-making for older adults with multiple chronic conditions.	Participant observation qualitative study – clinicians followed a training and had experiences in providing patient priorities care (PPC), clinicians and PPC implementation team participated in 21 case-based, group discussions. Using emergent learning, participants discussed challenges, posed solutions, and worked together to determine how to align care options with the health priorities of 35 patients participating in the patient priorities care pilot.

Papers identified through snowballing				
No.	Year	Authors	Title	Study design
16	2006	Hurn, Kneebone, Cropley [34]	Goal setting as an outcome measure: a systematic review	Systematic review – data sources included a computer-aid literature search of studies examining the reliability, validity, and sensitivity of goal-setting/ goal-attainment scaling, with snowballing.
17	2009	Bodenheimer, Handley [35]	Goal-setting for behavior change in primary care: an exploration and status report.	Exploration and Status report – literature search on goal-setting interventions for promoting behavior change; resulting in eight articles.
18	2011	Junius-Walker, Stolberg, Steinke, Theile, Hummers-Pradier, Dierks [36]	Health and treatment priorities of older patients and their general practitioners: a cross-sectional study.	Cross-sectional study – 123 older patients and 11 general practitioners evaluated the importance and severity of patients' individual health problems. Patients received a geriatric assessment, then GPS rated the importance and components of severity of each problem; assessing proportion of important problems and the chance corrected agreement; multilevel logistic regression models were used to relate the importance of a problem with its severity components.
19	2012	Rijken, Bekkema, Boeckxstaens, Schellevis, De Maeseneer, Groenewegen [2]	Chronic disease management programs: an adequate response to patients' needs?	Survey among country-experts resulting in information about existing disease management programs; in addition scientific literature.

20	2014	Lenzen, Daniëls, van Bokhoven, der Weijden, Beurskens [37]	Setting goals in chronic care: shared decision making as self-management support by the family physician.	Background paper to contribute to the understanding of goal-setting within self-management and to identify elements that need further development for practical use.
21	2016	Steel Gray, Wodchis, Upshur, Cott, McKinstry, Mercer, Palen, Ramsay, Thavorn [38]	Supporting goal-oriented primary health care for seniors with complex care needs using mobile technology: evaluation and implementation of the health system performance research network, Bridgepoint electronic patient reported outcome tool.	Pragmatic cluster randomized controlled trial – intervention groups using ePRO tool compared with control groups on measure of quality of life, patient experience, and cost-effectiveness; evaluating of tool.
22	2017	Kangovi, Mitra, Smith, Kulkarni, Turr, Huo, Glanz, Grande, Long [39]	Decision-making and goal-setting in chronic disease management: baseline findings of a randomized controlled trial.	Randomized controlled trial – patients used low-literacy aid to prioritize one of their chronic conditions and then set a goal for that condition with their primary care provider; patients created patient-driven action plans for reaching these goals.
23	2017	Mold [40]	Goal-directed health care: redefining health and health care in the era of value-based care.	Review
24	2017	Schellinger, Anderson, Frazer, Cain [41]	Patient self-defined goals: essentials of person-centered care for serious illness.	Descriptive qualitative analysis – initial inquiry to describe self-defined goals patients living with advanced heart failure, cancer, and dementia; goals were entered in electronic health record flow sheet using patients' quotes; analysis of 160 flow sheets with a deductive approach.

25	2017	Vermunt, Harmsen, Elwyn, Westert, Burgers, Rikkert, Faber [42]	A three-goal model for patients with multimorbidity: a qualitative approach.	Qualitative study – qualitative interviews with general practitioners and clinical geriatricians and analyzed following a thematic approach.
26	2017	Vermunt, Harmsen, Westert, Rikkert, Faber [17]	Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review.	Systematic review based on EPOC, PRISMA and MOOSE guidelines; Pubmed, PsychInfo, CINAHL, Web of Science, Embase, Cochrane Central Register of Controlled Trials were searched systematically; eligibility criteria: 1) Randomized (cluster) controlled trials, non-randomized controlled trials, controlled before-after studies, interrupted time series or repeated measures study design; 2) Single intervention directed specifically at collaborative goal setting or health priority setting or a multifactorial intervention including these elements; 3) Study population of patients with multimorbidity or at least one chronic disease (mean age ± standard deviation (SD) incl. age 65). 4) Studies reporting on outcome measures reducible to outcomes for collaborative goal setting or health priority setting.
27	2018	Kessler, Walker, Sauvé-Schenk, Egan [24]	Goal setting dynamics that facilitate or impede a client-centered approach.	Conversation analysis on goal-setting conversations; purposively selected from a pilot randomized controlled trial of OPC-stroke
28	2018	Naik, Dindo, Van Liew, Hundt, Vo, Hernandez-Bigos, Esterson, Geda,	Development of a clinically feasible process for identifying individual health priorities.	Prospective development and feasibility study – development team of patients, caregivers, clinicians using a user-centered design to develop and refine value-based patient priorities care

		Rosen, Blaum, Tinetti [4]		process and medical record template; descriptive statistics and qualitative analysis of barriers and enablers.
29	2019	De Groot, Schönrock-Adema, Zwart, Damoiseaux, Jaarsma, Mol, Bombeke [43]	Learning from patients about patient-centeredness: a realist review: BEME guide No.60	Realist review – realist review approach; literature search in scoping phase, deductive and inductive coding to extent rough program theory.
30	2019	Kuluski, Guilcher [44]	Towards a person-centred learning health system: understanding value from the perspectives of patients and caregivers.	Commentary; call to action to combine the tenets from person-centered care, value-based healthcare, and learning health systems.
31	2019	Kuluski, Peckham, Gill, Gagnon, Wong-Cornall, McKillop, Parsons, Sheridan [9]	What is important to older people with multimorbidity and their caregivers? Identifying attributes of person centered care from the user perspective.	Qualitative descriptive study; 1-1 interviews semi-structured interviews with 172 patients and caregivers from 9 community based primary healthcare.
32	2019	Reuben, Jennings [12]	Putting goal-oriented patient care into practice.	Review
33	2019	Salter, Shiner, Lenaghan, Murdoch, Ford, Winterburn, Steel [23]	Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations.	Qualitative analysis of general practice consultations – analysis of video recorded doctor-patient interactions; focus groups to identify core challenges of goal-setting.

34	2019	Tinetti, Naik, Dindo, Costello, Esterson, Geda, Rosen, Hernandez-Bigos, Smith, Ouellet, Kang, Lee, Blaum [45]	Association of patient priorities-aligned decision-making with patient outcomes and ambulatory health care burden among older adults with multiple chronic conditions.	Nonrandomized clinical trial with propensity adjustment conducted at one patient priorities care (PPC)and one usual care; participants included 163 adults aged 65 years or older who had three or more chronic conditions care for by ten primary care practitioners (PCP) trained in PPC and 203 similar patients who received usual care from 7 PCPs not trained in PPC.
35	2020	Eckhoff, Weiss [46]	Goal-setting: a concept analysis	Concept analysis – method of Walker and Avant, articles and book chapters were reviewed from Cumulative Index to Nursing and Allied Health Literature, Education Resources Information Center, Psych Index.
36	2020	Purkaple, Nagyaldi, Todd, Mold [47]	Physician's response to patient's quality-of-life goals.	Randomized controlled trial – patients were given a previsit questionnaire that included quality of life questions; physicians in the control were given no further prompting; intervention physicians were prompted to ask quality of life questions; a two-pronged design was used: prepost group where three physicians participated in 5 control and 5 intervention encounters (n = 30) and a randomized group in which 11 physicians and their patients were randomly assigned to control or intervention groups (n = 30). Video recordings of the encounters were reviewed to determine if QOL goals were mentioned and if they were utilized in decision making.

37	2020	Sathanpally, Sidhu, Fahami, Gillies, Kadam, Davies, Khunti, Seidu [48]	Priorities of patients with multimorbidity and of clinicians regarding treatment and health outcomes: a systematic mixed studies review.	Systematic review – MEDLINE, EMBASE, CINAHL, and Cochrane databases were searched; included studies reported health outcome and treatment priorities of adults with multimorbidity, defined as suffering from two or more chronic conditions, or of clinicians in the context of multimorbidity or both; no restriction by study design, and studies using quantitative and/ or qualitative methodologies were included.

STEP 4: ATTRIBUTES

The systematic analysis of the 37 selected papers could identify many different attributes of goal-oriented care (S1 Table 1). Synthesizing these attributes, goal-oriented care could be described as a multifaceted dynamic and iterative process of care (first main attribute) underpinned by patients' values (second main attribute). For the process of goal-oriented care five sub attributes and seven descriptive items could be identified (Table 4). These attributes interact and cannot be interpreted separately.

Table 4. Overview of attributes.

<table>
<tr><td rowspan="8">Goal-oriented care is a multifaceted, dynamic and iterative process.

1, 3, 4, 6, 12, 13, 17, 23, 24, 35, 37, 38, 41, 49, 50</td><td colspan="2">1.1 Goal-elicitation builds a patient-provider relationship. [1, 23, 24, 40, 51]</td></tr>
<tr><td rowspan="4">1.2 Goal-oriented care entails goal-setting.</td><td>1.2.1Patient-provider interaction guides goal-setting. [2, 4, 12, 13, 17, 23, 24, 30, 35, 37-40, 42, 44]</td></tr>
<tr><td>1.2.2 Patients' needs and preferences are the foundation of SMART formulated goals. [1-4, 6, 10, 13, 23, 24, 26, 30, 32, 36, 39, 41, 44, 45, 51, 52]</td></tr>
<tr><td>1.2.3 Care plan is based on patients' needs and preferences. [1, 3, 4, 6, 10, 12, 13, 17, 26, 28, 30, 33]</td></tr>
<tr><td>1.2.4 Care is delivered according to the care plan. [1, 6]</td></tr>
<tr><td rowspan="3">1.3 Goal-evaluation is a reflexive process.</td><td>1.3.1 Feedback should be given to the goals. [33, 49]</td></tr>
<tr><td>1.3.2 Evaluation entails questioning how goals are being met. [12]</td></tr>
<tr><td>1.3.3 Goals must be measurable. [13]</td></tr>
<tr><td rowspan="2">2. Goal-oriented care embraces patients' values.</td><td colspan="2">2.1 Goal-oriented care must be placed in patients' context. [3, 12, 26, 30, 37]</td></tr>
<tr><td colspan="2">2.2 Goal-oriented care must be tailored to patients' needs and preferences. [1, 6, 23, 24, 33]</td></tr>
</table>

Goal-oriented care is a multifaceted, dynamic and iterative process

The majority of the authors presented goal-oriented care as a stepwise approach [1, 3, 4, 6, 12, 13, 17, 23, 24, 35, 37, 38, 41, 49, 50]. Even though every paper defined their own approach, overall three stages could be identified: (a) goal-elicitation, (b) the actual stage of goal-setting, and (c) a reflexive goal-evaluation stage. These three stages will be further discussed.

Bernsten et al. emphasized the dynamic and iterative characteristics of the goal-oriented process of care [6]. They described that goal-oriented care entails going back and forth between the three stages [6]. From this perspective, goals are not described as an endpoint, but they can be adjusted, discarded, modified or new goals might be set [12, 33]. This will be further discussed in the stage of goal-evaluation.

Overall, in the goal-oriented process of care, the patient is described as an active partner [1]. Therefore, a good communication in a continuous patient-provider relationship is described to be of utmost importance [41]. In addition, goal-oriented care should be considered as care over time rather than a one-time intervention [53]. In terms of outcomes, it is not entirely clear whether goal-oriented care should focus on (a) maintaining the status quo or (b) improving the patients' situation [12]. Although there is consensus that the care process is oriented to the current needed care rather than care needed in the future [1].

Goal-elicitation builds a patient-provider relationship

As described earlier, the overall analysis could identify goal-elicitation as the first stage in the process of goal-oriented care. In this first stage, providers are presumed to offer time and space to patients to tell their stories in order to work towards the patients' agenda [24]. Therefore, patients have to be ready and should be actively encouraged to tell their story. Tinetti and colleagues described this as 'the patient's state of readiness' [1]. This first stage is considered to be essential to work towards a balanced patient-provider conversation and relation. Salter et al. described this stage as a shared process between patients and providers that reinforces and further builds their relationship [23]. This specific part of the process of goal-oriented care is also described as a means to achieving a greater level of shared understanding and mutual commitment between the patient and the provider [40]. Specific attention to the stage of goal-elicitation is described to create a supportive context for effective goal-setting in the next stage [23].

Goal-oriented care entails goal-setting

Besides the goal-elicitation stage, the literature identifies a goal-setting stage. Franklin and colleagues analyzed patient-provider conversations during goal-setting and concluded that the goal-setting stage serves as a mechanism to embrace patients' needs within the social context he lives in [32]. When this process is done properly, goal-setting should support the patients to continue doing what matters most to them which would help them to cope with their conditions [32]. Within this process of goal-setting different sub attributes, that are considered necessary for proper goal-setting, could be identified.

Patient-provider interaction guides goal-setting

The patient-provider interaction is characterized by a patient-centered approach [23] in which goals are set in collaboration [42]. Hereby, patients and providers agree on health-related goals [2, 12, 13, 35, 38, 42, 50, 54] and find common ground [53]. Tinetti et al. described the importance of considering patients as active partners in the goal-setting process [33]. Rijken et al. mentioned

that patients' goals have to be discussed in a dynamic conversation continuously taking the patients' needs, preferences, and abilities into account [2].

To facilitate a collaborative approach it is suggested that providers emphasize the patients' narratives reflecting their lived experience [40]. Besides a collaborative approach, negotiation is important and considered inevitable [4, 6, 23, 37, 49]. Lenzen et al. defined this as goal-negotiation, which involves discussion of any kind of problems, exploration of the patients' values, needs and capabilities, and deliberation on patients' goals [37]. In goal-negotiation, formulating and agreeing on a specific goal are important components [23].

Because the goal-setting process needs to be driven by patients' needs and preferences, there seems to be a general understanding to shift the focus from the provider to the patient [24]. Different authors reported various strategies to facilitate this shift. Mold stated that the shift implies that prioritization of the individual health-related goals and the amount of effort in achieving them should be made by the individual [13]. Naik et al. stated that patients are indeed encouraged to share their priorities, but adds that providers are encouraged to align their care with the patients' health priorities [4]. More recent publications talking about goal-setting describe a circular and shared process aimed at improving the balance and power differentials in the patient-provider relationship [4, 39]. This balance can be improved by putting themselves in someone's shoes to understand the other's constraints [44].

Patients' needs and preferences are the foundation to set goals

One of the important challenges in our understanding of the concept of goal-oriented care is the lack of clear understanding on patient goals. Nearly all authors described that goals should be grounded on the patients' needs and preferences [1-4, 6, 23, 24, 32, 33, 39, 41, 47, 49, 53, 55, 56]. It is described that goals should be based on the context, resources and capabilities of patients [47], that they should be approved by patients [6], and that they should foremost represent what the patients want and not necessarily what the providers want [12, 41]. Other authors recommended that goals should be a combination of both the patients' goals and the providers' goals which in turn is related to goal-negotiation [24, 44]. In conclusion, no overall understanding on the goals could be formulated.

Besides this lack in understanding, there also seems to be ambiguity about the categorization of goals. Some authors emphasized that goals should contain core values of patients (e.g. the broader aspects that matter most to the patient) [1, 4]. These goals are named as 'overarching goals' [6, 12, 24, 41] leading to a broad description of the goal (e.g., I want to live in my own home as long as possible [1]) [6]. Others argued that these overarching goals might not be easy to work with and describe that these goals should be broken down into sub goals (e.g., I want to walk two blocks without shortness of breath [1]) [6]. Goals differ for each individual and will change over time [13]. Aside from overarching goals and sub goals many of the authors mention the importance of setting SMART goals [1, 6, 23, 24, 35, 46, 49, 50, 53]. A SMART goal is created when patients and providers collaborate to untangle the goal itself, the importance of that goal is emphasized to the patient, the perceived achievability of the goal is evaluated, as well as the timing of the goal, and any supports and resources available [35]. On the meta-perspective, overarching goals are too broad to make SMART (think about the grandmother aiming to get her grandchildren from school as long as possible). Therefore they should be divided in the sub-goals (such as I need to be able to walk without being tired after 10 yards) that are specific enough to be measured.

In one of his first publications Mold brings in a specific discourse around the categorization of goals, namely that goal-oriented care should assist patients in achieving their maximum individual health potential [13], hereby making the link with health. One should however notice that health should be described from the patients' perspective; as the ability to live their life, and not as the absence of disease [1, 13]. Patients' goals are oriented towards health outcome goals. Patients hope to achieve these individual health outcomes through their health care (e.g., function, social activities, and symptom relief) [1]. Health outcome goals describe activities that promote change in physical and cognitive well-being or health [36]. Naik et al. specifically relate patient goals to the care they are willing to receive and able to perform [4].

Care plan is based on patients' needs and preferences

Many authors relate goal-oriented care to the construction of a care plan based on the patients' needs and preferences and specifically mention that these care plans should reflect the patients' personal goals that have been identified in the previous stage [1-3, 6, 12, 26, 28]. There is a consensus that the care plan should reflect the question: 'What matters to you?' [12, 33, 44, 49, 55]. Strategies to achieve the patients' needs and preferences should be implemented in the care plan [13]. Furthermore, Bernsten and colleagues stated that the care plan might also include an interprofessional review of the goals [6]. Therefore, it is necessary to involve all providers and preferably patients' informal caregivers and family in the whole process [3, 6, 17]. In case that providers are confronted with patients' goals that are out of their own scope, they could benefit from an interprofessional review as they are enabled to discuss with and hand over to other providers with the required expertise. This could improve the coordination of the care plans between the different providers and facilitate integrated care delivery [1, 4, 30]. To guide this interprofessional review, no specification was given about which profile would be the best fit for having the lead. Vermunt et al. (2017) illustrated this as they found variation in who (e.g. GP, nurse, practice nurse, psychological wellbeing practitioner) should contribute to goal-setting [17].

Care delivery according to the care plan

Patients and providers should implement the care plan and translate it into care delivery. Although, little is known about how care should be delivered, it is evident that it must be in accordance with the care plan that is set up in the previous stage [6]. For this stage Tinetti et al. specifically mentioned to start the stage of care delivery by prioritizing on simple interventions in order to achieve one or more small goals to keep patients motivated [1]. This simple interventions could focus on the sub-goals described in previous paragraphs to eventually work towards the overarching goals.

Goal-evaluation is a reflective process

The overall synthesis/analysis of the literature could identify goal-evaluation as the third and final stage in the process of goal-oriented care. For this stage authors described a dynamic and iterative process that allows reflection and feedback next to assessing whether and how goals have been met [33, 49]. In this process goals can be redefined and adjusted. Possible reasons to adjust goals might be that goals have been too difficult to achieve or were no longer desired or relevant to the patients' situation [12]. Although many authors acknowledge the possibility and importance of goal adjustment, there is also discussion that goal-oriented processes of care requires that goals can be measured [13]. Steele Gray and colleagues described the importance of qualifying and quantifying the process proceeded to achieve the goals [38]. In contrast, Salter

and colleagues described that making the goals measurable could overcomplicate and distance the patient from their own goal and might therefore not be beneficial to the process of goal-oriented care [23].

Goal-oriented care embraces patients' values

In the previous attributes, goal-oriented care is described as a dynamic and iterative process in which two underpinning values are identified [4]. First, goal-oriented care must be placed in the patient's context and second, goal-oriented care must be tailored to the patient's needs and preferences.

Goal-oriented care must be placed in patients' context

The whole goal-oriented process of care starting from goal-elicitation to goal-evaluation needs to be placed in the patient's context. According to different authors this means that the process must be tailored to the patient's situation [3, 12, 37, 55]. This does not only refer to the personal context, but also to the social and the cultural context. Therefore, this process is influenced by different contextual factors that should must be taken into account when developing the care plan [30, 37].

Goal-oriented care must be tailored to patients' needs and preferences

When reviewing the attributes, it is clear that patients' needs and preferences form the common thread. The question 'What is the matter with the patient' must be retranslated to 'What matters to the patient?' [1, 6, 23, 33]. This question enables patients to tell their story and open up in which they are considered to reflect on their achievements and personal agenda [24]. As a result, patients will have the feeling to be approached as a person instead of through their condition [6].

CASES

The method of Walker and Avant prescribes that several cases should be described to illustrate the attributes defined in step 4 [20]. The first case of Joseph (Box 1) encompasses all the attributes identified in the literature and is therefore identified as a model case. To make this case more lively, each attribute and sub attribute of goal-oriented care is labelled in the box. It is a fictive example of delivering care according to the goal-oriented process of care with focus on the underpinning attributes. The second case of Ben (Box 2) is identified as an additional case as it lacks one or more of the attributes. E.g. in the case of Ben the stage of goal-evaluation is missing. This stage is needed to make adjustment and reflections according to the process of achieving the personal goals. Finally, the third case of Mary (Box 3) is an example of the opposite of goal-oriented care. This is described as a contrary case. In this case, the health care provider does not take the needs and preferences of Mary into account. The provider only thinks about convincing Mary of a healthy lifestyle which for her is not the main reason to visit her health care provider. Her main focus is on being able to play with her children.

Joseph, 68- year old suffers from diabetes, hypertension, and chronic obstructive pulmonary disease. Throughout his entire working life, he was a secondary school teacher. He has been retired for three years now *(patients' context)*. Despite the fact that he is limited by his health condition, he loves spending time gardening and playing with his grandchildren *(patients' needs and preferences)*.

A few years ago he was a passionate cyclist, but his racing bike has been stored for a long time now. His friends encourage him to cycle with them on a weekly base *(patients' context)*. His wife supports this initiative and argues that this will be beneficial for his social contact *(patients' context)*. Every month Joseph visits his family doctor for a check-up. For each consultation, he prepares a list of things he wants to discuss. He has the chance to share his story in an open communication in which trust and mutual respect are key components *(goal-elicitation)*.

In his monthly check-up with his family doctor he suggests his wishes to cycle again with his friends *(patients' needs and preferences & goal-setting; interaction)*. His doctor doubts whether this will be possible and after discussion and negotiation *(goal-setting; interaction)*, they plan that he would join his friends in their weekly cycling trip but only for the first two hours *(goal-setting; foundation for SMART goal)*. The group will be asked to adapt their pace and Joseph will make sure that he does not need to return back home on his own. The doctor makes adjustments to the medication scheme according to the increased efforts Joseph will make *(goal-setting; care plan)*. He will also contact the cardiologist to inform him about the changes to the medication schema *(goal-setting; care plan)*. The family doctor and the cardiologist will collaborate in order to succeed in Joseph's goal *(goal-setting; care delivery)*. The family doctor and Joseph agree to discuss and evaluate the course after three months *(goal-evaluation; feedback & evaluation)*. It is possible to increase or decrease the intensity depending on Joseph's health state and his own preferences *(goal-evaluation; evaluation)*.

Box 1. Case of Joseph

Ben, a 30-year old man, was renovating a house that he bought with his girlfriend when he was diagnosed with MS *(patients' context)*. They made plans to marry next year and to make a world trip as honeymoon. These plans have been put aside due to the recent diagnosis. Although he was feeling down and did not have the energy to do anything he ended up with his physician. Initiated by the interaction and the conversation with his physician *(goal-elicitation)* he was enabled to set goals again and to look at the future *(goal-setting; interaction)*. The physician decided to discuss the things that Ben really likes to do as for example making travel plans and would make it possible to achieve his goals *(goal-setting; interaction)*. Although a plan has been devised towards Ben's goals *(goal-setting; care plan)*, there has never been an discussion whether or not the goals were achieved or required adjustments to new capabilities of Ben. For this reason the consultation Ben had with his physician could not labelled as goal-oriented care.

Box 2. Case of Ben

Mary is a 40-year old mother of two young children and has been obese since since her childhood. Due to her weight, she has a lot of pain in her joints and is short of breath which limits her exercising capacity. Her children are looking forward to playing outside with their mother during the summer holidays. Unfortunately, she is not able to play soccer or jump on the trampoline because of the pain. The pain becomes too much for her and after long hesitation she discusses this with her physician. The only thing she wants is to play and interact with her children as painless as possible and therefore asks her physician to prescribe some medication. Her physician does not support medication, but instructs her to first strive for a healthy weight as a solution to relieve the pain. This is not aligned with the wishes of Mary who only wanted a short-term solution to be able to play with her children. In the end, she leaves the consultation room with a referral to a dietician and sport coach.

Box 3. Case of Mary

ANTECEDENTS

Antecedents are events or incidents that occur prior to the investigated concept. In this concept analysis, provider preparedness and patient preparedness are required to provide goal-oriented care.

In terms of provider preparedness many authors discussed the importance of training [6, 7, 24, 28, 32, 42, 50]. Notwithstanding that several authors [1, 4, 17, 23, 28, 33, 39] mentioned the importance of trained health care providers, there was a difference in the training they received (supplementary file 3). Differences can be found in the target population reached with the training, both in monodisciplinary and interprofessional training (e.g. general practitioners [23], practice nurses [28], duration of the training (e.g. three hour [23], number of sessions [28]) and training method (e.g. role-play [33]). Thereby, the content of the training was tailored to the skills needed to carry out the intervention correctly and differ therefore in each training (S3 Table 3).

A second aspect that is discussed concerning provider preparedness focused on the personal skills of providers [1, 6, 17, 23]. These include communication and balancing skills in which an open communication with the patient is necessary and in which an equal balance between the patient and provider is a premise [1, 6, 17, 23]. Other defined skills were the provider's ability to listen, understand and bearing witness to the patient's story [23] and their willingness to change and learn new skills to provide care according to the goal-oriented process of care [1].

Besides provider preparedness some authors [1, 12, 42] specifically talked about the need of patient preparedness. Patients needed to be prepared to share their needs and preferences when entering a care relationship [1]. Some authors translate the importance of patient preparedness into patient education [1], others talked about patient guidance [11] or supporting patients in developing the skills to set personal goals [37].

CONSEQUENCES

Consequences are those events or incidents that occur as a result of a concept. For the concept of goal-oriented care, the consequences defined throughout the papers could be categorized in: (a) patient-related consequences [1, 3, 4, 24, 30, 49], (b) provider-related consequences [1, 23, 30, 49], (c) care-related consequences [1, 23, 30] and (d) general consequences [4, 6, 30].

Patient-related consequences are the results for patients themselves after they received care following a goal-oriented process. A goal-directed approach could be expected to increase patient satisfaction, since the values, preferences, knowledge and opinions that each patient brought to the provider-patient relationship was more valued [40]. Also, emphasis was put on the changed way of communicating in which patients felt more freely and able to speak [3]. This led to the overall feeling of being heard, understood, respected, and engaged in their care [30]. Furthermore, a goal-oriented process of care could lead to a better understanding and more in-depth knowledge of patients regarding their health, activation of patients to be more involved in their care, and an increase in their overall commitment. This resulted in the increase of adherence [3]. Also Mold argued that it could contribute to a better adherence [13]. In general, the gained in-depth knowledge of patients concerning their health and a better understanding of their tasks could help to improve their quality of life [3]. This was enhanced by the maximization of function and the independence patients gained [13].

For providers, goal-oriented care assisted healthcare them in their decision-making [30] and gave them the opportunity to get to know their patients better. It enhanced patient-provider collaboration [13] and contributed therefore to more job satisfaction [23].

Care-related consequences were mainly focused on reducing costs, overtreatment and fragmentation [1, 23, 30], since care oriented to patients' priorities would reduce tests and treatments [45]. Bernsten et al. stated also that goal-oriented care could lead to an improvement of quality of care and quality of life [6].

Although, many positive outcomes have been presented, Reuben et al. mentioned a possible downside of goal-oriented care [10]. They described that some decisions to strive for personal goals may worsen the providers' performance on aggregated health measures. For example, when a diabetic patient chooses to not follow his diet and keep on smoking, because it would be a too big lifestyle change, his HbA1c-level would not be aligned with the guidelines. Although, it could be a positive outcome from the patient perspective, it would influence the quality of care provided and the population health in a negative way.

EMPIRICAL REFERENTS

Empirical referents provide an overview of the identified assessments tools related to the attributes aiming to make the concept measurable.
None of the papers mentioned an empirical referent to measure the entire concept of goal-oriented care. Therefore, tools have been searched for each individual sub-attribute. Examples are listed in Table 5 which gives an overview of possible tools and presents an example item presented in that tool. Listing the existing individual empirical referents might initiate the development of an overall empirical referent.

Table 5. Overview empirical referents.

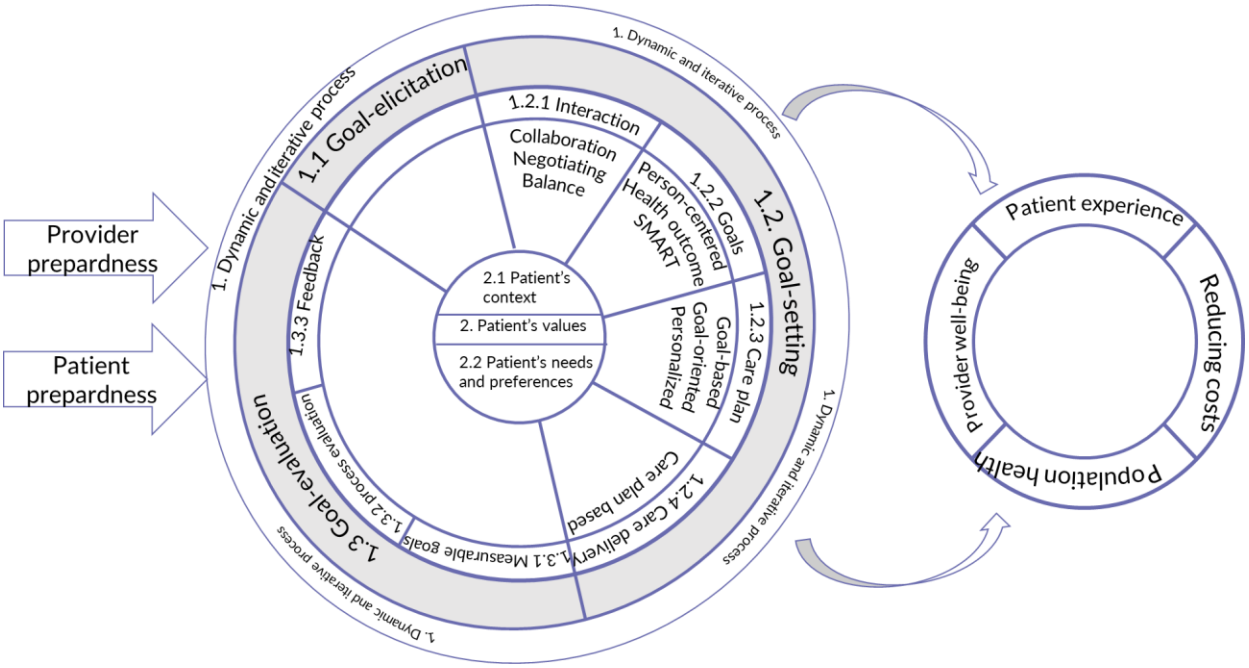
Attribute	Purpose of the tool	Example of item in the assessment tool
Goal-elicitation		
Davis Observation Code (DOC) [57]	20-item direct observation scale for physician-patient interactions	Discussing family, medical, or social history and/ or current family functioning.
Goal-setting		
Patient goal priority questionnaire [58]	Patient-specific measure for identification of behavioral goals and evaluation of clinically significant changes	Which activities are most important for you to manage?
Self-identified goals assessment [59]	1) Helps patients to identify personally meaningful occupational goals to be addressed in therapy 2) evaluate changes levels of patient-defined success in desired occupations	Think about all of the things you want to be able to do. It might help to think about the things you did at home before you went to the hospital, and things that are hard to do now. What types of things would you like to work on or improve on in therapy before you go back home?
Canadian Occupational Performance Measure (COPM) [60]	Measure of a client's self-perception of occupational performance in the areas of self-care, productivity, and leisure	Semi-structured interview – discussing daily functioning and personal life.

Health outcome prioritization tool [61]	Tool for decision-making among older persons with multiple chronic conditions	I would like to know how important 'keeping you alive', 'maintaining independence', 'reducing or eliminating pain' and 'reducing or eliminating symptoms of dizziness, fatigue, shortness of breath' is to you.
Electronic Patient Reported Outcome Tool (ePRO-tool) [62]	Tool can help patients and providers to collaboratively develop healthcare goals	Goal-setting for five different areas identified as most important.
Goal-evaluation		
Goal-attainment scale [63]	Tool to measure in which extent patients' goals have been met	Determining goal-attainment using 5-point scale.
Patient Assessment of Care for Chronic Conditions (PACIC) [64]	Tool to measure quality of chronic disease care	Asked to talk about my goals in caring for my condition.
Goal-setting evaluation tool [65]	Tool to rate the quality of goals and action plans	Does the plan identify specific actions or activities that could help to reach the goal?
Person's context and patient's needs and preferences		
Person-centered primary care measure (PCPCM) [66]	11-item patient-reported measure to assess primary care aspects	My doctor or practice knows me as a person/ Over time, the practice helps me to meet my goals.
Patient centered observation form (PCOF) [67]	Tool to help healthcare providers communicate effectively with patients	Collaborative upfront agenda setting.

CONCLUSION OF THE CONCEPT ANALYSIS

Fig. 2 represents the overall synthesis of this concept analysis of goal-oriented care. Goal-oriented care could be described as a health care approach encompassing a multifaceted, dynamic, and iterative process underpinned by the patient's context and values. The process is characterized by three stages: goal-elicitation, goal-setting and goal-evaluation in which patients' needs and preferences form the common thread. In order to be able to deliver care according to the principles of the goal-oriented care process, both providers and patients need to be prepared. In terms of the consequences of goal-oriented care literature points to the potential of goal-oriented care to improve patients' experiences and provider well-being, the potential to reduce costs and improve the overall health of the population. Furthermore, a model, a contrary and an additional case illustrated an example of goal-oriented care in practice. The empirical referents showed that it is currently not possible to measure goal-oriented care in its entirety and presented an overview of possible referents for each sub attribute. Although the literature allowed us to gain more insight into the concept of goal-oriented care, different aspects need to be further discussed.

Fig. 2 Schematic representation of the antecedents, attributes and consequences.



DISCUSSION AND CONCLUSION

This concept analysis aimed to tackle the lack of a common understanding of goal-oriented care by identifying the attributes, antecedents and consequences using the method of Walker and Avant [20]. The overall analysis showed that a goal-oriented care generally entails three stages. Despite these three stages the process of goal-oriented care cannot be implemented as a linear protocol or checklist. Two underpinning attributes, the patient's context and the patient's needs and preferences form the common thread throughout this goal-oriented process of care. These underpinning attributes represent the philosophy of care. Goal-oriented care is a continuous interaction where you go back and forth to gain a person-centered approach (Fig. 2).

In the stage of goal-elicitation, greater consideration should be given to the patients' peripheral narrative reflecting their lived experiences [32]. Several authors have investigated components of goal-elicitation. Murdoch and colleagues performed a conversation analysis of patients-providers interaction during their encounters and found that eliciting the patients' understanding is an important component [68]. Ospina et al. investigated the extent to which patients' concerns are elicited across different clinical settings [69]. They concluded that providers seldom elicit the patients' agenda. This reduces the chance that providers will orient their consultation towards the specific aspects that matter to the patient [69]. One of the prerequisites to succeed in goal-elicitation is the mutual understanding about the expectations of the consultations between patients and providers and a qualitative relationship between patients and providers [68]. The literature also mentions that patients need to have a set of skills to make appropriate health decisions and reflect on their health care choices [70]. They have to be capable to open up and tell their story [71]. It is important that patients understand the meaning of information communicated by the provider, must appreciate the consequences of the treatment options, and must reason about the information based on his or her own values and preferences [71].

Besides the stage of goal-elicitation, the stage of goal-setting was defined. One of the remaining knowledge gaps is on what kind of goals patients set. In goal-oriented care it seems important to set goals based on the patients' needs and preferences (e.g., I want to take my grandchildren to school), while in other chronic disease management programs emphasis is mainly still on health-related goals (e.g., I want the patient to walk without pain) [4]. Various work in different settings identified that patients do not necessarily have clearly defined goals for themselves [68]. Although, several authors performed research on the categorization of patients' goals. Vermunt et al. performed for example a qualitative study to develop conceptual descriptions of goal-oriented care [42]. They presented a three-level goal hierarchy containing disease- or symptom specific goals, functional goals, and fundamental goals which provides more insight in the type of goals. A second example is the distinction made by Schellinger et al. between medical, nonmedical, multiple, and global goals [41]. Not only is there ambiguity on what goals patients set, it is also not clear how goals are being set. What is clear is that patients and providers must collaborate and negotiate on which goals are important. Nevertheless, this can still cause conflicts between the patients' goals and providers' goals [26, 61]. To overcome these conflicts, it is suggested to first set the patients' goals and then discuss about the medical goals, because conflicts are more likely when goals are placed on the same level [27]. It should however be noticed that setting the patients' goals on top does not

legitimate full patients' responsibility over the care plan [27]. Another way to overcome these conflicts is to work with a facilitator as Naik et al. did in developing their *patients priorities identification process*. These facilitators supported patients in setting goals, choosing the most important goals to eventually communicate them with the provider [4]. Yet another strategy is to use tools to assess patient treatment priorities and preferences. Unfortunately, Mangin et al. found few relevant tools to set patients' goals [30]. They argue for the need to develop specific strategies to make patient priorities visible in the clinical record and medical-decision making [30].

Goal-evaluation was pointed out as the last stage. As presented in the results, several authors described that goals should be made measurable for evaluation [23, 62]. There are some pitfalls related to goal-evaluation. Salter et al. described that not all goals lend themselves to being measured [23]. It is for example challenging to evaluate the goal 'I want to take my grandchildren from school as long as possible'. Another pitfall is that patients' goals would be simplified to what can be measured. Working towards goal-evaluation might increase the pressure on patients and providers to work in the same way as disease-specific guidelines do [72]. Especially from the perspective of patients with multimorbidity it can be questioned whether disease-specific guidelines that are good for the disease are also good for the patient [72]. Furthermore, evidence shows that older multimorbid patients place quantitative health outcomes, such as longer survival, on a lower level of importance [72]. The focus must be on the patients' values and make healthcare more humane [40].

As mentioned for the antecedents it is important that patients and providers are prepared to work towards a goal-oriented process of care. The collaboration and co-creation between the two partners and in an interprofessional team is an important but insufficient prerequisite to succeed in providing goal-oriented care. Currently patients are not always stimulated to think about their care. They have to be stimulated to actively engage their narrative and to share their priorities. Also providers have to develop complementaty skills in which they learn to let go their own assumptions and solutions. They have to learn to integrate patients' narrative in their care plan and improve their communication skills to strengthen the mutual understanding between them [73]. Voigt et al. observed that GPs are often unaware of patients' priorities in daily life, which were in contrast with their perceived importance of patient's medical goals [73]. Training and tools could provide the guidance needed to improve the communication[1, 4, 17, 23, 28, 33, 39]. It could support providers in structuring the conversation, to set goals in collaboration with patients, and to align their care to those goals. Not only does goal-oriented care offer a specific approach for one-on-one interaction between patients and providers, it could also facilitate interprofessional collaboration. It gives providers from divers disciplines the opportunity to deliver care following the same principles and to focus on pursuing patients' goals [35]. Therefore training should also include the interprofessional perspective to facilitate a uniform attitude towards the patients' goals and principles of goal-oriented care in the entire team. This will potentially support providers to learn from and with each other's expertise and enable discussion between them in case that, for example, patients set goals that our out of the remit of the provider. Besides patient and provider preparedness, it could seem logical that also the system has to be prepared, but the current literature does not point to that.

In terms of the consequences of goal-oriented care, a limited number of studies have been able to demonstrate outcomes of goal-oriented care. Nonetheless, these studies showed mostly positive outcomes towards the patients, providers, health system, and overall population well-being. In that respect, goal-oriented care shows the potential to meet the components of the quadruple aim. It can be questioned if all providers experience increased satisfaction and well-being in providing goal-oriented care. Providers have to learn to cope with another way of delivering care. For example, a changed medication scheme as described in Josephs' case in order to work towards patients' goals. This goes against their basic principles to strive for the best possible health status including a comprehensive medication scheme. Besides that the provider well-being can be questioned, Blom et al. also contradicted the positive results for the health care system. They did not find a beneficial effect in health care use and costs when using a proactive, goal-oriented, integrated care model [28].

One of the reasons of the limited number of effectiveness studies of goal-oriented care is the lack of empirical referents. The concept must still undergo the transition towards an evaluable concept. Boyd et al. argue for measures for quality of care needed by older persons with multimorbidity as the current clinical guidelines have undesirable effects for this population [52]. Goal-oriented care is identified by Etz and colleagues as one of the main constructs when developing a new comprehensive measure of high-value aspects of primary care, however they did not mention how it has to be done [74]. Further Young et al. described outcome goals as a main construct when differentiating processes and outcomes for primary care and divided it further in goal-clarity for multimorbidity, goal-clarity for unique patient priorities and goal timing [75]. It is clear that in order to gain more insight in the consequences of goal-oriented care further research must primarily focus on how goal-oriented care is provided and can be supported. In order to investigate the potential benefits of goal-oriented care, research also needs to work on developing indicators of the goal-oriented process of care.

Strengths, limitations, and recommendations

The method of Walker and Avant provides a rigorous and systematic approach to refine the concept of goal-oriented care through the existing literature. A concept analysis is an exploration of an evolving concept which will need to be enriched by new knowledge. Therefore, it is influenced by contextual factors and must undergo adjustments to new implications and new insights based on further research. Since there is no specification given by Walker and Avant on how to conduct the literature review, we followed the guidelines from a scoping review as described by Levac (2010) [21]. The iterative process of adding new articles following the snowballing method is one of the strengths compared to other types of reviews. In this concept analysis, this led to a larger number of articles than the original search. A possible explanation for this might be that goal-oriented care was covered by synonyms or similar concepts that were not covered by the original search. Despite the systematic approach, a concept analysis does not comprise a quality assessment of the literature. However, it seemed to be an appropriate method to provide the knowledge needed to understand the different components of goal-oriented care in its entirety. The literature that was included in this study were only English written and peer reviewed. It would however be interesting to add also non-English literature to be able to capture more differences (e.g., cultural differences).

The literature search identified both original research papers and position papers. Some original research papers [3, 4, 23, 38, 41] evaluated goal-oriented care in clinical practice. These papers identified and described goal-oriented care as a stepwise intervention. Position papers [1, 12, 13, 35, 37] mostly described components of goal-oriented care rather than such a stepwise approach. The combination of both types gave more insight in the broad components of goal-oriented care.

This concept analysis could also be considered as a preliminary step to facilitate further research. One of the knowledge gaps revealed in this concept analysis is the lack of knowledge on what patients' goals are set, how goal-oriented care is delivered, and how it is best put into practice in both one-on-one interactions between patients and providers and in interprofessional collaboration. Regarding patients it is important to gain more insight into how they are preferably prepared for discussing their personal goals. In addition, the list of empirical referents made clear that a golden standard to evaluate goal-oriented care is missing. Initiating the development of an evaluation method could enable future intervention studies to gain more insight into the consequences of goal-oriented care and to make results comparable. Increasing insights from effective goal-oriented care could highlight its multiple benefits towards providers and policy makers. These results might also inform the healthcare system in which resources they need to facilitate goal-oriented care. A following step will first be to discuss these theoretical insights with patients and providers and deepen this information with insights from practices. Then, when goal-oriented care is well understood, a critical review can be set up to perform in-depth comparison between other concepts and frameworks. At this moment, we have (unfortunately) insufficient information to do this.

Goal-oriented care shows the potential to be a way forward for patients with chronic conditions and multimorbidity. However, further research is needed to translate the current knowledge on the concept of goal-oriented care into a tangible workflow process of care that entails the three stages. This workflow should consists of tools to prepare patients and providers to offer goal-oriented care. This could contribute to finding a common ground in the goals and implementing goal-oriented care in practice.

Conclusion

This concept analysis aimed to translate the concept of goal-oriented care into a common understanding so providers can better understand and use this concept in clinical practice. The various literature on goal-oriented care, based on position and original research papers, showed a stepwise approach of three stages. Overall, the underpinning attributes of patients' context and patients' values form a philosophy of care to which the process must be reflected. Furthermore, both patients and the providers need to develop new skills in order to rethink the way care is provided. Patients must therefore be enabled to open up and reflect on their own agenda. Providers instead must learn to let go their own assumptions and solutions and communicate with their patients in a more balanced context. Based on the literature goal-oriented care shows the potential to improve patients' experience by listening to their needs and preferences, improve providers' well-being by the feeling of more satisfaction and reduce health care costs. Goal-oriented care could answer the challenges patients face with multiple care processes by initiating interprofessional collaboration. However, further research must focus on what and how goals are

set, the translation of these findings into a workflow and must initiate the development of an evaluation method in order to investigate the effects of goal-oriented care processes on patients, providers and the health care system.

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REFERENCES

(1) Tinetti, M. E.; Esterson, J.; Ferris, R.; Posner, P.; Blaum, C. S. Patient Priority-Directed Decision Making and Care for Older Adults with Multiple Chronic Conditions. *Clinics in geriatric medicine* **2016**, *32* (2), 261-275.

(2) Rijken, M.; Bekkema, N.; Boeckxstaens, P.; Schellevis, F. G.; De Maeseneer, J. M.; Groenewegen, P. P. Chronic Disease Management Programmes: an adequate response to patients' needs? *Health Expect* **2014**, *17* (5), 608-621. DOI: 10.1111/j.1369-7625.2012.00786.x From NLM.

(3) 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. *Journal of the American Geriatrics Society* **2019**

67 (7), 1379-1385.

(4) Naik, A. D.; Dindo, L. N.; Van Liew, J. R.; Hundt, N. E.; Vo, L.; Hern; ez-Bigos, K.; Esterson, J.; Geda, M.; Rosen, J.; et al. Development of a Clinically Feasible Process for Identifying Individual Health Priorities. *Journal of the American Geriatrics Society* **2018**, *66* (10), 1872-1879.

(5) 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. *Br J Gen Pract* **2018**, *68* (669), e245-e251. DOI: 10.3399/bjgp18X695465 From NLM.

(6) 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.

(7) Ploeg, J.; Matthew-Maich, N.; Fraser, K.; Dufour, S.; McAiney, C.; Kaasalainen, S.; Markle-Reid, M.; Upshur, R.; Cleghorn, L.; Emili, A. Managing multiple chronic conditions in the community: a Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers. *BMC Geriatr* **2017**, *17* (1), 40.

(8) Kramer, M. H.; Bauer, W.; Dicker, D.; Durusu-Tanriover, M.; Ferreira, F.; Rigby, S. P.; Roux, X.; Schumm-Draeger, P. M.; Weidanz, F.; van Hulsteijn, J. H. The changing face of internal medicine: patient centred care. *European journal of internal medicine 25* (2), 125-127.

(9) 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.

(10) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* **2012**, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM.

(11) Kuipers, S. J.; Cramm, J. M.; Nieboer, A. P. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Serv Res* **2019**, *19* (1), 1-9.

(12) Reuben, D. B.; Jennings, L. A. Putting Goal-Oriented Patient Care Into Practice. *Journal of the American Geriatrics Society* **2019**, *67* (7), 1342-1344.

(13) Mold, J. W.; Blake, G. H.; Becker, L. A. Goal-oriented medical care. *Family medicine* **1991**, *23* (1), 46-51. From NLM.

(14) Sackett, D. L.; Rosenberg, W. M.; Gray, J. M.; Haynes, R. B.; Richardson, W. S. Evidence based medicine: what it is and what it isn't. British Medical Journal Publishing Group: 1996.

(15) Baker, A. *Crossing the quality chasm: a new health system for the 21st century*; British Medical Journal Publishing Group, 2001.

(16) Elwyn, G.; Frosch, D.; Thomson, R.; Joseph-Williams, N.; Lloyd, A.; Kinnersley, P.; Cording, E.; Tomson, D.; Dodd, C.; Rollnick, S. Shared decision making: a model for clinical practice. *Journal of general internal medicine* **2012**, *27* (10), 1361-1367.

(17) Vermunt, N.; Harmsen, M.; Westert, G. P.; Olde Rikkert, M. G. M.; Faber, M. J. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC Geriatr* **2017**, *17* (1), 167. DOI: 10.1186/s12877-017-0534-0 From NLM.

(18) Poitras, M. E.; Maltais, M. E.; Bestard-Denomme, L.; Stewart, M.; Fortin, M. What are the effective elements in patient-centered and multimorbidity care? A scoping review. *BMC Health Serv Res* **2018**, *18* (1), 446. DOI: 10.1186/s12913-018-3213-8 From NLM.

(19) Hobbs, F. R.; Bankhead, C.; Mukhtar, T.; Stevens, S.; Perera-Salazar, R.; Holt, T.; Salisbury, C. Clinical workload in UK primary care: a retrospective analysis of 100 million consultations in England, 2007–14. *The Lancet* **2016**, *387* (10035), 2323-2330.

(20) Walker, L. O. A., K.C. *Strategies for theory constructing in nursing.*; 2019.

(21) Levac, D.; Colquhoun, H.; O'Brien, K. K. Scoping studies: advancing the methodology. *Implement Sci* **2010**, *5*, 69. DOI: 10.1186/1748-5908-5-69 From NLM.

(22) Mourad Ouzzani, H. H., Zbys Fedorowicz, and Ahmed Elmagarmid. Rayyan - a web and mobile app for systematic reviews. . *Systematic Reviews* **2016**, *5* (210). DOI: 10.1186/s13643-016-0384-4.

(23) Salter, C.; Shiner, A.; Lenaghan, E.; Murdoch, J.; Ford, J. A.; Winterburn, S.; Steel, N. Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations. *Br J Gen Pract* **2019**, *69* (684), e479-e488. DOI: 10.3399/bjgp19X704129 From NLM.

(24) Kessler, D.; Walker, I.; Sauve-Schenk, K.; Egan, M. Goal setting dynamics that facilitate or impede a client-centered approach. *Scandinavian journal of occupational therapy* **2018**, *26* (5), 315-324.

(25) De Maeseneer, J.; Boeckxstaens, P. Care for noncommunicable diseases (NCDs): time for a paradigm-shift. *World hospitals and health services : the official journal of the International Hospital Federation* **2011**, *47* (4), 30-33.

(26) Bayliss, E. A.; Bonds, D. E.; Boyd, C. M.; Davis, M. M.; Finke, B.; Fox, M. H.; Glasgow, R. E.; Goodman, R. A.; Heurtin-Roberts, S.; Lachenmayr, S.; et al. Understanding the context of health for persons with multiple chronic conditions: moving from what is the matter to what matters. *Annals of family medicine* **2014**, *12* (3), 260-269. DOI: 10.1370/afm.1643 From NLM.

(27) Berntsen, G. K.; Gammon, D.; Steinsbekk, A.; Salamonsen, A.; Foss, N.; Ruland, C.; Fønnebø, V. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care. *BMJ Open* **2015**, *5* (12), e009403. DOI: 10.1136/bmjopen-2015-009403 From NLM.

(28) Blom, J.; Elzen, W. D.; Houwelingen Anne, H. V.; Heijmans, M.; Stijnen, T.; Van Den Hout, W.; Gussekloo, J. Effectiveness and cost-effectiveness of a proactive, goal-oriented, integrated care model in general practice for older people. A cluster randomised controlled trial: Integrated systematic care for older people-the ISCOPE study. *Age and Ageing* **2016**, *45* (1), 30-41, Article. DOI: 10.1093/ageing/afv174 Embase

Medline.

(29) Boeckxstaens; Willems; Lanssens; Decuypere; Brusselle; Kühlein; Maeseneer, d.; Sutter, D. A qualitative interpretation of challenges associated with helping patients with multiple chronic diseases identify their goals. *Journal of comorbidity* **2016**, *6* (2), 120-126.

(30) Mangin, D.; Stephen, G.; Bismah, V.; Risdon, C. Making patient values visible in healthcare: a systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. *BMJ open* **2016**, *6* (6), e010903.

(31) Schmidt, K.; Babac, A.; Pauer, F.; Damm, K.; von der Schulenburg, J. M. Measuring patients' priorities using the Analytic Hierarchy Process in comparison with Best-Worst-Scaling and rating cards: methodological aspects and ranking tasks. *Health economics review* **2016**, *6* (1), 50.

(32) 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. *Qualitative health research* **2019**, 1049732318774324.

(33) Tinetti, M.; Dindo, L.; Smith, C. D.; Blaum, C.; Costello, D.; Ouellet, G.; Rosen, J.; Hern; ez-Bigos, K.; Geda, M.; et al. Challenges and strategies in patients' health priorities-aligned decision-making for older adults with multiple chronic conditions. *PloS one* **2019**, *14* (6), e0218249.

(34) Hurn, J.; Kneebone, I.; Cropley, M. Goal setting as an outcome measure: A systematic review. *Clinical rehabilitation* **2006**, *20* (9), 756-772. DOI: 10.1177/0269215506070793 From NLM.

(35) Bodenheimer, T.; Handley, M. A. Goal-setting for behavior change in primary care: an exploration and status report. *Patient education and counseling* **2009**, *76* (2), 174-180. DOI: 10.1016/j.pec.2009.06.001 From NLM.

(36) Junius-Walker, U.; Stolberg, D.; Steinke, P.; Theile, G.; Hummers-Pradier, E.; Dierks, M.-L. Health and treatment priorities of older patients and their general practitioners: a cross-sectional study. *Quality in primary care* **2011**, *19* (2).

(37) Lenzen, S. A.; Daniels, R.; van Bokhoven, M. A.; van der Weijden, T.; Beurskens, A. Setting goals in chronic care: Shared decision making as self-management support by the family physician. *Eur J Gen Pract* **2015**, *21* (2), 138-144. DOI: 10.3109/13814788.2014.973844 From NLM.

(38) Steele Gray, C.; Wodchis, W. P.; Upshur, R.; Cott, C.; McKinstry, B.; Mercer, S.; Palen, T. E.; Ramsay, T.; Thavorn, K. Supporting Goal-Oriented Primary Health Care for Seniors with Complex Care Needs Using Mobile Technology: Evaluation and Implementation of the Health System Performance Research Network, Bridgepoint Electronic Patient Reported Outcome Tool. *JMIR research protocols* **2016**, *5* (2), e126.

(39) Kangovi, S.; Mitra, N.; Smith, R. A.; Kulkarni, R.; Turr, L.; Huo, H.; Glanz, K.; Grande, D.; Long, J. A. Decision-making and goal-setting in chronic disease management: Baseline findings of a randomized controlled trial. *Patient Educ Couns* **2017**, *100* (3), 449-455. DOI: 10.1016/j.pec.2016.09.019 From NLM.

(40) Mold. Goal-directed health care: redefining health and health care in the era of value-based care. *Cureus* **2017**, *9* (2).

(41) Schellinger, S. E.; Anderson, E. W.; Frazer, M. S.; Cain, C. L. Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness. *The American journal of hospice & palliative care* **2018**, *35* (1), 159-165. DOI: 10.1177/1049909117699600 From NLM.

(42) Vermunt, N. P.; Harmsen, M.; Elwyn, G.; Westert, G. P.; Burgers, J. S.; Olde Rikkert, M. G.; Faber, M. J. A three-goal model for patients with multimorbidity: A qualitative approach. *Health expectations : an international journal of public participation in health care and health policy* **2018**, *21* (2), 528-538.

(43) de Groot, E.; Schonrock-Adema, J.; Zwart, D.; Damoiseaux, R.; Van den Bogerd, K.; Diemers, A.; Grau Canet-Wittkampf, C.; Jaarsma, D.; Mol, S.; Bombeke, K. Learning from patients about patient-centredness: A realist review: BEME Guide No. 60. *Medical teacher* **2019**, 1-13. DOI: 10.1080/0142159x.2019.1695767 From NLM.

(44) 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.

(45) 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 Intern Med* **2019**.

(46) Eckhoff, D. O.; Weiss, J. Goal setting: A concept analysis. *Nursing forum* **2020**. DOI: 10.1111/nuf.12426 From NLM.

(47) Purkaple, B. A.; Nagykaldi, Z. J.; Allahyar, A.; Todd, R.; Mold, J. W. Physicians' Response to Patients' Quality-of-Life Goals. *The Journal of the American Board of Family Medicine* **2020**, *33* (1), 71. DOI: 10.3122/jabfm.2020.01.190169.

(48) Sathanapally, H.; Sidhu, M.; Fahami, R.; Gillies, C.; Kadam, U.; Davies, M. J.; Khunti, K.; Seidu, S. Priorities of patients with multimorbidity and of clinicians regarding treatment and health outcomes: a systematic mixed studies review. *BMJ open* **2020**, *10* (2), e033445. DOI: 10.1136/bmjopen-2019-033445 From NLM.

(49) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care - An alternative health outcomes paradigm. *New England Journal of Medicine* **2012**, *366* (9), 777-779, Short Survey. DOI: 10.1056/NEJMp1113631 Embase

Medline.

(50) Heisler, M.; Bouknight, R. R.; Hayward, R. A.; Smith, D. M.; Kerr, E. A. The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *Journal of general internal medicine* **2002**, *17* (4), 243-252.

(51) Purkaple, B. A.; Nagykaldi, Z. J.; Allahyar, A.; Todd, R.; Mold, J. W. Physicians' Response to Patients' Quality-of-Life Goals. *J Am Board Fam Med* **2020**, *33* (1), 71-79. DOI: 10.3122/jabfm.2020.01.190169 From NLM.

(52) Boyd, C. M.; Darer, J.; Boult, C.; Fried, L. P.; Boult, L.; Wu, A. W. Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: implications for pay for performance. *Jama* **2005**, *294* (6), 716-724. DOI: 10.1001/jama.294.6.716 From NLM.

(53) Mangin, D.; Stephen, G.; Bismah, V.; Risdon, C. Making patient values visible in healthcare: A systematic review of tools to assess patient treatment priorities and preferences in the context of multimorbidity. *BMJ Open* **2016**, *6* (6), Article. DOI: 10.1136/bmjopen-2015-010903 Embase

Medline.

(54) Vermunt, N. P.; Harmsen, M.; Westert, G. P.; Rikkert, M. G. O.; Faber, M. J. Collaborative goal setting with elderly patients with chronic disease or multimorbidity: a systematic review. *BMC geriatrics* **2017**, *17* (1), 167.

(55) Boyd, C. M.; Wolff, J. L.; Giovannetti, E.; Reider, L.; Weiss, C.; Xue, Q.-l.; Leff, B.; Boult, C.; Hughes, T.; Rand, C. Health care task difficulty among older adults with multimorbidity. *Medical care* **2014**, *52* (0 3), S118.

(56) Locke, E. A.; Latham, G. P. *A theory of goal setting & task performance*; Prentice-Hall, Inc, 1990.

(57) Callahan, E. J.; Bertakis, K. D. Development and validation of the Davis Observation Code. *Fam Med* **1991**, *23* (1), 19-24. From NLM.

(58) Åsenlöf, P.; Siljebäck, K. The patient goal priority questionnaire is moderately reproducible in people with persistent musculoskeletal pain. *Physical therapy* **2009**, *89* (11), 1226-1234.

(59) Melville, L. L.; Baltic, T. A.; Bettcher, T. W.; Nelson, D. L. Patients' perspectives on the self-identified goals assessment. *Am J Occup Ther* **2002**, *56* (6), 650-659. DOI: 10.5014/ajot.56.6.650 From NLM.

(60) Dedding, C.; Cardol, M.; Eyssen, I. C.; Dekker, J.; Beelen, A. Validity of the Canadian Occupational Performance Measure: a client-centred outcome measurement. *Clinical rehabilitation* **2004**, *18* (6), 660-667. DOI: 10.1191/0269215504cr746oa From NLM.

(61) Fried, T. R.; Tinetti, M.; Agostini, J.; Iannone, L.; Towle, V. Health outcome prioritization to elicit preferences of older persons with multiple health conditions. *Patient education and counseling* **2011**, *83* (2), 278-282.

(62) Steele Gray, C.; Gill, A.; Khan, A. I.; Hans, P. K.; Kuluski, K.; Cott, C. The Electronic Patient Reported Outcome Tool: Testing Usability and Feasibility of a Mobile App and Portal to Support Care for Patients With Complex Chronic Disease and Disability in Primary Care Settings. *JMIR Mhealth Uhealth* **2016**, *4* (2), e58. DOI: 10.2196/mhealth.5331 From NLM.

(63) Toto, P. E.; Skidmore, E. R.; Terhorst, L.; Rosen, J.; Weiner, D. K. Goal Attainment Scaling (GAS) in geriatric primary care: a feasibility study. *Arch Gerontol Geriatr* **2015**, *60* (1), 16-21. DOI: 10.1016/j.archger.2014.10.022 From NLM.

(64) Glasgow, R. E.; Wagner, E. H.; Schaefer, J.; Mahoney, L. D.; Reid, R. J.; Greene, S. M. Development and validation of the Patient Assessment of Chronic Illness Care (PACIC). *Med Care* **2005**, *43* (5), 436-444. DOI: 10.1097/01.mlr.0000160375.47920.8c From NLM.

(65) Teal, C. R.; Haidet, P.; Balasubramanyam, A. S.; Rodriguez, E.; Naik, A. D. Measuring the quality of patients' goals and action plans: development and validation of a novel tool. *BMC medical informatics and decision making* **2012**, *12*, 152. DOI: 10.1186/1472-6947-12-152 From NLM.

(66) Etz, R. S.; Zyzanski, S. J.; Gonzalez, M. M.; Reves, S. R.; O'Neal, J. P.; Stange, K. C. A New Comprehensive Measure of High-Value Aspects of Primary Care. *Annals of family medicine* **2019**, *17* (3), 221-230.

(67) Adam, P.; Murphy, C. F.; Dierich, M.; Hager, K. D. Seven Years of Teaching Communication With the Patient-Centered Observation Form. *Fam Med* **2018**, *50* (2), 132-137. DOI: 10.22454/FamMed.2018.516713 From NLM.

(68) Murdoch, J.; Salter, C.; Ford, J.; Lenaghan, E.; Shiner, A.; Steel, N. The "unknown territory" of goal-setting: Negotiating a novel interactional activity within primary care doctor-patient consultations for patients with multiple chronic conditions. *Soc Sci Med* **2020**, *256*, 113040. DOI: 10.1016/j.socscimed.2020.113040 From NLM.

(69) Singh Ospina, N.; Phillips, K. A.; Rodriguez-Gutierrez, R.; Castaneda-Guarderas, A.; Gionfriddo, M. R.; Branda, M. E.; Montori, V. M. Eliciting the Patient's Agenda- Secondary Analysis of Recorded

Clinical Encounters. *J Gen Intern Med* **2019**, *34* (1), 36-40. DOI: 10.1007/s11606-018-4540-5 From NLM.

(70) Hersh, L.; Salzman, B.; Snyderman, D. Health Literacy in Primary Care Practice. *Am Fam Physician* **2015**, *92* (2), 118-124. From NLM.

(71) Sine, D. M.; Sharpe, V. A. Ethics, risk, and patient-centered care: how collaboration between clinical ethicists and risk management leads to respectful patient care. *J Healthc Risk Manag* **2011**, *31* (1), 32-37. DOI: 10.1002/jhrm.20077 From NLM.

(72) Tinetti, M. E.; Bogardus Jr, S. T.; Agostini, J. V. Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *N Engl j Med* **2004**, *351* (27), 2870-2874.

(73) Voigt, I.; Wrede, J.; Diederichs-Egidi, H.; Dierks, M. L.; Junius-Walker, U. Priority setting in general practice: health priorities of older patients differ from treatment priorities of their physicians. *Croatian medical journal* **2010**, *51* (6), 483-492. DOI: 10.3325/cmj.2010.51.483 From NLM.

(74) Etz, R.; Stange, K. C. Measuring what matters in primary care. *Global Advances in Health and Medicine* **2018**, *7*, 263, Conference Abstract. DOI: 10.1177/2164956118773837 Embase.

(75) Young, R. A.; Roberts, R. G.; Holden, R. J. The Challenges of Measuring, Improving, and Reporting Quality in Primary Care. *Annals of family medicine* **2017**, *15* (2), 175-182. DOI: 10.1370/afm.2014 From NLM.

SUPPORTING INFORMATION

Overview of preliminary version attributes

Goal-elicitation
- Three main components to make goal-setting effective: were patient and GP engagement, preparation, supportive goal-elicitation and collaborative action planning [23]. - Effective goals elicitation is geared to each patient's state of readiness [1]. - Allowing clients to tell their stories and reflect on their achievements may facilitate elicitation of client-centered goals [24]. - Goal-elicitation was a shared process that involved relationship building between patient and GP [23] - Eliciting goal-directed conversations may lead to more tailored and effective care and has been shown that enabling patients in such a way increase adherences to evidence-based guidelines and patient satisfaction [47]

Goal-setting	
- Goal-setting may be useful to facilitate patient-centered communication for patients with multimorbidity [23] - Explicit focus on goal-setting or priority setting and goals are specifically determined [54] - Goal-setting is promoted as a mechanism for health professionals to engage with patient's psychosocial needs and social context to support individuals in what matters most to them live well with their conditions [32] - Goal-setting is the action of a person who has the confidence, commitment, motivation and knowledge necessary to attain a goal that is specific, challenging, measurable and relevant within specified amount of time [38] - Goal-setting is a key feature of coordinated care plans intended to support coordination and continuity of care for older adults, and others with complex needs [35]	
Interaction	*Negotiating* - goals of care are negotiated between patient and healthcare provider [6, 23] - translation of the overarching goal into relevant and realistic goals of care is a complex negotiating and balancing act [6] - elaborating clear and concise priorities that inform decision-making is a challenge, requiring a reliable and efficient process for ascertain patient's goals and preferences [4] - the clinician needs to explain what is possible and negotiate potentially achievable goals with the patient [49] - elaborate more until he feels he understand what he is looking for [24]

	- One of the most important aspects of goal-setting was the ability of the patient to discuss, formulate and agree the goals specific [23] - Goal negotiation involves discussion of any problems, exploration of patient's personal values, needs and capabilities, patient education and deliberation optional goals [37]. *Collaborative goal-setting* - Collaborative goal-setting is a structured form of patient engagement in which providers discuss and agree on a health goal [4, 39] - collaborative goal-setting is an evidence based process [4] - collaborative action plan [23] - doctors and patients with multimorbidity working together on what really matters to patients [23] - patients as active partners [33] - finding common grounds [30] - collaborative process taking place within goal-setting consultation [23] - collaborative goal setting are necessary elements [54] - collaborative goal-setting defines as a process by which health care professionals and patients agree on a health-related goal [54] - the GP's described their role as collaborative and as a facilitator of the goal-setting process [23] - Greater consideration to patient's narratives reflecting their lived experiences [40] - Process by which caregiver and patient agree on a health related goal [50] - Personal target of the patients are discussed, while taking into account the individual patient's needs, preferences and abilities [2] - A unique interplay between the patient, the clinician, and the goals developed collaboratively both the patient and the clinician [49] *Balance between patient and provider* - involvement of patients, both in relation to the choice of intervention [6, 24] - providers help patients to set measurable goal for their chosen condition [39] - Shift in power from the therapist to the client and facilitated goal identification [24] - it is allowed to drop by the therapist and the decision was accepted by the client [24] - Together with the person, professionals make the overarching goal as drive for decision making [6]

	- patients are encouraged to share their priorities with their clinicians and prompt their clinicians to consider how currently recommended care aligns with the patient's health priorities [4] - Shift in power due the fact that provider accomplish the achieved goals of the patients [24] - GP's role had been a form of moral support and seemed to be to listen, validate and support patient to articulate their goals rather than take actions [23] - Patient and providers put themselves in the shoes of the other to understand the other constraints [44] - Final decisions should be made by the individual [13] - A goal-directed approach would create more equality in relationships between clinicians and patients [39]
Goals	*Person-centered goals* - Person legitimate what the overarching goal should be [6] - person identifies his or her core values [1, 4] - prompts to articulate which health states are important to them and their relative priority [49] - prioritizing one actionable thing that is most important to the patient [33] active listening, clarify meaning attached to goals and respect clients choice [24] - goals were person-centered and focused on the things that could change [23] - focusing on desired activities rather than eliminating symptoms [33] - Underlying foundation of goals should be the patient's values [41] - Achieving personal goals [55] - Care is personalized to accommodate patient's goals, preferences and resources [12] - Interpersonal medicine care is based on the patient's circumstances, capabilities and preferences [47] - Health must be defined by each individual and will therefore be different [13] *Health outcome goals* - identifying priorities provides a means of reducing the tradeoffs between outcome goals, between healthcare preference [4] - what individuals are able and willing to do to achieve their health outcomes and includes activities [1] - health outcome goals are the individual health outcomes that persons hope to achieve through their health care [1] - health outcome goals are distinct from behavioral goals [1] - health outcome goals are patients personalized health outcome priorities [1]

	- health outcome goals: what they want from their --healthcare and their healthcare preferences, what healthcare activities they are willing and able to perform, and the care they are willing or not willing to receive [4] *Overarching goals* - Overarching goal must be translated in an open and non-judgmental process [6] - Overarching goals can be broken down into supporting sub-goals [6] - goals can be disease specific or overarching, across multiple diseases [12] - Setting overarching goals can take longer than setting biomedical goals [41] - tentative goals: clients seemed to be considering goals that they were not sure met the therapist's criteria or whether their attainment was a possibility [24] - goals can be objective or subjective [12] - goals can be focused on maintaining the status quo or improving the current situation [12] *SMART* - Make overarching goals explicit [6] - Participants share clear goals [6] - Person needs, values and preferences [6] - realistic [6, 50] - relevant [6] - requirement that the goal should be interesting and meaningful [24] - underlying foundation of goals should be the patient's values [12] - negotiating goals that are relevant, realistic and observable [6, 23, 30] - not all patients goals may be realistic or attainable [49] - SMART goals [1, 4, 12, 24] - SMART framework is helpful for operationalizing personal goals [46] - To create SMART goal, the patient and provider collaboratively specify the goal itself, the importance of that goal to the patient, perceived achievability of the goal, the timing of the goal and any supports and resourced available [35]

Care plan	*Goal-based care plan* - start with assessing and negotiating the overarching individual goals [6] - patient-priority directed care begins with patients and caregivers identifying and communicating their health outcome goals and treatment and care preferences with the help of a trained and skilled member of the healthcare team [1] - overarching goals defines the scope of the care plan [6] - aligning treatment towards common goals [49] - Plan consists sub-goals and sub-tasks [6] - Explore what life goals may be and translate into goals relevant for care [6] - Goals, wishes and expectations of the patient are the starting point for the care plan [56] - Important to align care with patient's personal histories, values and priorities [12] *Goal-oriented care plan* - aligning healthcare recommendations to achieve specific health outcome goals [4] - when your clinicians understand what you want of your health, they can offer you healthcare options that give you the best chance of reaching the goals [1] - sets targets for patients and clinicians to plan a course of action and measure success [12] - Creating action plans for achieving the goals [50] - Planning on how to work on the established goals [76] *Personalized care plan ('what matters to you')* - prioritizing interventions most important to the patient [30] - starting with one actionable thing that matters most and conducting serial trials [33] - should meet the overarching personalized goals which reflect 'what matters to the person' [1, 3, 4, 6, 12, 30, 33] - patients creates action plans for achieving this goal [39] - Plan should be evidence-based, should support health literacy, patient involvement and self-management [6] - Patient preferences, needs and values and ensuring that patient values guide all clinical decisions [33] *Multidisciplinary approach*

	- clinician should provide a treatment plan, encouragement and advocacy to help the patient meet agreed on-goals and readdress them if the situation change [49] - Plan should identify roles, tasks, responsibilities [6] - The care plan is based on a multidisciplinary review of the goals [6] - involvement of care givers [54] - the decision process should involve all relevant providers and the patient/ caregivers [6] - it is important to include caregivers, family members and other social support [3] - priorities guide interactions between patients, caregivers and clinicians [4] - The personalized goals are used to identify the multidisciplinary team needed to assess patient's health issues [6] - priorities and preferences are visible in integrating care between multiple treatment providers. Care is consistent with patients outcome goals and preferences [1, 4, 30] - deciding which care within their area of expertise is most likely to help patients achieve their goals [1] - all members of the team, including patients and caregivers, must be willing and able to carry out their agreed- on roles and responsibilities [1]
Care delivery	*Care plan based delivery* - delivered according to the plan [6] - providing better care would be to focus on a patient's individual health goals within or across a variety of dimensions [10] - the team and person is responsible for care delivery according to the plan [6] - if possible, begin with simple and quick interventions that address one or more patient goals [1] - bearing witness to patients goals [23]

Goal-evaluation	
Measurable goals	- making goals measurable [23] - priorities and preferences are visible so that measures of care and health policy and service delivery models van value person-focused care [30] - Making goals measurable could overcomplicate and distance the patient from their own goal [23] - Measurement of both the quality and quantity of work necessary to attain the goal and the development of strategies to reach the goals [38] - Goals should be quantified whenever possible and measurable so that progress toward achievement can be monitored [13]

Evaluation of GOC process	- GP valued the process [23] - determine how well these goals are being met [49] - goals may have been met or unmet perhaps because they were too difficult or are no longer relevant or desired [12] - quality of care delivery depends on how well it provides the expected and planned care [6]
Feedback	- Goal evaluation as feedback to all contributors [6] - success or failure of trials should be defined by whether patients achieved their health outcome goals or healthcare preferences [33] - if providers do not access success or failure, then no learning or adjustment will occur [6] - Setting goals include feedback on the performance toward the goal [38]
Continue process	*Ongoing process* - Person needs, values and preferences as they develop over time [6] - goal-oriented process [6] - cyclic process framework [6] - preference elicitation is a constant, iterative process [1] - patient priorities care is a continuous process that begins when patients identify SMART goals - Talking about goals in the context of a continuous relationship between the provider and the patient [41] *Reevaluation of the process* - Regular review of goals, plan and goal attainment whenever needed [6] - Goal adjustment and learning for the next cycle [6] - continue to align with their desires and abilities, even if their disease progresses [1, 3] - reevaluation during which goals can be discarded, modified or recalibrated or new goals might be set [12] [33] - Goals can be met or unmet perhaps because there were too difficult or are no longer relevant or desired. This leads to reevaluation [41] *Duration of the process* - care over time [30] - patient priority-directed care focuses on current care rather than future care [1] - Goals can be focused on maintaining the status quo or improving the current situation

Person context	- Attaining their goals and preferences in the context of their current functioning or life circumstances [3, 12] - understanding the whole person [30] - The context in which interactions occur is important [40] - Goal-oriented care could be tailored to the context of the individual patient [55] - The social and cultural context are taken into account when setting the patient's personal goals and developing the personalized care plan [2] - it is important to set goals from a holistic perspective, tailored to each patient [37]
Person-centeredness	- What matters to you? [1, 6, 23, 33] - being treated as a person and not a diagnose [6] - Developing goals that align with client's values, interests and hopes is therefore a key first step in client-centered practice [24] - taking account of individual preferences as well as their priorities in decisions about care [30] - allowing clients to tell their stories and reflect on their achievement [24] - Health from the viewpoint of the individual [47]

Overview of training

Article	Trained population	Training
Blom (2016)	General practicioners and practice nurses	Session 1: theory on care plans using a functional integrative approach. Practicing care plans for own patient and discussing care plans in the group. Planning for the 10 care plans in the study. Session 2: Discuss care plans for own patients. Plan organising the intervention in own practice, allocate responsibilities, care plan making and registering, organising multidisciplinary meetings, evaluating care plans, organising list of community resources for older people. Session 3: Develop an overview of local resources for own region together with practice nurse. Discussion on fall interventions with occupational therapists.
Kangovi (2017)	Primary care providers	60 minute training session on collaborative goal-setting, which reviewed principles of goal-setting theory, including importance of setting realistic goals
Naik (2018)	Advanced practice registred nurse and a member of the healthcare team with case management experience.	Facilitators prepared for training with a face-to-face session in which facilitators practiced the process with a member of the development team and then with a standarized patient. Facilitators tested the process with 10 patients, during which time they observed each other and gave feedback.
Salter (2019)	General practicioners from three intervention practices.	3-hour experiental workshop, including a discussion of key principles, skill spotting, using video examples of goal-setting in action, and role-play.
Tinetti (2019)	Ten primary care clincians, cardiologists	Introductory webinar of patient priorities care, participated in two case-based face-to-face training sessions. During these training sessions they role played patient-clinician and clinician-clinician scenarios involving commonly encountered decisional issues for older adults with multiple chronic conditions.
Tinetti (2016)	Member of the clinical team, such as an advanced practice registered nurse or physician assistant	Goals and preferences elicitation requires training and sufficient time to ensure that the goals elicited are SMART.

Building an understanding of goal-oriented care through the experiences of people living with chronic conditions

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ABSTRACT

Objective: To understand the concept of goal-oriented care (GOC) through the experiences of people with chronic conditions.

Method: Interviews with people living with chronic conditions (n=50) were analyzed in two ways. A deductive approach based on GOC attributes generated in a concept analysis on GOC: goal-elicitation, goal-setting, goal-evaluation, patients' context, and patients' needs and preferences. An inductive approach based on a thematic analysis using descriptive phenomenology.

Results: The phase of goal-elicitation was recognized by the participants, whereas goal-setting and goal-evaluation were experienced to a lesser extent. Regarding the underpinning attributes, mixed feelings were reported concerning the integration of the patient's context and the presence of their needs and preferences throughout the care process. The inductive analysis revealed specific attention to informing patients about their condition and treatment options and discussing goals in interprofessional collaboration.

Conclusion: Goal-elicitation was already present and seems to be a good foundation for GOC. More attention should be given to goal-setting and goal-evaluation.

Practice implications: Developing guidance by means of a workflow, tools, or questions might support people with chronic conditions and providers to underpin the entire care process with patients' personal goals.

INTRODUCTION

Over the last decades, efforts have been made to achieve a shift from a disease-oriented type of care towards person-centered care (PCC). PCC has been defined as "being respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" [1]. Whereas disease-oriented care can be of value in the treatment of acute and treatable disorders, chronic disorders often entail a more complex approach [2, 3]. People with chronic conditions (i.e., "patients") indicate they receive care that is often fragmented and of unclear benefit. Additionally, they prefer to focus on their personal well-being and quality of life rather than on their medical problems [2, 3]. As such, a shift from "what is the matter with the patient" to "what matters to the patient" is intended to provide a solution to the reported burden of people with chronic conditions [4]. Such approaches to reorienting care back to patients can be found in the concept of goal-oriented care (GOC). In GOC, care processes are organized around the patients' personal goals, which has the potential to improve quality of care and increase the appropriate use of finite care resources [5].

GOC has appeared in literature in various definitions. A first definition was posed in 1991 by Mold who stated that "the primary purpose of care is to help each individual set and achieve her or his personal health-related goals and elucidate the patients' values, wishes, hopes, preferences, and beliefs" [6]. In 2012, Reuben and Tinetti described an alternative health outcome paradigm that "above all must consider patients' preferred outcomes" [5]. More recently, in 2020, Secunda et al. generated an operational definition and conceptual model of goals in care, which they defined as "the overarching aims of medical care for a patient that are informed by patients' underlying values and priorities, established within the existing clinical context, and used to guide decisions about the use of or limitation on specific medical interventions." [7].

The variety of definitions of GOC, each with their own emphasis, made it difficult to comprehensively understand the concept. To bridge this knowledge gap, a concept analysis was conducted to identify the attributes, or key characteristics, of GOC [8]. This concept analysis revealed that GOC is a multifaceted, dynamic process including three phases. The first phase, goal-elicitation, focuses on getting to know the patients and unraveling their narrative, reflecting their lived experiences. In the second phase, goal-setting, providers discuss and negotiate the patients' personal goals and their own goals to find a common goal to be integrated into the care plan. In the last phase, goal-evaluation, providers and patients reflect on how care is proceeding and take time to reflect upon whether goals have been changed or not. In addition to these three phases, two underpinning attributes were defined that guide the process of care. First, GOC should be placed in the patient's context, and second, GOC should be tailored to the patient's needs and preferences [8].

Despite the growing insights into the theoretical concept, little is known about how GOC is experienced by people living with chronic conditions [9]. Most of the studies have focused on how providers adopt GOC in their care delivery [10]. To successfully implement GOC, it is important to learn from people with chronic conditions as they can give insight into how care should be best delivered [9]. Therefore, the first aim of this study was to map the experiences of people with chronic

conditions to the attributes defined in the concept analysis described above. Secondly, this study sought to explore what additional aspects people with chronic conditions relate to GOC.

METHODS

RESEARCH TEAM

An interprofessional research team consisting of occupational therapists, general practitioners, a pharmacist, a gerontologist, and health care managers conducted this study. This diverse expertise guaranteed a broad and reflexive perspective on the experiences of people with chronic conditions regarding GOC.

STUDY DESIGN

In a qualitative design, in-depth interviews with people with chronic conditions living in Flanders (Belgium) were conducted. A semi-structured interview guide was used for interviewing and was structured according to the attributes of GOC as identified in the concept analysis: goal-elicitation, goal-setting, goal-evaluation, patient's context, and patients' needs and preferences. The questions were worded in such a way that participants who were not familiar with the concept were able to reflect on it.

A two-step analytic approach based on a deductive and inductive analysis was applied. On the one hand, a deductive analysis was performed to map the a priori theory consisting of the attributes of GOC generated in the concept analysis to the new context of patients' experiences [8, 11]. On the other hand, an inductive analysis was conducted to identify additional aspects related to GOC and was based on a thematic analysis using a descriptive phenomenology [12,13].

PARTICIPANTS AND SAMPLING

A purposive sampling was used to include people living with chronic conditions who met the following inclusion criteria: 1) being 18 years or older, and 2) having one or more chronic conditions for which they consulted one or more primary care providers. They were excluded if 1) they were unable to share experiences regarding their care in the primary care context, or 2) cognitively unable to reflect on a life with chronic conditions. The participants were recruited through the professional network of the researchers via flyers and social media.

DATA COLLECTION

Data were collected between February 2021 and May 2021, guided by a semi-structured interview guide. The interview guide consisted of five parts: 1) providing information about the study and signing informed consent, 2) breaking the ice by posing questions relating to the participant's daily life (*"Tell me. What did your last week look like?"*) to have a first exploration of what was meaningful for them, 3) asking general questions to gain insight in the interactions and relationships the participants have with their primary care providers (*"How would you describe your relationship with your primary care provider?" or "Which aspects do you value in the interaction with your provider?")*, 4) asking whether and how personal goals were addressed during interactions with their primary care providers (*"Which personal goals do you have at the moment and are these included in your care plan?")*, and finally 5) explaining the concept of GOC to explore the participants' thoughts and experiences regarding GOC. All interviews were conducted in Dutch

by junior researchers who were trained in qualitative research techniques and audio-recorded and transcribed afterwards.

The interviews were conducted physically in the home environment of the participant or by videocall due to COVID-19 measures imposed by the Flemish and national government of Belgium.

DATA ANALYSIS
Data analysis consisted of a deductive and an inductive part.

2.5.1 Deductive analysis

For this study, the deductive part of the analysis was based on the attributes generated in the concept analysis of GOC. The patients' experiences with GOC were mapped onto these attributes (Table 1 provides an overview of the attributes) [8]. This deductive analysis included seven steps: 1) in-depth reading of the concept analysis, 2) gaining an overall understanding and interpretation of the data by reading the full transcripts, 3) individually categorizing the data of the first 21 interviews to one or more attributes while reading the transcripts a second time, 4) reviewing all analyses with a second researcher (LD or DL), 5) presenting the analysis to the research team (DB, DVdV, PB, PDV) to finalize the categorizations, 6) analyzing 11 additional interviews to reach data saturation, and 7) comparing the results of the remaining interviews of both independent researchers (LD and DL) to identify possible discrepancies. An extract of how the deductive analysis was conducted is depicted in Table 2.

Table 1 Overview of the attributes [8]

Attributes	
1. Goal-oriented care is a multifaceted, dynamic and iterative process.	1.1 Goal-elicitation builds a patient-provider relationship.
	1.2 Goal-oriented care entails goal-setting.
	1.3 Goal-evaluation is a reflexive process.
2. Goal-oriented care embraces patients' values.	2.1 Goal-oriented care must be placed in patients' context.
	2.2 Goal-oriented care must be tailored to patients' needs and preferences.

Table 2 Extract of the deductive analysis

Citation	Keywords	Attribute
"If there are certain things that I'm struggling with, I can easily speak about my problems. Of course, that's important. If I didn't trust him [general practitioner], I wouldn't tell him that easily either. On the other hand, if I ask him about certain things he will always answer. He also knows that the trust between us is mutual." (p21)	the trust between us is mutual	Goal-elicitation
"No, if it doesn't fit within their [care providers] expertise, it stopped for them. But at least, refer me to another [care providers] and I have missed that very much in all my trajectory that I have already completed so far. I have had very little follow-up, there is very little guidance." (p17)	very little follow-up, there is very little guidance	Goal-evaluation
"Yes, if you look with what doctor X [general practitioner] prescribed, I can get by with 35 euros during more than a month, so he always looked: what budget do the patients have.... I don't have much budget, so, this is very important." (p12)	what budget do the patients have	Patients' context

2.5.2 Inductive analysis

A thematic analysis based on a descriptive phenomenology was chosen to explore additional aspects that the participants relate to GOC [13]. This thematic approach comprised six steps: 1) achieving familiarity with the data through open-minded reading the transcripts, 2) marking meaningful parts of the first 21 interviews which resulted in an initial overview of meaning units, 3) comparing and organizing the meaning units into patterns in order to translate them into themes, 4) comparing the results of both independent researchers (LD and DL) to identify potential discrepancies, 5) analyzing 11 more interviews until saturation was reached, and 6) comparing the results of the remaining interviews of both independent researchers (LD and DL). Throughout the entire process, regular meetings with the research team (DB, DVdV, PB, PDV) were organized to present, discuss, and validate the analyzing process and finalize the themes.

ETHICAL APPROVAL

Ethical approval was obtained from the Ethical Committee of University of Antwerp (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. They all gave written informed consent. Participating in this study was completely voluntary, and no incentives in any form were given.

RESULTS

PARTICIPANT CHARACTERISTICS

	Mean (range) or frequencies
Interview duration (min)	63.58 (27-120)
Age (years)	53.64 (23-88)
Gender	Men: n =15 Women: n=34 Not reported: n =1
Marital status	Single: n=15 Cohabitants: n=13 Married: n=16 Widow: n=4 Not reported: n=2
Education level	Primary education: n=9 Secondary education: n=15 Higher vocational education: n=3 Professional bachelor: n=12 Academic bachelor: n=1 Academic master: n=6 Higher education – non-specified: n=4
Employment	Unemployed: n=5 Retired: n=19 Student: n=4 Disabled n=8 Employed: n=14

Table 3 Participants' characteristics

Fifty people living with one or more chronic conditions, with a mean age of 53.64 years, were interviewed for this study. Of these 50 participants, most (n=34) were female (n=15 males), and 1 person preferred not to indicate their gender. Interviews lasted on average 63.58 minutes with a

range between 27 and 120 minutes. Table 3 provides an overview of the participant characteristics.

DEDUCTIVE ANALYSIS

The phase of goal-elicitation was recognized by the participants, whereas goal-setting and goal-evaluation were experienced to a lesser extent. Regarding the underpinning attributes, mixed feelings were reported concerning the integration of the patient's context and the presence of their needs and preferences throughout the care process.

Goal-elicitation

Goal-elicitation refers to building a relationship between the patient and provider and exploring the patient's narrative. This was reflected in the data by participants who experienced a trustful relationship with their providers and even compared it as if they were friends by expressing the words "good bond", "trust relation", "long-term relationship". Participants talked about sharing more than their medical problems and indicated that it is important that providers take time to listen to them. Participants also reported how they appreciated that providers set their medical expertise aside and created room to talk about their personal lives and feelings, and as such explored their lived experiences. In this way, they felt recognized as a person instead of a patient.

"With a good bond, you can discuss a bit more, if you don't have a bond, you won't put all your problems or things you still want to achieve on the table" (p21).

Goal-setting

Participants were asked if they had specific goals in their life and if these were addressed in the conversations with their providers, but they did not report this. Despite the openness to talk about their feelings, the participants still preferred that providers directly ask them what their goals are and what they still want to achieve.

"So, there was little interaction, and I was never asked what my expectations were. If you are now asking "What is your goal", well, my goal is still to return to active work and I have not been asked that very often." (p17)

Aside from this, participants also reported personal barriers to share goals as they did not feel the need to set them, providers were not interested in them, or thought they would not be able to achieve them.

"When you set expectations of goals and you don't achieve them, that will cause frustration. If you don't set those goals and just live day by day, then you won't have those frustrations. So I rather prefer to not set goals." (p22)

Goal-evaluation

Goal-evaluation refers to having regular reflections upon whether patients' personal goals are still integrated into the care plan. This was echoed to a lesser extent in the interview data. The participants did not experience any kind of follow-up on their goals which can be related to the

fact that patients' goals were not being discussed. In the interviews, participants did talk about their preferences regarding ongoing reflection and expressed the need to have attention for such follow-up visits.

"The provider could follow up a little better to see if those things are really happening, and if they are not happening, perhaps take a little more initiative themselves" (p8).

Patients' context

Participants recognized the importance of providers understanding their personal situation (e.g., financial resources, health limitations, social support, etc.) when developing the care plan, which would help to better individualize the care process. In some cases, participants shared that their personal situation was considered, for example, the provider "*always tried to find affordable treatment options because of a limited budget" (p14)*. In other cases, it was not clear if and how providers took their personal situation into account.

"You should be able to talk with your doctor about more things than just your disease. They should for example ask how I'm doing at home." (p16)

Patients' needs and preferences

Despite participants reporting an ability to speak about their feelings and having a strong relationship with their providers, they did not experience explicit attention to their needs and preferences throughout the entire care process. They acknowledged the importance of being able to take the lead during the care process and stressed that providers should *"listen to the patient, be open-minded, and not just think about one's own vision [for care]"* (p18).

INDUCTIVE ANALYSIS

Based on the inductive analysis, two additional themes could be identified: 1) informing about the patients' condition and treatment options, 2) discussing goals in interprofessional collaboration.

Informing about the patients' conditions and treatment options

Participants wished to be informed about their conditions in a "human" language. They were interested in what was going on in their bodies and why. Only then can they learn more about themselves and reflect on goals they want to strive for. In addition, adequate explanation and education do not only seem to be important to understanding treatment options, it also enabled participants to engage in decision making as *"informing patients about disadvantages, side effects of treatments, medications, and the impact on their personal life accordingly" (P6).*

"If you are well-informed and can absorb the information, you understand a part of your body it is much easier to cope with your conditions in your daily life. Education is the key word for me." (p3)

Discussing goals in interprofessional collaboration

Participants hypothesized that in the event that providers collaborated more and included patient goals, care would be more aligned and there would be less frustration as they would not have to share their story over and over again. Currently, a large discrepancy could be observed regarding the experiences of collaboration among those providers. On the one hand, participants experienced good collaboration and indicated that *"it is all taken care of in one day and they walk me from one doctor to another" (p1)*. This was mostly experienced when different disciplines were already working in the same place (e.g., day hospital, interdisciplinary health, and welfare center). On the other hand, participants did not recognize adequate interprofessional collaboration in their care trajectory, mostly in primary care where providers more often work in solo practices. This led to the feeling of not being supported in the care process.

"*Because those providers didn't take time to read reports of other providers I always had to repeat everything and that's really not good psychologically wise… being confronted with that every time." (p17)*

DISCUSSION AND CONCLUSION

Discussion

This study aimed to gain insight in the experiences of people living with chronic conditions regarding GOC. The participants recognized the phase of goal-elicitation, whereas goal-setting and goal-evaluation were experienced in lesser extent. Regarding the underpinning attributes, mixed feelings were reported concerning the integration of the patient's context and the presence of their needs and preferences throughout the care process. The inductive analysis revealed two additional aspects when talking about GOC, namely the importance of informing the patients about their condition and treatment options and discussing goals in interprofessional collaboration.

Participants experienced goal-elicitation when providers tried to build a relationship with them and approached them as more than their medical diagnosis. This seems to be important for GOC since the literature confirms that it is crucial to invest time in building a profound relationship as a premise to delivering quality care [14, 15]. Aside from that, goal-elicitation is a critical step in allowing providers to focus care on what matters most to patients [15]. That is pivotal, as our participants and the literature reported that people with chronic conditions want to be recognized as more than their disease [16]. Therefore, providers are presumed to dedicate sufficient time to their patients to unravel their narratives [17].

While goal-elicitation was clearly reflected in the data, this was less the case for goal-setting. Participants did not report that their personal goals got a prominent place in the care plan. A result that was also found in other qualitative studies that reported that people with chronic conditions did not recognize any kind of explicit goal-setting and care planning discussions [3], [18]. To improve patients' experiences regarding goal-setting, it is suggested to be more explicit in communication and explication of goals [3]. Participants also reported personal barriers to talk about and express goals e.g., do not feel the need to share goals, think they will not achieve them. The literature also

defines barriers to define personal goals such as the difficulty for patients to identify themselves with the concept of goal-setting or different communication styles of providers [19]. Goal-setting is not a "one size fits all" approach for which the same type of care is suitable for every person [20]. In fact, it is determined by a variety of factors, including the patients' chronic condition and personal preferences [21].

It is therefore important that providers get to know the person sitting in front of them and adapt their approach to the individual patient and open the conversation to explicitly start talking about goals. To support both patients and providers to set goals, the literature suggests to using tools such as photos or a set of quality of life questions ("What activities give purpose to your life?") to guide communication [4, 10]. In particular, patients who find it difficult to articulate goals can bring photos about that which give them meaning in life as a conversation starter, making goal-setting conversations more tangible. In this way, photos can be a prompt for patient activation and be a steppingstone for GOC [4, 10].

The participants did not experience the phase of goal-evaluation. However, as written in the concept analysis, goal-evaluation will allow to have an ongoing reflection on whether patients' goals are still integrated in the care process or not [8]. Because goals can change over time, it might be recommended to have regular reflection moments on whether the care plan is still focusing on the patients' goals [22]. Participants also expressed that one of the reasons that they do not set goals is they think they could not achieve them. Though, by negotiating goals, patients might recognize that it is not about achieving goals but about making the shift to what matters most to them. A recent scoping review also questioned if goal-attainment is necessary as it would implicate a focus on outcomes measures which are often standardized rather than a focus on the individual care process [23]. Further work needs to be done to explore the topic of goal-attainment.

As written in the concept analysis, the patient's context and patient's needs and preferences underpin these phases [8]. Unfortunately, the participants in our study did not experience that their needs and preferences were integrated in the care plan. The lack of the patients' needs and preferences throughout the care process might be explained by the fact that the participants did not experience that their goals were discussed and thus also cannot be integrated in the care plan. It could be that this attribute is already present but that patients do not recognize it in such an explicit way. Based on this assumption, it can be recommended to communicate more directly about the patients' goals and how they should be integrated into the care plan and guide care delivery. It is also important to take the patient's context into account, as everyone is influenced by distinct factors that could influence their health. The care plan should thus be tailored to these factors [24].

Our study pointed to two additional, but not exclusive, aspects relating to GOC: informing patients about their conditions and treatment options and discussing goals in interprofessional collaboration. The participants mentioned that if they had more insight into their own conditions and were informed about treatment options, they felt better equipped to make well-considered decisions regarding their goals. The literature mentions that by informing patients, the distance in knowledge between patients and providers could be reduced [25]. This could potentially help to

better engage patients in goal-setting discussions. Relating to interprofessional collaboration, the participants had no clear understanding of whether it was already in place or not, but expressed that interprofessional collaboration is important to guarantee care continuity.

The findings of this study should be interpreted in light of methodological strengths and limitations. A first strength was the large sample of fifty participants representing a maximal variation of conditions since no specification regarding diseases was predetermined. On the one hand, this increased the representativeness of the experiences of people living with chronic conditions regarding GOC and ensured data saturation (after 32 interviews). On the other hand, no conclusion could be made on conditions that might lead to GOC which can be seen as a limitation. A second strength was that data analysis was performed by two independent researchers, which increased the credibility and reduced the risk of interpretation bias of the findings. Lastly, the analyzing process was characterized by an iterative process with regular team meetings in an interdisciplinary setting which increased the reflexivity and critical awareness. Concerning the limitations, the major limiting factor was that the participants were not sufficiently familiar with the concept of GOC. To overcome this problem, the interview guide was focused on characteristics and attributes of GOC than on the concept itself. A second limitation is that no member check was performed, and transcripts were not returned to the participants. This was covered by thorough discussions in the interdisciplinary research team that increased rigor towards the process of data analysis.

Conclusion

This study provided insight into how people living with chronic conditions experience GOC by mapping their experiences to the GOC attributes generated in a concept analysis on GOC and exploring additional aspects, besides these attributes, that could be related to GOC. It can be concluded that there is a foundation for GOC as goal-elicitation was clearly recognized throughout the interviews. However, there is still room for improvement because patients and providers should be encouraged to engage in goal-setting conversations and continuous reflexive evaluations on whether care is still meaningful for patients in their context. The concept of GOC might be expanded with two additional aspects that were found in our data, namely patients' need to be informed about their conditions treatment options to make decisions regarding their own goals and the importance of interprofessional collaboration to guarantee care continuity.

Practice implications

People living with chronic conditions experience a strong foundation of GOC. Based on the findings, implications for practice could be suggested.

First, it is recommended that providers take a moment to unravel the patients' narrative and get to know them, as this will help patients to open up, feel more comfortable to share any concern¸ and encourage them to take an active role in their care process [26]. Because it mainly depends on the providers' competencies to succeed in unraveling the patients' narrative, it is crucial to equip them with the appropriate competences and tools to be able to do so [27]. Providers could use questions like 'What would you like me to know about you?' as a starting point to unravel the patient's narrative [28]. In addition, it is recommended that they also learn to actively listen to

patients, pay attention to their body language, avoid to interrupting them, ask open questions, and explore their personal background [29]. Also, patients should be better equipped to be able to share their narrative and manage the changing roles they are dealing with due to their complex health situation [30]. Therefore, they could acquire self-management techniques such as enhanced decision-making, action planning, and effective communication to have more ownership of their own care process and overview their personal goals [31]. The degree to which patients are enabled to acquire such techniques is context-specific and might range from informing patients to referring them to intensive courses [32]. By deploying these techniques, patients might also be able to reflect on their goals during the care process and prepare themselves for goal-setting conversations with their providers [33]. To prepare, they can reflect on goals that are important to them, prepare a list of questions they have for the provider, discuss any personal problems that may be related to their condition [34].

A crucial step in equipping patients with competencies to self-manage their care process, is to inform them about their condition and treatment options [35]. In this way they could also make decisions regarding their own goals [35]. Important to note is that these techniques must always be tailored to the patients' needs and capabilities, so they are best supported to reflect on their personal goals. In addition, these techniques should be considered in light of engaging patients in the goal-oriented process of care.

It is also suggested to initiate interprofessional collaboration around patients' goals, as this might improve the patients' experiences regarding care continuity and make them less frustrated as they do not have to tell their story repeatedly.

Lastly, practice implications have been formulated to engage patients and providers in the goal-oriented process of care, but more work is needed to explore where the additional aspects should be integrated in the dynamic and iterative process that was identified in the concept analysis.

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REFERENCES

(1) Plsek, P. E.; Greenhalgh, T. Complexity science: The challenge of complexity in health care. *BMJ (Clinical research ed.)* 2001, *323* (7313), 625-628. DOI: 10.1136/bmj.323.7313.625 From NLM.

(2) 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. 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.

(3) Ploeg, J.; Matthew-Maich, N.; Fraser, K.; Dufour, S.; McAiney, C.; Kaasalainen, S.; Markle-Reid, M.; Upshur, R.; Cleghorn, L.; Emili, A. Managing multiple chronic conditions in the community: a Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers. *BMC geriatrics* 2017, *17* (1), 40.

(4) Purkaple, B. A.; Mold, J. W.; Chen, S. Encouraging Patient-Centered Care by Including Quality-of-Life Questions on Pre-Encounter Forms. *Annals of family medicine* 2016, *14* (3), 221-226. DOI: 10.1370/afm.1905 From NLM.

(5) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* 2012, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM.

(6) Mold, J. W.; Blake, G. H.; Becker, L. A. Goal-oriented medical care. *Family medicine* 1991, *23* (1), 46-51. From NLM.

(7) Secunda, K.; Wirpsa, M. J.; Neely, K. J.; Szmuilowicz, E.; Wood, G. J.; Panozzo, E.; McGrath, J.; Levenson, A.; Peterson, J.; Gordon, E. J.; et al. Use and Meaning of "Goals of Care" in the Healthcare Literature: a Systematic Review and Qualitative Discourse Analysis. *J Gen Intern Med* 2020, *35* (5), 1559-1566. DOI: 10.1007/s11606-019-05446-0 From NLM.

(8) Boeykens, D.; Boeckxstaens, P.; De Sutter, A.; Lahousse, L.; Pype, P.; De Vriendt, P.; Van de Velde, D. Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: A scoping review and concept analysis. *PLoS One* 2022, *17* (2), e0262843. DOI: 10.1371/journal.pone.0262843 From NLM.

(9) Grover, S.; Fitzpatrick, A.; Azim, F. T.; Ariza-Vega, P.; Bellwood, P.; Burns, J.; Burton, E.; Fleig, L.; Clemson, L.; Hoppmann, C. A.; et al. Defining and implementing patient-centered care: An umbrella review. *Patient education and counseling* 2022, *105* (7), 1679-1688. DOI: 10.1016/j.pec.2021.11.004 From NLM.

(10) Ho, E. Y.; Leung, G.; Fung, J.; Jih, J. "I didn't know you were such a good cook": Photos as a tool for primary care clinician-patient communication. *Patient education and counseling* 2021, *104* (6), 1356-1363. DOI: 10.1016/j.pec.2020.10.033 From NLM.

(11) Hsieh, H.-F.; Shannon, S. E. Three approaches to qualitative content analysis. *Qual Health Res* 2005, *15* (9), 1277-1288.

(12) Elo, S.; Kyngäs, H. The qualitative content analysis process. *J Adv Nurs* 2008, *62* (1), 107-115. DOI: 10.1111/j.1365-2648.2007.04569.x From NLM.

(13) Sundler, A. J.; Lindberg, E.; Nilsson, C.; Palmér, L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open* 2019, *6* (3), 733-739. DOI: 10.1002/nop2.275 From NLM.

(14) Henderson, L.; Bain, H.; Allan, E.; Kennedy, C. Integrated health and social care in the community: A critical integrative review of the experiences and well-being needs of service users and their families. *Health Soc Care Community* 2021, *29* (4), 1145-1168. DOI: 10.1111/hsc.13179 From NLM.

(15) Singh Ospina, N.; Phillips, K. A.; Rodriguez-Gutierrez, R.; Castaneda-Guarderas, A.; Gionfriddo, M. R.; Branda, M. E.; Montori, V. M. Eliciting the Patient's Agenda- Secondary Analysis of Recorded Clinical Encounters. *J Gen Intern Med* 2019, *34* (1), 36-40. DOI: 10.1007/s11606-018-4540-5 From NLM.

(16) Boeykens, D.; Sirimsi, M. M.; Timmermans, L.; Hartmann, M. L.; Anthierens, S.; De Loof, H.; De Vliegher, K.; Foulon, V.; Huybrechts, I.; Lahousse, L.; et al. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. *J Clin Nurs* 2022. DOI: 10.1111/jocn.16243 From NLM.

(17) Kessler, D.; Walker, I.; Sauve-Schenk, K.; Egan, M. Goal setting dynamics that facilitate or impede a client-centered approach. *Scandinavian journal of occupational therapy* 2018, *26* (5), 315-324.

(18) Newbould, J.; Burt, J.; Bower, P.; Blakeman, T.; Kennedy, A.; Rogers, A.; Roland, M. Experiences of care planning in England: interviews with patients with long term conditions. *BMC family practice* 2012, *13*, 71. DOI: 10.1186/1471-2296-13-71 From NLM. Kuluski, K.; Gill, A.; Naganathan, G.; Upshur, R.; Jaakkimainen, R. L.; Wodchis, W. P. A qualitative descriptive study on the alignment of care goals between older persons with multi-morbidities, their family physicians and informal caregivers. *BMC Family Practice* 2013, *14* (1), 1-10.

(19) Murdoch, J.; Salter, C.; Ford, J.; Lenaghan, E.; Shiner, A.; Steel, N. The "unknown territory" of goal-setting: Negotiating a novel interactional activity within primary care doctor-patient consultations for patients with multiple chronic conditions. *Soc Sci Med* 2020, *256*, 113040. DOI: 10.1016/j.socscimed.2020.113040 From NLM. Boeckxstaens, P.; Willems, S.; Lanssens, M.; Decuypere, C.; Brusselle, G.; Kuhlein, T.; De Maeseneer, J.; De Sutter, A. A qualitative interpretation of challenges associated with helping patients with multiple chronic diseases identify their goals. *J Comorb* 2016, *6* (2), 120-126.

(20) Kuipers, S. J.; Nieboer, A. P.; Cramm, J. M. Views of patients with multi-morbidity on what is important for patient-centered care in the primary care setting. *BMC family practice* 2020, *21* (1), 71. DOI: 10.1186/s12875-020-01144-7 From NLM.

(21) Davis, A. H. Exercise adherence in patients with chronic obstructive pulmonary disease: an exploration of motivation and goals. *Rehabilitation nursing* 2007, *32* (3), 104-110. Schellinger, S. E.; Anderson, E. W.; Frazer, M. S.; Cain, C. L. Patient Self-Defined Goals: Essentials of Person-Centered Care for Serious Illness. *The American journal of hospice & palliative care* 2018, *35* (1), 159-165. DOI: 10.1177/1049909117699600 From NLM. Tinetti, M. E.; Costello, D. M.; Naik, A. D.; Davenport, C.; Hernandez-Bigos, K.; Van Liew, J. R.; Esterson, J.; Kiwak, E.; Dindo, L. Outcome goals and health care preferences of older adults with multiple chronic conditions. *JAMA network open* 2021, *4* (3), e211271-e211271.

(22) 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.

(23) Damiaens, A.; Maes, E.; Van Roosbroek, H.; Van Hecke, A.; Foulon, V. Methods to elicit and evaluate the attainment of patient goals in older adults: a scoping review. *Patient Education and Counseling* 2022.

(24) Dahlgren, G.; Whitehead, M. The Dahlgren-Whitehead model of health determinants: 30 years on and still chasing rainbows. *Public health* 2021, *199*, 20-24. DOI: 10.1016/j.puhe.2021.08.009 From NLM.

(25) Vermunt, N.; Elwyn, G.; Westert, G.; Harmsen, M.; Olde Rikkert, M.; Meinders, M. Goal setting is insufficiently recognised as an essential part of shared decision-making in the complex care of older patients: a framework analysis. *BMC family practice* 2019, *20* (1), 76. DOI: 10.1186/s12875-019-0966-z From NLM.

(26) Lenzen, S. A.; van Dongen, J. J.; Daniels, R.; van Bokhoven, M. A.; van der Weijden, T.; Beurskens, A. What does it take to set goals for self-management in primary care? A qualitative study. *Family practice* 2016, *33* (6), 698-703. DOI: 10.1093/fampra/cmw054 From NLM.

(27) Freilich, J.; Nilsson, G. H.; Ekstedt, M.; Flink, M. "Standing on common ground" - a qualitative study of self-management support for patients with multimorbidity in primary health care. *BMC family practice* 2020, *21* (1), 233. DOI: 10.1186/s12875-020-01290-y From NLM.

(28) Peterkin, A. Practical strategies for practising narrative-based medicine. *Canadian Family Physician* 2012, *58* (1), 63-64.

(29) Timmermans, L.; Boeykens, D.; Sirimsi, M. M.; Decat, P.; Foulon, V.; Van Hecke, A.; Vermandere, M.; Schoenmakers, B. 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), 63. DOI: 10.1186/s12875-022-01652-8 From NLM.

(30) Haywood, K.; Marshall, S.; Fitzpatrick, R. Patient participation in the consultation process: a structured review of intervention strategies. *Patient education and counseling* 2006, *63* (1-2), 12-23. DOI: 10.1016/j.pec.2005.10.005 From NLM.

(31) Lorig, K. R.; Sobel, D. S.; Stewart, A. L.; Brown, B. W., Jr.; Bandura, A.; Ritter, P.; Gonzalez, V. M.; Laurent, D. D.; Holman, H. R. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomized trial. *Med Care* 1999, *37* (1), 5-14. DOI: 10.1097/00005650-199901000-00003 From NLM. 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.

(32) https://selfmanagementresource.com/resources/bibliography/ (accessed 2022 29 September).

(33) Forjuoh, S. N.; Ory, M. G.; Jiang, L.; Vuong, A. M.; Bolin, J. N. Impact of chronic disease self-management programs on type 2 diabetes management in primary care. *World J Diabetes* 2014, *5* (3), 407-414. DOI: 10.4239/wjd.v5.i3.407 From NLM.

(34) Osborne, R. H.; Elsworth, G. R.; Whitfield, K. The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient education and counseling* 2007, *66* (2), 192-201. DOI: 10.1016/j.pec.2006.12.002 From NLM.

(35) Van de Velde, D.; De Zutter, F.; Satink, T.; Costa, U.; Janquart, S.; Senn, D.; De Vriendt, P. Delineating the concept of self-management in chronic conditions: a concept analysis. *BMJ Open* 2019, *9* (7), e027775. DOI: 10.1136/bmjopen-2018-027775 From NLM.

Goal-oriented care: from the theoretical concept to a descriptive understanding based on experiences of primary care providers

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Ready for submission

ABSTRACT

Objectives: First, to validate the attributes of goal-oriented care (GOC), as identified in a concept analysis on GOC. Second, to identify if providers report additional aspects of GOC in extent to the attributes.

Methods: A secondary analysis of interviews with primary care providers (n=48) on their experiences related to GOC in practice. A deductive analysis using the GOC attributes (i.e., goal-elicitation, goal-setting, goal-evaluation, patients' context, and patients' needs and preferences), and an inductive analysis using a thematic approach.

Results: Goal-elicitation was identified in an implicit way, in goal-setting providers prioritize patients' goals over health-related goals, and goal-evaluation was identified as a reflexive process of care; attention was paid to the patients' context, and needs and preferences. Interprofessional collaboration was identified as an additional aspect of GOC.

Conclusions: Providers did not explicitly talk about attributes as a stepwise approach, they seemed to have found their own way of applying GOC in their practice.

Practice implications: This study identified some practical suggestions such as key questions or tools that providers use to apply GOC in their practice. More work should be done to explore about what providers actually need to apply the goal-oriented process of care more explicitly in their practice.

INTRODUCTION

One out of three adults live with multiple chronic condition(s). It is projected that this number will increase in the next several years [1]. Multimorbidity, commonly understood as the co-occurrence of two or more chronic conditions, creates a burden for patients, care providers, and care systems. Patients report a negative impact on their everyday lives, personal relationships, and a poorer quality of life. On top of this, they have to complete a vast amount of tasks to manage their conditions (e.g., medication management, medical appointments, exercise) [2]. Patients also frequently rely on multiple care providers who often propose quite distinct or contradicting interventions based on their own expertise. At the same time, patients are at risk for fragmented care [2, 3]. The complexity of multimorbidity is also amplified by the variety of problems patients present, often a combination of physical, psychosocial, and socioeconomic needs [4]. Lastly, multimorbidity also affects care and social systems that have to deal with an overuse of diagnostic tests, high number of visits, and generally higher costs [2, 3].

Much of the burden that has been described is rooted in the disease-oriented paradigm that is built on disease-oriented guidelines [5]. However, the complex care needs patients with multimorbidity present, are often not well addressed by these guidelines [6]. To overcome this problem, a shift from a disease-oriented approach of care to goal-oriented care (GOC) has been proposed by dr. Mold [7]. GOC as a concept was introduced in literature for the first time in 1991 where dr. Mold argued that patients should be recognized as people with individual experiences, values, and goals and should be encouraged to strive for their highest possible level of health defined by themselves [7]. After the initial introduction of GOC, the concept was noticed by other (clinician) researchers and studied with increased interest [8]. This increasing interest came however with mounting ambiguity on how GOC is understood and how it should be implemented into practice. For example, 'patient priority directed decision making', 'goal-oriented patient care', 'person-centered goal-setting', appeared in literature [9, 10]. To gain more clarity on this concept, a concept analysis was conducted and identified two main attributes of GOC [11]. First, that GOC is a dynamic and iterative process and second that this process of care is underpinned by the patient's needs and preferences and embedded in their specific context. The process attribute identified three phases of GOC: goal-elicitation, goal-setting, and goal-evaluation. In the phase of goal-elicitation, providers listen to the patients' narrative that reflects their lived experience. By doing this, a greater level of shared understanding between providers and patients can be created. In the phase of goal-setting, providers and patients try to find each other on the crossroads of their own agendas, formulate their own goals, and try to integrate them. In the phase of goal-evaluation, providers and patients reflect on the care process which allows adjustments to the care plan that might needed as patients' care or life situation change over time. By having ongoing reflections, the dynamic and iterative character of GOC is stressed. This entire process is underpinned by the patient's context (personal, social, and cultural) and patient's needs and preferences that emphasize the shift from 'what is the matter with the patient' to 'what matters to the patient' [11].

While the concept analysis outlined a theoretical approach to the GOC attributes, there remains a need to explore how primary care providers put GOC into practice. It is important to acknowledge that theories could not be applied as linear processes, but have to be adapted to the real world [12].

In 2020 a case report of three international team-based primary care practices who were trying to implement GOC has been published [13]. Without the existence of guidance or theoretical frameworks, these cases approached and implemented GOC each in their own way. Their main aim was to address the growing needs of their practices such as the need to improve care for patients with complex care needs or to optimize the process of interprofessional collaboration. In addition, the unique context of each case dictated how GOC was introduced and differed across them [13]. These practices can be considered as GOC pioneers as they started their implementation trajectory (between 2009-2012) before GOC gained momentum in primary care practices or before the concept analysis was published [13].

This case report illustrated that there are multiple interactional components, including different (inter)actions by different actors, that take place at the same time in order to implement GOC [14]. This study expands further on these cases by exploring if the attributes identified in the concept analysis on GOC could be validated by the experiences of providers in practice, and to explore if providers report additional aspects in extent to the attributes of GOC. To summarize, the aim of this study is two-folded. First, explore if and how GOC experiences, as described in the case report, align with the GOC attributes found in the concept analysis and whether they could be validated. Second, this study aims to identify additional aspects that primary care providers report about GOC when they apply this care approach during patient interfaces.

METHOD

STUDY DESIGN

This study consists of a qualitative secondary analysis of interview data derived from primary care providers working in primary care practices either in Ghent (Belgium), Vermont (USA), or Ottawa (Canada) [15]. The researchers of the original study conducted these interviews as part of an international cross case comparison study on the implementation of GOC[13] . The same group of researchers were involved in this study to look at the original data with a different lens. Two methods to analyze the data have been applied. First, a deductive analysis was conducted using the attributes goal-elicitation, goal-setting, goal-evaluation, patients' needs and preferences, and patients' context as a framework to see how the participants' experiences align with them [11]. Second, an inductive analysis using a thematic approach based on a descriptive phenomenology was performed to identify additional aspects of GOC that have not been identified in the concept analysis [16].

PARTICIPANTS AND SAMPLING

The senior researchers (PB – Belgium, CSG – USA, AG – Canada) selected primary care practices who were in the process of implementing or had implemented GOC. For each practice, a key person was identified who was knowledgeable about the adoption and implementation process of GOC. This person was responsible for identifying and recruiting team members, both providers and leaders, who were experienced in delivering GOC. The recruiting process was based on a maximal variation sampling approach to capture an interprofessional perspective on GOC.

DATA COLLECTION

For the initial study, data was collected through a semi-structured interview guide with open-ended questions (Supplementary File 1: interview guide). Interviews took place at the practice of the participants and were performed in-person. Three main research questions were originally formulated: 1. 'How do primary care providers and teams understand and interpret the theoretical concept of GOC?', 2. 'How do providers and teams engage in GOC practice?', and 3. 'Which barriers and facilitators do providers and teams encounter in relation to the adoption and implementation of GOC?'. Probes and additional questions were used to support collection of rich data. Interviews were first conducted with individuals at the practices who were deemed to have the most knowledge about the implementation of GOC. In this way, the interviewers got more familiarity with the situation in the practice and created a solid foundation to guide their further interviews. Interviews were conducted by lead researchers (PB, CSG, AG) and trainees and were either held in English (Vermont and Ottawa) or Dutch (Ghent). All interviewers were trained in qualitative research methods. Data were collected between June and October 2017.

DATA ANALYSIS

2.4.1 Deductive analysis

Deductive analysis is useful in cases in which theories are retested or placed into new contexts [17]. In this study, interview data of primary care providers were mapped onto the attributes of GOC generated in the concept analysis (Table 1). To start, transcripts were thoroughly read to gain an overall understanding of the data. Then, data of nine interviews, three from each case, were categorized onto one or more attributes (DB). This resulted in an initial overview which was presented to the research team (PDV, ADS, AG, LL, PP, CSG, DVdV, PB). As a last step, the remaining transcripts were analyzed and mapped onto the attributes. Throughout this process, regular meetings with the research team were organized to discuss and finalize the categorizations. An extract of how the deductive analysis was conducted is depicted in Table 2.

Table 1 Overview of the GOC attributes

Attributes	
1. Goal-oriented care is a multifaceted, dynamic and iterative process.	1.1 Goal-elicitation builds a patient-provider relationship.
	1.2 Goal-oriented care entails goal-setting.
	1.3 Goal-evaluation is a reflexive process.
2. Goal-oriented care embraces patients' values.	2.1 Goal-oriented care must be placed in the patient's context.
	2.2 Goal-oriented care must be tailored to the patient's needs and preferences.

Table 2 Extract of the deductive analysis

Citation	Keywords	Attribute
"How do you kind of bring them together? Oh, that's complex [laugh]. That is something I'm still honestly trying to figure out. The best that I can do is when an individual comes in to see me, I try to establish who's the identified client." (VT03 – behavioral consultant)	I try to establish who's the identified client	Goal-elicitation
"I usually see those goals change over time as people get engaged in treatment of some sort and begin to see they can make changes or can accomplish something. Or they begin to gain more insight into something that begins to open the door into, well, maybe this is a problem too. And then you can see a progression, I think, of what people are willing to engage in for goals and for treatment." (VT07 – operations director)	Goals change over time, see they can make changes or accomplish things, can see the progression	Goal-evaluation
"But the idea is, you know, after connecting with the client, establishing some goals, identifying who they see as part of their care team. So that may be professionals and family members or friends or anybody that they view as somebody that's supportive and important for them." (O11 – care coordinator)	Identify who they see as part of their care team, somebody that is supportive	Patients' context

2.4.2 Inductive analysis

A thematic analysis based on a descriptive phenomenology was used to answer the second research question '*What are additional aspects that primary care providers report about GOC based on the experiences they have with GOC?'*. This inductive analysis was performed after the deductive analysis and comprised six steps: 1) achieving familiarity with the data through open-minded reading of the transcripts, 2) marking meaningful parts of the first nine interviews, three from each case, which resulted in an initial overview of meaning units, 3) presenting this first overview to the research team with the aim to compare and organize the meaning units into patterns, 4) translating the patterns into meaningful themes, 5) analyzing the remaining interviews until data saturation was reached, meaning that no new information was found, and 6) presenting and discussing the themes with the research team to validate the analysis process and agree on the themes.

ETHICAL APPROVAL

Ethics approval was given for the original study by all relevant agencies in each of the three countries.

RESULTS

In total, interview data from 48 primary care providers and leaders (17 in Ghent, 18 Vermont, and 13 Ottawa) were analyzed. The interviews lasted approximately 60 minutes.

Table 2 Overview participants

Profession	number
Ghent (G)	17
Family physician	8
Social worker	3
Nurse	2
Coordinator	2
Physiotherapist	1
Office manager	1
Vermont	18
Case manager	4
Coordinator	3
Quality improvement	2
Behavioral health consultant	1
Emergency physician	1
Social worker	1
Project manager	1
Public health manager	1
Physician assistant	1
Mental health manager	1
Nurse	1
Family physician	1
Ottawa	13
Coordinator	4
Social worker	2
Nurse	2
Family physician	2
Director of health services	1
Program coordinator	1
Project manager	1

DEDUCTIVE ANALYSIS

By mapping the interview data onto the GOC attributes (goal-elicitation, goal-setting, goal-evaluation, patient's context, and patient's needs and preferences) it was possible to explore how the experiences of primary care providers align with them.

Goal-elicitation

The concept analysis defined a goal-elicitation phase in which patients are given sufficient time and space to share their personal narratives and build a trusting relationship with their provider. Goal-elicitation appeared to be more implicitly present during care delivery as participants did not seem to explicitly talk about this attribute. This was illustrated by some participants who described it as a more subtle act during care delivery, as something that has to be continuously present when interacting with patients. Others experienced it more as a precondition to set the stage for discussing patients' personal goals. Overall, participants reflected on goal-elicitation as creating a supportive and welcoming context for the patient to set them at ease and to share their narrative.

"But at some point you also have to listen to what they've come to see you about, and to try and be supportive and understanding and welcoming." (O7)

Participants also reported to occasionally using tools to explore the patients' narrative.

"And so we have these Domain Cards with all different types of titles, like themes on them for individuals to look at. And then from that, start gathering this person-centered story." (VT9)

Goal-setting

In the phase of goal-setting, patients' personal goals are negotiated and discussed to guide care delivery. Participants reported that they mainly put emphasis on patients' goals rather than on providers' health-related goals for the patient.

"It's the patient's own life. But following the patients' goals might be for their own life, and trying to tailor care and plan care to those goals rather than goals that might be my own." (O6)

To set patients' goals, participants used questions like *"What is meaningful for you?"(VT2), "What do you want?", "Is there anything in particular, it could be one thing, it could be a couple of things that you [the patient] would improve upon your wellbeing or your overall wellness?" (VT16)*. Participants reported that they would aim to translate patients' personal goals into actionable treatments in such way that patients could understand them. In this way, the focus remained on the patients' personal goals while being able to meet medical care objectives (e.g., "*working on the medical piece to keep the patient healthy enough to attend her child's graduation" (VT4))*.

"For me goal-oriented care is engaging in a conversation with the patient about his goals and how we can meet those goals as physicians or as a team. How can we organize care towards these goals, are these goals realistic and do they add to better care for the patient. It's important not to try and change the goals of the patient but it is important to start a dialogue. If the patient defines a goal that is not good for his health or care then I would share my opinion with the patient without imposing." (G2)

Goal-evaluation

The phase of goal-evaluation stresses the dynamic character of GOC by allowing providers and patients to reflect on the care process. This definition resonated with participant feedback as they tended to reflect on the process of care rather than on goal-achievement. For them, it was most important that patients were enabled to guide the process of care and reflect upon whether the care that is provided is meaningful for them.

"I mean not whether or not they are complete or incomplete but more, you know, are we on the right path, is this moving in the direction, do you feel like these goals are working towards the things that you still value, can you measure improvement from the time before having this goal to now that we've started working on it? So our program itself is not measured based on okay, did we complete this goal or that goal." (O11)

To ensure patient involvement and engagement throughout the care process, participants also reflected on their own practice. Therefore, they reported that they ask patients questions like "*Was there enough time spent with you?", "Did you have the opportunity to ask questions?", "Did you contribute when the care plan was developed." (G3)*

Goal-evaluation and its reflective process was also mentioned in the light of already embedded workflows in the organization to overview care for patients with complex needs.

"Well, chronically ill patients are reevaluated once a year anyway, or every six months, it depends how much work we've got: What were our goals back then? Did we get there? Are there new aspects, new goals in the meantime?" (G5)

Patients' context

The patient's context reflects the personal, social, and cultural situation that influences the patient's health and is seen to underpin the goal-oriented process of care. Participants mentioned that they were attentive to factors such as the patient's home situation throughout the care process.

"People are slowly coming to realize that if somebody has diabetes, it could be that they're not in a home that has a running refrigerator. Or out of control diabetes where they can't store their insulin that has to be cooled." (VT14)

Participants also referred to people who play a supportive role in the patient's life as the patient's context. To get an overview of these people, they asked questions like *"Who is really important in your life?"* (G7). Some participants also reported to use tools to obtain this overview.

"I'm a big fan of the Bronfenbrenner's' ecological model. So the micro system are the direct interactions with primary supports. So for a patient, that might be their family member and friends. And one more level out is still direct relationships but not necessarily regular relationships. It ends up in the macro system, which are social dialogues individuals interact with." (VT3)

Patients' needs and preferences

Patients' needs and preferences underpin the care process and underline the shift from "what is the matter with the patient" to "what matters to the patient". Participants mentioned that their patients should be the directors of their own care process and must "sit in the driver' seat".

"The person is the director. "It's always, you know, the client has to be at the center of the care. It has to be goal-oriented. It always comes up in so many areas. And we want to work towards that. We are committed as a center. Everyone matters – that's our motto." (O9)

INDUCTIVE ANALYSIS

Most of how participants reflected on GOC aligned with the attributed identified in the concept analysis, but the inductive analysis unveiled interprofessional collaboration as an additional aspect of GOC.

Participants reported that discussing patients' goals as a care team allowed them to align their care plan to each other and thus work into the same direction. They expressed that patients' goals could be used as a linchpin for bringing all providers together who could play a supportive role in pursuing patients' goals.

"I think it is not very goal-oriented if you're the only one to go a certain way with your patient while others don't. Anyway, it is a task as a team to work towards the goals, but sometimes an individual brings up a goal and then we shape that further as a team." (G3)

Notably, interprofessional collaboration was organized differently across the three setting varying from informal interactions in the hallway, to weekly scheduled team meetings, to even monthly external meetings with other organizations.

"Who are the people that are going to help him achieve that goal? You know, it can be three people but it can be ten. It can be the physician, the specialist. And then we do a care conference where people actually have a chance to discuss – Okay, this is the client's goal. Who's going to do what? How are we going to support the client? So that makes a difference." (O2)

DISCUSSION

Discussion

This study explores how the GOC experiences of primary care providers align with the attributes of GOC derived from a concept analysis of GOC and what additional aspects they identify when they put GOC into practice. All GOC attributes identified the concept analysis were found in the data.

The concept analysis described a goal-elicitation phase in which attention is paid to the patient's narrative and the patient-provider relationship [9]. Findings from this secondary analysis support the original definition from the literature. Literature on GOC stated that it is important to listen to patients' narratives as they reflect the person's uniqueness and allowed for a better understanding of the patients' living situation [18]. The papers did not clearly propose a standardized approach. Similarly, in this study the participants did not mention one specific strategy or procedure for goal-

elicitation. However, it seemed that participants found their own method in the form of key questions or tools. Further research should clarify if these methods are required and can be proposed as guidance to explicate goal-elicitation.

The goal-setting phase appeared as more complex in our data compared to the structure and procedures proposed in the concept analysis. The participants described a reflexive process where questions are raised about how patients' goals relate to health-related goals. The discussion about whether patients' goals are precedent over health-related goals is also prominent in literature [19]. Bernsten et al. proposed a goal hierarchy and stated that patients' goals take priority as providers translate these goals into tangible health-related goals [20]. This is in line with the findings of this study where providers reflect that they park their own agenda and put patients' goals first. However, literature also describes that connecting patients' goals with health-related goals requires a more complex provider-patient interplay and co-production of goals rather than just a translation of them. What this interplay should consists of and how this should take place, is subject for further research.

The phase of goal-evaluation also revealed a continuous reflection on the patients' personal goals. Participants reported that they focus on the process of care instead of on goal-achievement. This is in line with the concept analysis that described that creating care processes based on patients' personal goals does not necessarily include evaluating whether goals have been achieved [12]. These experiences might inform that GOC is not about 'ticking boxes', but more likely about being a reflexive practitioner with a critical eye to determine whether patients' personal goals are still guiding the care process. Being a reflexive provider is described in the literature as an integral part of healthcare and is one of the main drivers for personal growth and improvement of providers [21]. Guidance is available in literature to structure the stages of a reflection process and support providers in being critical of their own practice [22]. In this study it appeared that providers reflected by using a set of questions. Since GOC implies a change in conversation and a focus on patients' goals instead of health-related goals, it is important to take time to reflect on the process of care delivery.

The underpinning attributes of GOC were also identified in our data. Literature indicates that it is important to be fully informed about the patients' personal and living situation as a provider and use this information as a resource to strengthen patients in their abilities to focus on personal goals [23]. Regarding patients' needs and preferences, participants mentioned that patients should be the director of their own care. Changing the conversation to "What matters to the patient?" has been suggested as a prompt to drive patients'/provider consultations into a goal-oriented process of care and can accordingly be adopted as a key question for GOC [24]. In particular, a focus on what is important for patients has proven to be associated with social well-being, physical well-being, and satisfaction with care for patients [25]. Therefore, taking patients' needs and preferences into account throughout the entire care process, is crucial for their understanding of receiving good care [26].

Besides the discussion of the attributes based on the deductive analysis, the inductive analysis revealed that GOC might facilitate interprofessional collaboration. Having a common vision in the

team and be ready to collaborate as a team is essential to facilitate interprofessional collaboration [27]. In that respect, a focus on patients' goals in a team setting might initiate this common vision and even lead to less fragmentation and better continuity of care [28]. To support a common vision, it is important to invest in relationship building and organize regular trainings and meetings to provide the opportunity to connect [29].

This study has some strengths and limitations. First, the different backgrounds of the research team increased the reflexivity throughout the entire process starting from collecting to analyzing the data. Second, the participants represented a broad range of professions present in primary care. Third, data from different international settings were used. The included primary care practices each implemented GOC in a different way which resulted in a broad understanding on how primary care providers operationalize GOC. This increased the transferability of the results, which is often a limitation of qualitative research. Fourth, data were read three times to gain familiarity and to start the inductive analysis tabula rasa which supported a solid inductive analysis. Fifth, the data analysis was characterized by an iterative process for which several analysis meetings were organized with the lead investigators and co-authors which improved the credibility of this study. Despite the strengths, this study comes along with some limitations. First, it might seem that a deductive analysis is not compatible with a thematic analysis grounded in a descriptive phenomenology. However, the data used in this study were considered 'naïve data' as the interviews were conducted before the knowledge of the attributes were gained and there was as such no preunderstanding of the attributes. To also avoid that this preunderstanding would influence the inductive analysis, the deductive and inductive analysis were performed separately, ensuring an open-mind reading. Second, the senior researchers in this study might be considered pioneers in goal-oriented care which might have positively influenced the data analysis. However, by applying the techniques of researcher triangulation and exemplifying the themes with illustrative quotations, trustworthiness of this study was guaranteed. Third, the results might have been biased by the way how GOC was introduced in the cases (e.g., interprofessional practice) so the inductive finding might be a direct result of this work structure. Third, we did not verify if GOC was actually applied in the participating practices.

Conclusion and practice implications

This study provides (1) insight into how providers' experiences with GOC align with the GOC attributes identified in a concept analysis, and (2) what additional aspects they report in extent to these attributes. It can be concluded that all GOC attributes were found and thus the concept analysis seems to match the actual practice of GOC although providers developed more implicit approaches and techniques to put GOC into practice. Moreover, they did not clearly identify a stepwise approach. Interprofessional collaboration was identified as an additional aspect that had not been found in the concept analysis. Even though GOC already seems to be implemented in practice, questions remains about how providers can best be supported to move GOC forward. One of the questions is whether the phases of the goal-oriented process of care should be made implicit or explicit.

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REFERENCES

(1) 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.

(2) 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. Noël, P. H.; Frueh, B. C.; Larme, A. C.; Pugh, J. A. Collaborative care needs and preferences of primary care patients with multimorbidity. *Health expectations : an international journal of public participation in health care and health policy* 2005, *8* (1), 54-63. DOI: 10.1111/j.1369-7625.2004.00312.x From NLM.

(3) 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.

(4) Van Wilder, L.; Devleesschauwer, B.; Clays, E.; De Buyser, S.; Van der Heyden, J.; Charafeddine, R.; Boeckxstaens, P.; De Bacquer, D.; Vandepitte, S.; De Smedt, D. The impact of multimorbidity patterns on health-related quality of life in the general population: results of the Belgian Health Interview Survey. *Qual Life Res* 2022, *31* (2), 551-565. DOI: 10.1007/s11136-021-02951-w From NLM.

(5) Kramer, M. H.; Bauer, W.; Dicker, D.; Durusu-Tanriover, M.; Ferreira, F.; Rigby, S. P.; Roux, X.; Schumm-Draeger, P. M.; Weidanz, F.; van Hulsteijn, J. H. The changing face of internal medicine: patient centred care. *European journal of internal medicine 25* (2), 125-127.

(6) Hughes, L. D.; McMurdo, M. E.; Guthrie, B. Guidelines for people not for diseases: the challenges of applying UK clinical guidelines to people with multimorbidity. *Age Ageing* 2013, *42* (1), 62-69. DOI: 10.1093/ageing/afs100 From NLM.

(7) Mold, J. W.; Blake, G. H.; Becker, L. A. Goal-oriented medical care. *Fam Med* 1991, *23* (1), 46-51. From NLM.

(8) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* 2012, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM.

(9) Tinetti, M. E.; Esterson, J.; Ferris, R.; Posner, P.; Blaum, C. S. Patient Priority-Directed Decision Making and Care for Older Adults with Multiple Chronic Conditions. *Clinics in geriatric medicine* 2016, *32* (2), 261-275.

(10) Reuben, D. B.; Tinetti, M. E. Goal-oriented patient care--an alternative health outcomes paradigm. *N Engl J Med* 2012, *366* (9), 777-779. DOI: 10.1056/NEJMp1113631 From NLM.

(11) Boeykens, D.; Boeckxstaens, P.; De Sutter, A.; Lahousse, L.; Pype, P.; De Vriendt, P.; Van de Velde, D. Goal-oriented care for patients with chronic conditions or multimorbidity in primary care:

A scoping review and concept analysis. *PLoS One* 2022, *17* (2), e0262843. DOI: 10.1371/journal.pone.0262843 From NLM.

(12) Biggs, J. B. From theory to practice: A cognitive systems approach. *Higher education research and development* 1993, *12* (1), 73-85.

(13) Steele Gray, C.; Grudniewicz, A.; Armas, A.; Mold, J.; Im, J.; Boeckxstaens, P. Goal-Oriented Care: A Catalyst for Person-Centred System Integration. *Int J Integr Care* 2020, *20* (4), 8. DOI: 10.5334/ijic.5520 From NLM.

(14) McDaniel Jr, R. R.; Lanham, H. J.; Anderson, R. A. Implications of complex adaptive systems theory for the design of research on health care organizations. *Health care management review* 2009, *34* (2), 191.

(15) Szabo, V.; Strang, V. R. Secondary analysis of qualitative data. *ANS Adv Nurs Sci* 1997, *20* (2), 66-74. DOI: 10.1097/00012272-199712000-00008 From NLM.

(16) Sundler, A. J.; Lindberg, E.; Nilsson, C.; Palmér, L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open* 2019, *6* (3), 733-739. DOI: 10.1002/nop2.275 From NLM.

(17) Elo, S.; Kyngäs, H. The qualitative content analysis process. *J Adv Nurs* 2008, *62* (1), 107-115. DOI: 10.1111/j.1365-2648.2007.04569.x From NLM.

(18) Zaharias, G. What is narrative-based medicine? Narrative-based medicine 1. *Can Fam Physician* 2018, *64* (3), 176-180. From NLM.

(19) Oksavik, J. D.; Kirchhoff, R.; Sogstad, M. K. R.; Solbjor, M. Sharing responsibility: municipal health professionals' approaches to goal setting with older patients with multi-morbidity - a grounded theory study. *BMC Health Serv Res* 2020, *20* (1), 141. DOI: 10.1186/s12913-020-4983-3 From NLM. Salter, C.; Shiner, A.; Lenaghan, E.; Murdoch, J.; Ford, J. A.; Winterburn, S.; Steel, N. Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations. *The British journal of general practice : the journal of the Royal College of General Practitioners* 2019, *69* (684), e479-e488. DOI: 10.3399/bjgp19X704129 From NLM.

(20) Berntsen, G. K.; Gammon, D.; Steinsbekk, A.; Salamonsen, A.; Foss, N.; Ruland, C.; Fønnebø, V. How do we deal with multiple goals for care within an individual patient trajectory? A document content analysis of health service research papers on goals for care. *BMJ Open* 2015, *5* (12), e009403. DOI: 10.1136/bmjopen-2015-009403 From NLM.

(21) Quilty, T.; Murphy, L. Time to review reflective practice? *International Journal for Quality in Health Care* 2022, *34* (2), mzac052.

(22) Koshy, K.; Limb, C.; Gundogan, B.; Whitehurst, K.; Jafree, D. J. Reflective practice in health care and how to reflect effectively. *Int J Surg Oncol (N Y)* 2017, *2* (6), e20. DOI: 10.1097/ij9.0000000000000020 From NLM.

(23) Van Wilder, L.; Pype, P.; Mertens, F.; Rammant, E.; Clays, E.; Devleesschauwer, B.; Boeckxstaens, P.; De Smedt, D. Living with a chronic disease: insights from patients with a low socioeconomic status. *BMC family practice* 2021, *22* (1), 1-11.

(24) Fried, T. R.; Street, R. L., Jr.; Cohen, A. B. Chronic Disease Decision Making and "What Matters Most". *J Am Geriatr Soc* 2020, *68* (3), 474-477. DOI: 10.1111/jgs.16371 From NLM. Olsen, C. F.; Debesay, J.; Bergland, A.; Bye, A.; Langaas, A. G. What matters when asking,"what matters to you?"—perceptions and experiences of health care providers on involving older people in transitional care. *BMC Health Serv Res* 2020, *20*, 1-13.

(25) Kuipers, S. J.; Cramm, J. M.; Nieboer, A. P. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. *BMC Health Serv Res* 2019, *19* (1), 13. DOI: 10.1186/s12913-018-3818-y From NLM.

(26) Boeykens, D.; Sirimsi, M. M.; Timmermans, L.; Hartmann, M. L.; Anthierens, S.; De Loof, H.; De Vliegher, K.; Foulon, V.; Huybrechts, I.; Lahousse, L.; et al. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. *J Clin Nurs* 2023, *32* (3-4), 422-437. DOI: 10.1111/jocn.16243 From NLM.

(27) Sirimsi, M. M.; De Loof, H.; Van den Broeck, K.; De Vliegher, K.; Pype, P.; Remmen, R.; Van Bogaert, P. Scoping review to identify strategies and interventions improving interprofessional collaboration and integration in primary care. *BMJ Open* 2022, *12* (10), e062111. DOI: 10.1136/bmjopen-2022-062111 From NLM.

(28) Organization, W. H. *WHO global strategy on people-centred and integrated health services: interim report*; World Health Organization, 2015. Kringos, D. S.; Boerma, W. G.; Hutchinson, A.; Saltman, R. B.; Organization, W. H. *Building primary care in a changing Europe*; World Health Organization. Regional Office for Europe, 2015.

(29) Im, J.; Evans, J. M.; Grudniewicz, A.; Boeckxstaens, P.; Upshur, R.; Steele Gray, C. On the same page? A qualitative study of shared mental models in an interprofessional, inter-organizational team implementing goal-oriented care. *J Interprof Care* 2022, 1-9. DOI: 10.1080/13561820.2022.2113048 From NLM.

SUPPLEMENTARY FILE 1: interview guide

Today we will be talking about how you and your team have adopted goal oriented care as part of delivering care to your patients. Before we get started could you tell me a little bit about yourself and your role in the practice/network/organization.

SECTION 1: Perceptions of goal-oriented care

The first set of questions will focus on how you define and understand goal-oriented care.

1. What does goal oriented care mean to you?

2. How did you learn about goal-oriented care?

3. How does goal-oriented care fit into how you deliver care to your patients?

4. What do you see as the advantages and disadvantages of adopting this in your practice?

SECTION 2: Implementing goal-oriented care in practice

This next set of questions focus more on how goal-oriented care has been implemented in your practice/organization/network.

5. How was goal-oriented care first introduced in your practice?
PROBES

a. How and when was goal-oriented care introduced? By whom? In what way?

b. How were providers informed about and/or trained in goal-oriented care?

c. Have you personally adopted this method with your patients? Why or why not?

6. Please walk us through the process of delivering goal-oriented care to patients.
PROBES

a. Who is involved? (patients, families, team members)

b. How are goals elicited?

c. How do you document the process?

d. Is information accessible to other providers? What types of information are shared? e. Do you engage in goal-oriented care as a team or on your own?

7. Has this process changed over time since you first adopted it?
Please elaborate on why or why not.

8. What did care delivery look like before you adopted goal-oriented care?

9. Do you feel like you have the necessary skills and training to do goal-oriented care?

10. What are some of the challenges you encounter in practicing goal-oriented care with your patients?
PROBE: May be related to the organization and system, or how you feel about goal-oriented care.

11. How is goal-oriented care supported by your practice/organization/network?
PROBES

a. Are resources and training provided?

b. Do you have the time needed?

c. Are there appropriate communication systems and processes in place?

12. Do you think you and your practice/organization should continue to adopt goal-oriented care?

PROBES

a. Should other practices adopt this approach?

GENERAL DISCUSSION

There is an overall recognition that a strong primary health care system is key to deliver quality of care for people with moderate complex care needs (i.e., 'patients'). As described in the introduction, there is a constant search for strategies to manage multimorbidity. This continuous thinking has already led to the acknowledgement that care should be underpinned by what matters to patients. This dissertation aims to contribute to the body of knowledge on models of care that are well-suited to facilitate a shift from "what is the matter with the patient" to "what matters most to the patient".

Six studies, underlined by the MRC Framework, have been performed for doing so. The first three studies intended to build an evidence base to support the development of a goal-oriented care intervention. The fourth study supported the identification and development of the theory by means of a concept analysis that resulted in comprehensive understanding of goal-oriented care. The final two studies expanded on this understanding through learnings from people with chronic conditions and primary care providers and their experiences with goal-oriented care, and as such modelled the processes and outcomes of a goal-oriented process of care.

The first part of the general discussion will start with summarizing the main research findings. Then, these findings will be compared with literature to further discuss what patients, providers, and the care system need to embed goal-oriented care in their way of working and thinking. Subsequently, the main building blocks of goal-oriented care for primary health care interventions will be described. This will be followed by the general strengths and limitations that go beyond the individual studies. To end, we will describe the recommendations and implications for practice, policy, education, and further research.

SUMMARY of the FINDINGS

The findings will be described accordingly to the three steps of the development phase as described by the UK Medical Research Council Framework: identifying the evidence base, identifying/ developing the theory, and modelling processes and outcomes.

Identifying the evidence base

The first study captured the experiences of people living with chronic conditions and their informal caregivers (abbreviated as 'PCDs') on how they receive primary health care. More specifically, this study depicted their daily lives, the support they need from primary care providers, and how primary health care is optimally organized. This study described that PCDs found it important to retain their autonomy as long as possible, which was demonstrated by their ability to perform meaningful and essential activities. To perform these activities, patients needed support from their social environment such as friends and family. As they engaged in these activities and relationships, PCDs emphasized the importance of considering their personal values. During their interactions with primary care providers, they expected to be approached as equal partners, encouraged to share their story, have an open communication, and create an environment that fosters collaboration. PCDs concluded that the roles of primary care providers need to be revised to motivate and support patients in performing meaningful activities. Additionally, PCDs reflected that quality of care should be considered in the light of how it pays attention to their needs, how it promotes their autonomy so they can still engage in activities, and how they are supported by a team of formal caregivers. Without realizing it, the PCDs indirectly emphasized the significance of goal-oriented care.

The second study presented the findings of six focus groups organized to elicit the perspectives of primary care stakeholders towards putting patients' personal goals first during care delivery, strategies they use, and the challenges they encounter. Four main strategies were formulated which included that stakeholders created space to explore what is meaningful for their patients (1), combined their medical expertise with patients' personal goals to striving for best quality of life as defined by the individual (2), listened to the patients' significant others to elicit their goals (3), and integrated patients' personal goals during interprofessional collaboration (4). Two main challenges were shared, namely that providers should be better equipped with competences to discuss patients' personal goals (1), and that organizational transformations have to occur to allow providers to focus on patients' personal goals (2). In goal-oriented care, patients' personal goals are key. It thus seemed that goal-oriented care was not something new to primary care stakeholders.

The third study explored the potential for implementing goal-oriented care into primary care settings in Flanders through the theoretical implementation lens of the NoMAD survey based on the Normalization Process Theory (NPT). The survey was completed by primary care providers after they attended a two-hour community meeting about goal-oriented care. Primary care providers indicated that they have an initial understanding of goal-oriented care and recognized its potential. Furthermore they showed much interest to embed goal-oriented care in their way of

working and even believed that it can easily be integrated into existing work without disrupting working relationships with colleagues or patients. However, primary care providers should be encouraged to reflect and share experiences about how to use goal-oriented care in practice to get a full comprehension.

Identifying/ developing the theory

Whereas the first three studies already seemed to implicitly point to key elements of goal-oriented care, in the fourth study we sought to ascertain the antecedents, attributes, and consequences of goal-oriented care in the literature by means of a concept analysis. This resulted in a comprehensive understanding of goal-oriented care. The identification of the attributes, goal-elicitation, goal-setting, and goal-evaluation, demonstrated that goal-oriented care is a multistage, iterative process. The attributes could provide an initial overview of actions that should be undertaken to put goal-oriented care into practice. The underpinning attributes, patients' needs and preferences and patients' context, present a philosophy of care and the common thread to orient care to what matters to the patient. The latter foremost indicates that goal-oriented care is about making a paradigm shift from "what is the matter with the patient" to "what matters to the patient". To engage in goal-oriented care, patients and providers need to be educated to develop the needed competences to communicate, listen, and reflect on (the patients') goals. In terms of consequences, goal-oriented care seems to have the potential to improve patients' experiences, provider well-being, reduce costs, and improve overall population health.

Modelling process and outcomes

The fifth study expanded further on the comprehensive understanding of the concept analysis by learning about goal-oriented care through the experiences of people living with chronic conditions. The participants experienced a goal-elicitation stage as they felt that providers took time to listen to them and create space to talk about their personal lives and feelings. Goal-setting and goal-evaluation were experienced in lesser extent. In terms of the underpinning attributes, participants reported mixed experiences. In some case, the patient's context was taken into account whereas others experienced that no attention was being paid to their personal situation. Similarly, participants did not experience that their needs and preferences were acknowledged throughout the care process. In addition to these attributes, participants mentioned the importance of interprofessional collaboration and being informed about their treatment options and conditions. By adding the latter ones to the attributes, the process of goal-oriented care was further modelled.

The sixth study explored how experiences of primary care providers align with the attributes identified in the concept analysis. Goal-elicitation was found to be more implicitly present as providers did not explicitly talk about building a relationship with their patients. For goal-setting, providers seemed to emphasize patients' personal goals instead of their own health-related goals. For goal-evaluation, providers appeared to focus more on the reflexive character of GOC instead of on goal achievements. In some cases, providers reported that they used key questions or instruments to guide them in eliciting or setting goals; as such they found their own way for applying goal-oriented care, and their own way in supporting them in making the shift to what matters most to patients. Regarding the underpinning attributes, participants reported to be

attentive to their patients' living situation, and put patients in the driver's seat of their care process. Likewise the fifth study, the inductive analysis revealed an additional aspect of GOC, interprofessional collaboration.

GENERAL DISCUSSION

The studies entailed a multi-perspective lens involving primary care stakeholders and literature, enabling comprehensive reflections on all domains within primary health care. The first part of this general discussion is structured according to the micro, meso, and macro level to address this comprehensiveness. In the second part of this general discussion, we formulate these findings as building blocks for goal-oriented care interventions. In the third and last part, we adopt a broader perspective to explore how goal-oriented care can contribute to strengthening primary health care while making the link with the quintuple aim and person-centered integrated care.

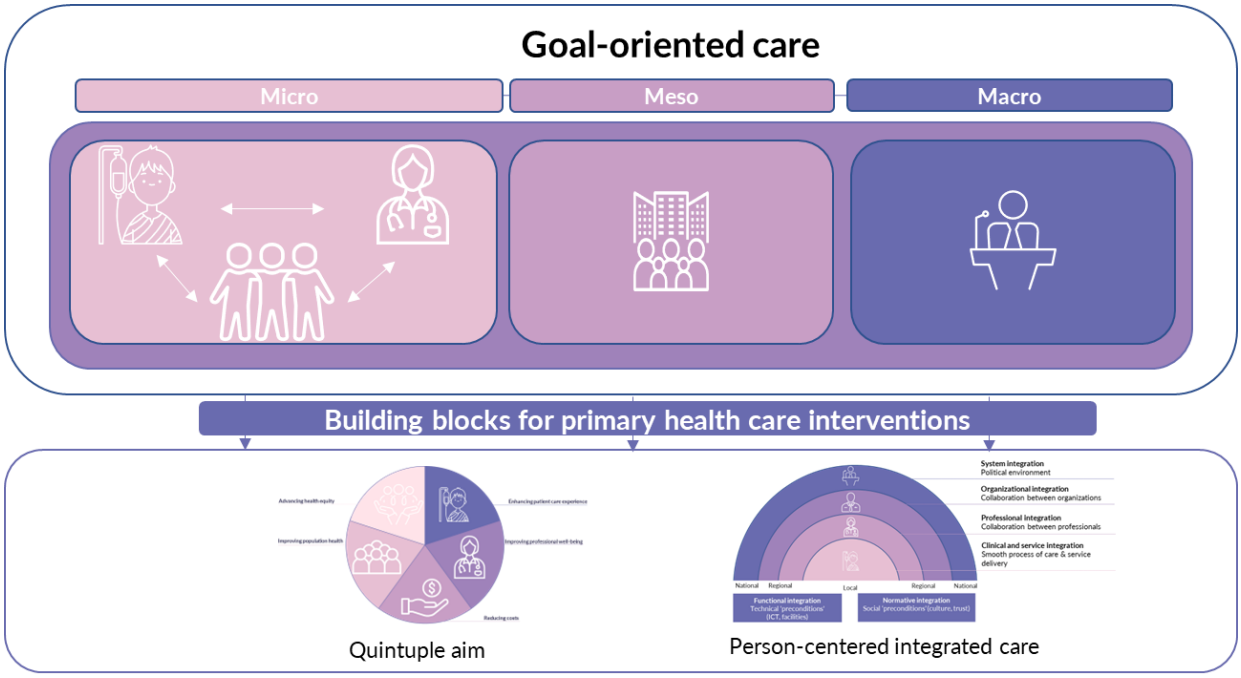

Figure 1 Overview of the discussion

Micro level

Based on the literature regarding intervention development, the micro level refers to the individuals targeted by the intervention [1, 2]. In the context of this dissertation, the micro level focusses on patients and primary care providers. The first three studies revealed that both groups were open to goal-oriented care but lacked guidance, tools, and resources to fully embrace it. The fourth study emphasized the need for both patients and providers to be prepared to engage in goal-oriented care. The final two studies identified differences between patients and providers in their experiences and delivery of goal-oriented care.

The main findings for patients and providers will be discussed separately, followed by a more in-depth exploration of the patient-provider relationship in goal-oriented care.

Patients

In essence, goal-oriented care is about reorienting care back to the patients by focusing on the patients' personal goals to direct the care process. In study one, patients and informal caregivers expressed that interactions with providers should be about more than only their health issues. These interactions should also facilitate their ability to maintain or promote autonomy, to find meaning in relationships, or to engage in meaningful activities. The latter, being able to perform meaningful activities was found as one of the top priorities of people with moderate complex care needs. Further on, we identified a goal-elicitation phase in the fourth study as a core attribute of goal-oriented care. In this phase, conversations about what is meaningful for patients could take place. Besides the focus on what is meaningful for patients, the fourth and fifth study noticed the importance of preparing patients for goal-oriented care.

The following sections will first discuss the role that meaningful activities can take in the life of people with moderate complex care needs. Then, we will provide information on how patients can be prepared to engage in goal-oriented care.

Meaningful activities as a driving force for goal-oriented care

The terminology of meaningful activities is widely spread but a clear definition is lacking. Commonly they are defined as "*all activities or occupations that are significant or meaningful for the person and reflect someone's current and past interests, routines, habits, and roles and are adjusted to someone's abilities."* [3].

It has been proven that participating in meaningful activities creates a sense of belonging and contributes to the fulfillment of three basic psychological needs as presented in the self-determination theory of Deci and Ryan: need for autonomy, need to belong, and need for competence [4]. Hence, greater engagement in meaningful activities can be presented as a predictor of greater well-being [5]. There is also a growing body of evidence that the performance of meaningful activities are a means for a purposeful life, and are a way to improve (health-related) quality of life (HR)QOL. In the light of a decrease in (HR)QOL for patients with multimorbidity, it might be beneficial to address what is meaningful for patients.

In other words, meaningful activities can be seen as a barometer of health [5-7]. Indeed, meaningful activities can indicate how healthy someone is feeling as White et al. described in their mixed method study on sixteen adults with one or more chronic conditions [5]; they can reveal, explain, manage, and overcome chronic conditions [5]. As such, meaningful activities can be an important source of information for providers to assess the patients' situation, improvements, or deterioration [7]. They can also tell what gives purpose in someone's life and identify what is worth striving for. Therefore, they can provide valuable input for setting and reflecting on personal goals. In a certain sense, querying meaningful activities can be a driving force and foundation for goal-oriented care [8].

Unfortunately, in our fifth study we found that providers seldom inquire about the meaningful activities of their patients. Though, providers play a significant role in supporting patients to maintain or regain their meaningful activities and should therefore be open to identify these

activities. Nevertheless, what can be regarded as meaningful activities only depends on the patient's perspective and cannot be imposed by providers. In some cases this might contradicts what can be conceptualized as the best health-related choice. For example, watching a movie with friends may be a highly valued activity that promotes social participation, but is unlikely to be considered an activity that promotes health under traditional health promotion frameworks that approach health as a static concept, despite its importance to the person's well-being [9].

Patient preparedness

As aforementioned, the fourth and fifth study pointed to patient preparedness as an antecedent of goal-oriented care.

Strategies for patient preparedness come down to equipping them with the capabilities to take an active role in their care process. Based on this reasoning, the concept of "patient engagement" which encompasses patient activation and empowerment, arises as well [10]. Patient engagement implies behavioral changes in patients to stimulate them to share their illness narrative and personal goals [11]. One of the techniques to enhance patient engagement is developing self-management skills [12]. Self-management, as defined by Barlow et al., is "*the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic conditions*" [13]. Briefly stated, it is about the ability to adapt your life to the changing circumstances that chronic conditions come with. Having self-management skills also enable patients to find ways to pursue personal goals, and in that respect, can be considered as a pillar of goal-oriented care. On the contrary, to enhance self-management, care must align with patients' personal goals. In this context, goal-oriented care can serve as an effective approach to offer guidance [14]. Therefore, exploring strategies to enhance patients' self-management skills might be interesting.

A vast number in literature already described key components for developing self-management skills in patients [15]. Generally taken, they comprise a focus on understanding (medical) information, enhancing problem-solving skills, symptom management, and the ability to participate in daily life [15]. Self-management also involves self-regulating processes to describe the processes of pursuing and attaining goals [16]. However, self-regulation processes aim to achieve health-related goals (e.g., losing weight, stop smoking) while goal-oriented care underpins care processes by the patients' personal goals (e.g., attending weekly family dinner) and focus on an ongoing process of care rather than achieving those goals [16, 17]. It might therefore not complement goal-oriented care in the best way.

Besides a focus on developing self-management skills, offering guidance to patients to come prepared to a consultation, might be an initial action that could be undertaken to engage patients in goal-oriented care. Guidance can mean that patients are given for example preparation sheets with key questions to think about their goals prior to a clinical encounter [18, 19]. For example, Purkaple et al. drafted three quality of life questions that patients could reflect upon before entering a consultation. These questions probe for things that patients are unable to do because of their condition(s), things that patients would like to be able to do they cannot do now, and

activities that make life worthwhile (e.g., flowering, spending time with loved ones, taking care of a child) [18].

Lastly, actions in terms of patient education were formulated. However, most literature only targets providers as an actor to be educated in goal-oriented care [20]. Nevertheless, patients also have a role to fulfill as they need to be stimulated to think about their own healthcare. Based on the previous paragraphs, we could suggest that patient education should include a certain part of developing self-management techniques and encourage reflection on what matters most to them.

Primary care providers

For providers, goal-oriented care is going back to the essence of caregiving. In study two, primary care stakeholders expressed that centering care around patients' personal goals to direct care was not novel for them. Our third study indicated that providers have already a good idea about what goal-oriented care is and how it can become an intrinsic part of care. The sixth study learned us that providers apply goal-oriented care in their own unique ways by either using key questions or tools. In contrast to these findings, the fifth study revealed that patients did only experience a goal-elicitation phase, but not goal-setting, or goal-evaluation, indicating that providers may struggle with shifting from a problem-solving role to goal-oriented care. In addition, the fourth study emphasized the importance of providers being prepared for goal-oriented care; likewise our findings concerning patients.

At first, we will further elaborate on the unique ways to put goal-oriented care into practice. Then, we will try to understand why it is so difficult to make this shift and fully grasp goal-oriented care. At the same time, we will discuss how providers can be prepared for goal-oriented care.

Unique ways of adopting goal-oriented care

Goal-oriented care is about making a paradigm shift from "what is the matter with the patient" to "what matters most to the patient". It requires a certain level of reflexivity and ability to change the conversation with their patients. To enable this shift, we found that providers employ different techniques. Just like the patients can prepare key questions, providers can prompt questions to get an understanding of the patients' meaningful activities, how their conditions are affecting their lives, or what matters most to them. Hence, questions such as "How do you define a good day?", "What motivates you to get out of your bed in the morning?", and "What is meaningful for you?" can guide providers through the phases of goal-elicitation and goal-setting.

Another technique is the use of instruments that provide more structured guidance to providers in supporting them in changing the conversation with their patients. Our studies did not specifically refer to instruments for goal-oriented care, but did point to more generic ones or frameworks to map for example who is important in the patients' life. In literature, instruments to stimulate patients to reflect on their personal goals and what is meaningful for them are scarce as well [21]. In the Flemish context, various primary care stakeholders (e.g., researchers, patient organizations) have invested to creating instruments that help patients and providers in setting personal goals, identifying patients' meaningful activities, or guiding patient-provider interactions [22].

Key questions and instruments can support providers in making their first steps towards goal-oriented care. As mentioned earlier, the primary focus is on changing the conversation and making a shift in focus. It can be assumed that once providers gain more familiarity with goal-oriented care, they may rely less on those questions and tools and will likely develop their own techniques.

From a conviction to action

Despite providers claim to have an understanding of goal-oriented care and already put patients' goals first in care, patients do not perceive it as such. There appears to be a gap between the belief that goal-oriented care is an integral part of care and actually implementing goal-oriented care in practice. This gap is better known as the "intention-behavior" gap [23]. Commonly, the gap is described in the context of health behavior interventions, but can also be used as an underlying rationale in the context of goal-oriented care. Behavior change, that also implies "the ability to change the conversation", is influenced by various barriers and facilitators across different domains that can interchange with each other (i.e., knowledge, environmental context, and social influences) [24]. In our studies, barriers such as time constraints, lack of organizational support, lack of knowledge on how to discuss goals were often in the way of making the shift towards goal-oriented care. The most frequently addressed barrier was the need for preparing providers to engage in goal-oriented care.

The first study pointed out that providers need to acquire practical and emotional competences to enable an open communication with their patients about their personal goals. Practical competences were defined as having theoretical knowledge and skills to provide the appropriate and technical treatment. Emotional competences referred to competences that give patients the feeling of being heard and treated as a person 'who has an illness' instead of someone 'who is the illness'. The second and fourth study also addressed that provider preparedness is an antecedent of goal-oriented care. Providers need to learn to assess non-medical information, such as patients' personal goals, during their patient interactions [20]. To enable providers to do this, they should develop soft competences [25]. Competences are defined as *"observable ability of a provider, integrating multiple components such as knowledge, skills, values, and attitudes."* [26]. Most of these competences that providers need to acquire in goal-oriented care relate to communication techniques. Providers need to embody the art of listening, learn to sit back, and create an atmosphere in which the patients feel encouraged to open up [25]. Herewith, providers have an important role in just listening to patients and bearing witness when patients are sharing their personal goals [19]. In line with these competences, providers also need to learn to being reflective about their own actions, how they interact with their patients, and how your course of actions as a provider align with the patients' personal goals [27]. In addition to these communication techniques, providers should also learn to work interprofessional, which will later be discussed.

Patients – providers

In the previous paragraphs we have already discussed the patients and providers individually, but goal-oriented care is foremost about the interplay between patients and providers. According to the first study, patients and their informal caregivers expressed that providers must possess a mix of emotional and practical competences. In the fourth study we identified a goal-elicitation phase specifically dedicated to building a profound patient-provider relationship. This phase was validated in our fifth study by patients sharing that they appreciated if providers set their medical expertise aside and allowed them to share their lived experiences. Building a strong patient-provider relationship appears to be key in a goal-oriented process of care. It is described as a first step before discussing patients' personal goals. Though, the dynamic character of goal-oriented care also emphasized that patients and providers should pay attention to work on that relationship throughout the entire care process.

Drawing from our studies, there appear to be six key principles that underline this patient-provider relationship in goal-oriented care: trust, dialogue, balance, dynamic, collaboration, and reflexivity.

Trust

Trust is a key principle in the goal-oriented process of care because it allows a psychological safe environment for the patient to share personal information and what matters most to them beyond their medical history. In literature, trust can refer to the expectations patients have from their providers and the confidence they put in them [28]. In general, when patients have trust in their provider it leads to greater satisfaction, continuity of care, and improved health [29].

Dialogue

Goal-oriented care requires an ongoing interaction between patients and providers. Through dialogue, providers can respond to the narratives shared by patients, while patients can provide further elaboration on the information communicated by providers.

Balance

In goal-oriented care, interactions involve equal input from both patients and providers, recognizing their unique expertise; patients with their lived experiences, and providers with their theoretical knowledge and own experience of caring for someone. They are both recognized as "knowers" whereas patients used to be seen as "the unknow" which might imply a power disbalance [30].

Collaboration

Collaboration involves a joint effort between providers and patients to address the conditions that patients are dealing with as a team. In goal-oriented care, collaboration is key to combine each other's expertise and establish a plan of actions to progress towards the patients' personal goals. It also relates to the equitable contribution that patients and providers have in the care process. In goal-oriented care, collaboration not only applies to patients and providers, but also within an interprofessional setting (cfr. Section 'meso level').

Dynamic

A goal-oriented process of care is dynamic in nature, as such the patient-provider relationship can also vary over time. This also means that providers need to have the ability to assess of what kind of care the patient would benefit the most of [31]. This can change from consultation to consultation.

Reflexivity

Reflexivity refers to the awareness of patients and provider to shift away from either their hope to be cured or their problem-solving role [32]. Both patients and providers need to adjust their viewpoint on how the consultation will proceed. Reflexivity will lead to patients and providers that are conscious of their own role they have in the patient-provider relationship.

The six key principles we have identified in our studies are not claimed to be exclusively attributed to goal-oriented care. By our knowledge, a comprehensive framework on patient-provider relationships is lacking, but other studies did found similar principles to ours for characterizing the patient-provider relationship [33]. Most aligned with our principles, are the components identified by Moira Stewart for patient-doctor relationships in patient-centered care: compassion and empathy, power, healing and hope, self-awareness and practical wisdom, transference and countertransference [34]. Although they are named differently they come down to gaining an understanding of the whole person by finding a common ground and exploring the patients' lived experiences [34].

Besides the discussion on the key principles of the patient-provider relationship, study two and five also highlighted the importance of, on the one hand, informing patients about treatment options, and on the other hand the wish to being informed about the treatments options and conditions. These findings might assume that shared-decision making (SDM) is part of goal-oriented care. However, it is important to note that this thought requires some degree of nuance. The SDM model describes three steps of introducing choice, describing options often by integrating the use of patient decision support, and helping patients explore preferences and make decisions [35], and might show some commonalities with the goal-oriented process of care as they both have the common ground of centering care around the patient. While SDM prioritizes informed decision-making about screening, treatment, or management options based on the best available evidence to set foremost health-related goals [36], goal-oriented care places emphasis on personal goals that address all domains in a patient's life. This key difference suggests that goal-oriented care takes an additional step in incorporating the patient's perspective into their care compared to SDM.

Significant others

Based on the previous paragraphs, one can assume that goal-oriented care is an individual-oriented approach of care. The role of significant others such as partners, family, friends, and neighbors appears to be given less attention. However, in our first study, the patients shared that their informal caregivers play an important role in supporting the performance of essential and meaningful activities. The second study revealed that significant others allowed providers to get more insight into the patients' living situation. Study four identified the patients' context as an

underpinning attribute in the goal-oriented process of care. Nevertheless, the broader 'patient's context' more implies the patient's living situation in which the social context is placed at the same level as the cultural or physical context. In the fifth study we found mixed results regarding whether patients perceived that their social context was taken into account or not. Lastly, the sixth study did found that providers were attentive to the patients' social context and asked questions such as "Who is really important in your life?". From our studies it appeared that significant others can take a supporting or impeding role in the patients' life. Either in cases no social network is present or, conversely, in cases patients are surrounded by a large network, it influences how the patients' care process will be completed [37].

On the one hand, involving significant others is in most literature indicated as something beneficial for patients [38]. As being outsiders, significant others can provide valuable input and offer another perspective on the patient's living situation and the way how the patients is dealing with the conditions. As such, they can help to create a shared understanding of the patients' situation. They are also directed related to the patient and may thus play a supportive role in making a daily and meaningful life possible for the patient.

On the other hand, by involving significant others in care planning, conflicting goals might arise. They can have unspoken concerns or frustrations that might come to the surface when involving them. To avoid conflicts, patients must still be afforded the time to express their own goals, determine whether they want their significant others to be involved, and feel that they are being heard [39].

Meso level

The meso level refers to the organizational level in primary health care. Whereas the studies in this dissertation mainly talk about the individual encounter between patients and providers, the meso level is addressed by participants of our studies by means of a reference to interprofessional collaboration. The different studies point the way to interprofessional collaboration, but it is not clear whether interprofessional collaboration facilitates goal-oriented care or vice versa. In study one and five, patients mentioned that interprofessional collaboration is key to experience continuity of care. In study two, three, and six providers mentioned that a focus on patients' personal goals made them feel connected with team members, guided them in aligning different care plans, or brought all providers together that could take a supportive role in pursuing patients' personal goals. Furthermore, in study six we learned that interprofessional collaboration was organized differently depending on the organizational structure. In the following paragraphs we will make reflections on how goal-oriented care and interprofessional collaboration can be complementary.

Patients as a member of the team

In study one, patients reported that they often lack the feeling that their providers are really collaborating with each other. Patients in our first and fifth study explicitly expressed their frustration about having to repeatedly tell their story which hindered continuity of care and hampered a clear focus on their personal goals. In the second study, primary care stakeholders

reported different perspectives on whether and how to include patients in the process of interprofessional collaboration. To guarantee a focus on their personal goals, it will be pivotal to give them the feeling of being involved in outlining the care plan and of being a member of the care team [40]. This does not necessarily mean that patients have to physically sit at the table, but rather get the feeling that providers are not discussing their situation without them. For patients, being surrounded by a team will likely contribute to gaining more knowledge about their condition, enhancing psychosocial wellbeing, and promoting greater independence in managing their healthcare [41]. Developing shared care plans that specifically start from patients' personal goals, might also improve patients' experiences regarding continuity of care [42].

Goal-oriented care as common philosophy

At the level of providers, adopting a goal-oriented care approach also shows the potential for more connectedness among team members and may facilitate the development of a common philosophy within the organization. In our studies, a common philosophy is described as a main facilitator for integrated care by getting all providers on the same page to put patients' personal goals first. In study three it appeared that 61% of the providers already found that a common philosophy was present. In the same study, providers confirmed that having key people or champions in the organization are crucial to initiate such common philosophy. One of the suggestions we can derive from our studies is that it might be interesting to invest in champions to further disseminate goal-oriented care within an organization. These champions should be knowledgeable and willing to share their expertise and experiences in goal-oriented care with their colleagues. In this way, providers can learn from each other and reflect on cases they might find challenging, and enhance interprofessional collaboration. Organizing discussion groups about cases are one of the levers to enhance interprofessional collaboration, others are having mutual respect, trust, and a safe working environment among team members [43]. When these levers are established, team members are more likely to actively participate in team discussions and contribute to developing a shared care plan and adopting a goal-oriented care approach.

Goal-oriented care across primary care organizations

At the level of organizations, this can be further supported by investing time and resources into discussion groups aimed at sharing experiences with, in this context, cases in which they have applied goal-oriented care among team members [44]. The sixth study revealed the important differences across primary care organizations that varied from a team-based setting to providers working in silos. In those latter cases, more efforts will be required to engage providers in the process of interprofessional collaboration. The same will account for the efforts to adopt an explicit focus on patients' personal goals in these collaborations. An important facilitator would likely be the ability to share electronic health records that include patients' personal goals across organizations and individual providers. Such records could probably encourage a focus on goal-oriented care among individual providers [45], and is likely to be a facilitator for developing a common philosophy and promoting interprofessional collaboration. Tange et al. suggested a record that focusses on patients' personal goals and shows the flow of information directed by these goals [46]. In Flanders, the Flemish Agency for Care and Health presented 'Alivia' as a digital application to enable individuals with care and support needs along with their informal caregivers,

and providers to develop and monitor a digital care and support plan. This application is built upon five main pillars to foster goal-oriented care: patients' personal goals, goals of care, tasks of care, care team, and communication. In the following years it is aimed that Alivia will improve care continuity by enhancing transparency between providers, facilitating communication and coordination among patients, informal caregivers, and providers [47].

Macro level

The macro level oversees more than the variables that are specific to individuals or organizations by referring to socio-economic and policy factors [1, 47]. In regard to this dissertation, this encompasses discussions about how the care system should be organized to support the implementation of goal-oriented care into practice. What can be learned from study one to four is that not only patients and providers reflect on their own contribution in goal-oriented process of care, but also demand transformations in the care system to make a full implementation possible. This demand also includes discussing the role that the government can play in facilitating the implementation of goal-oriented care. In addition, different points of discussion could be generated from the studies including the results that can be booked by investing in goal-oriented care, questioning the disease-oriented paradigm in which the current system is rooted, and the associated remunerations.

The facilitating or impeding role of the government

While our studies did not specifically center the government's involvement in implementing goal-oriented care in practice, they did emphasize certain obstacles that the government can help overcome. The obstacles identified include insufficient time for goal-setting conversations, limitations within the financing system, administrative barriers, inadequate training, and the absence of an electronic health record to document patients' personal goals.

The government's role in overcoming these obstacles and supporting the implementation of goal-oriented care can either be facilitating or impeding. To effectively integrate goal-oriented care into strategic healthcare objectives, it is crucial that the government acknowledges the evolving epidemiologic context [48]. The obstacles identified in our studies often revolve around a healthcare system that primarily emphasizes acute care, while the need for a comprehensive strategy to address chronic care becomes increasingly urgent. More investments should be made to support follow-up and coordination of care in this new context [48].

According to a previous study exploring the drivers of implementation, goal-oriented care should be recognized as a label of quality care in chronic conditions and multimorbidity. Additionally, the same study highlighted that financial incentives for providers and organizations are likely the most effective driver for implementation of goal-oriented care [49]. Based on our studies, it is recommended that providers should be given dedicated time for goal-elicitation and goal-setting conversations, and financial incentives should be provided to support this approach. However, providers expressed that implementing goal-oriented care could lead to time savings on the long run, although the exact underlying mechanisms are not yet fully understood.

The government holds the responsibility to establish these drivers through initiatives and actions aimed at reevaluating strategic objectives and offering financial incentives. By incorporating goal-oriented care into policy plans as the primary strategy to enhance the quality of care in chronic conditions and multimorbidity, organizations and primary care stakeholders are likely to develop strategies to effectively implement this approach in practice. Even more important is the need to reassess the current financing system in healthcare and consider alternative strategies that prioritize patients' needs over pay-for-performance, allowing sufficient time for patients who require it [48].

In conclusion, the government can play a dual role in supporting the implementation of goal-oriented care. Firstly, by incorporating goal-oriented care into their policy plans and strategic objectives, they can facilitate the shift towards this approach to improve quality of care. Secondly, the government should offer incentives and create an environment with adequate financial resources to enable the effective implementation of goal-oriented care. Specifically in the Belgian context, the government has recently taken some action to support goal-oriented care. These initiatives are described in 'Recommendations and Implications'.

Outcomes of goal-oriented care

Studies capturing outcomes of goal-oriented care in facts and numbers are still scarce. Notwithstanding, some preliminary conclusions may be drawn from studies examining the effects of patient-centered care. An often cited study is the one of Bertakis and Azari with the promising title 'Patient-centered care is associated with decreased health care utilization' [50]. In their one year study, they investigated the association between patient-centered care and health care utilization in new patients requesting outpatient appointments at a universal medical center. They developed an adapted version of the Davis Observation Code by adding patient-centered care items to measure a patient-centered interaction style. Health care utilization was assessed by reviewing the patients' medical records, and medical charges by the centralized institutional billing unit. Controlled for sex, age, education, income, self-reported health status, and health risk behaviors, Bertakis and Azari found that patient-centered care was related to a significantly decreased annual number of visits for specialty care, less frequent hospitalizations, and fewer laboratory and diagnostic tests. Regarding the costs, they found that medical charges and charges for specialty care clinic visits were significantly reduced [50].

These positive results are somewhat countered by Blom et al. who performed a clustered randomized controlled trials, the ISCOPE study, to assess the effectiveness and cost-effectiveness of a goal-oriented, integrated care model in primary care [51]. In the intervention group, family physicians made an integrated care plan for patients with three or more problems by means of the functional geriatric approach. During a one-year follow-up they investigated differences in quality of life, activities of daily living, satisfaction with health care, and cost-effectiveness. Contrary to Bertakis and Azari, they did not find any effects for quality of life, patients' functioning, and healthcare utilization, and costs. However, family physicians did experience a better overview of the care provided to patients [51].

Lastly, a recent systematic review and meta-analysis, presented an overview of randomized trials assessing the outcomes of goal-oriented care compared to usual care. Barbato et al. extracted data on quality of life, hospital admission, patients' satisfaction, patient and provider burden. In line with the results of Blom et al. they also did not find any effect on quality of life and hospital admission. A rather small effect was noted for patients' satisfaction and provider burden [52].

Based on the three studies we just described, no firm conclusions could be drawn on the effects of goal-oriented care. What we have learned from our own studies is that providers experienced that providing goal-oriented care contributed to a better relationship with their patients. We hypothesize that a setting wherein patients feel more relaxed to share their concerns and have more trust in their providers by experiencing a profound relationship, might result in less need to consult other providers or specialized care. By assuming this, goal-oriented might indeed reduce healthcare utilization and costs. To prove, more research should be done.

Moving away from disease-oriented guidelines

Many of the discussions on how to best manage multimorbidity, stems from the disease-oriented guidelines that fail to cover the patients' needs. We have widely addressed the advantages and disadvantages of these guidelines in the introduction, but elaborate in this part further on the limitations they have in the context of (multiple) moderate complex care needs. Particularly because the participants in the second and third study raised more concerns about this system.

While providers have the intrinsic feeling and urge to reorient care to what matters most to patients, they are forced to abide to the disease-oriented guidelines. Disease-oriented guidelines imply that providers should follow strict protocols to achieve certain outcomes e.g., lowering HbA1c level in diabetes [53]. However, what we have already mentioned and what providers in our studies confirm, offering care to people with multiple problems cannot be directed by guidelines [54]. More recommended is to acknowledge that care processes are not straightforward, but that the term 'process' in 'care process' should be more stressed [55]. This means that certain outcomes will not necessarily be achieved.

Taking this in mind when reflecting on goal-oriented care, our concept analysis stressed the dynamic and iterative character of a goal-oriented process of care, meaning that there is no end-point to work to. Our sixth study emphasized the continuous reflexive process that goal-oriented care is; being reflexive as a patient about what matters most to you, being reflexive as a provider about the actions you undertake in the care process to accommodate patients' goals, being reflexive about the system you work in as a primary care stakeholder, and being reflexive about care innovations and interventions that can improve quality of care. 'Being reflexive' is a crucial component of a qualitative care process, but cannot be captured in guidelines or data. There is thus a need for a more qualitative way of approaching care processes rather than the quantitative way of guidelines in improving quality of care. We suggest that goal-oriented care can provide such approach.

Evaluating quality of care

A more qualitative approach also comes with discussions about how quality of care should ideally be evaluated. The quantitative approach and standardization with set structures and outcomes leaves little room for individualizing the evaluation method. However, there have been attempts to capture the patients' preferences and values in the form of patient-reported experiences and outcomes, better known as the PREMS and PROMS [55]. Particularly in the context of multimorbidity, more emphasis will be placed on how patients value their care. Domains such as quality of life will increase in importance.

When talking about value in care, the concept of value-based healthcare (VBHC) comes to the fore. The impetus for VBHC was given by Porter and Teisberg in their book "Redefining health care". They referred to values as outcomes that matter to patients divided by the cost to achieve these outcomes [56].

Condition-specific results that matters most to patients (e.g., quality of life, functional recovery)
Total spending for the full cycle of care

Despite that VBHC and goal-oriented care have the common ground of improving care that matter most to patients, they are essentially different. Whereas the focus of VBHC is placed on achieving standardized outcomes for which PROMS form the cornerstones, goal-oriented care is focused on a process of care for the individual [56, 57]. However, both concepts are gaining interest and reflections should be made on how VBHC and goal-oriented care can complement each other. A similar exercise has already been made by Sprink who published a report on "analyzing the approaches to bringing together VBHC, person-centered health care and population equity" [58]. Translating their recommendations to goal-oriented care, we can conclude that goal-oriented care could be attributed to VBHC. Indeed, we suggest that goal-oriented care can offer guidance to map what matters most to patients, which is important to get the nominator to measure value in VBHC. However, it would not be possible to translate patients' personal goals into measurable standardized outcomes that is required in VBHC. By doing this, the core of goal-oriented care would be lost. The same applies for PREMS and PROMS. As being said, PROMS are prominent in VBHC, but having a set of indicators to capture patients' outcomes also come with pitfalls [59]. One of the main concerns we can assume will be that a new set of indicators might, on the long run, also be approached in a more standardized way, and thus return to the initial problems we faced with the disease-oriented paradigm.

Building blocks of goal-oriented care interventions

The first part of this general discussion was attributed to comparing the main research findings with the literature at three levels: micro, meso, and macro. Through this analysis we identified the main building blocks of goal-oriented care for primary health care interventions which we will now describe.

Building blocks

Although we followed the steps of the development phase of the MRC-Framework, we did not end up by proposing a strict intervention of goal-oriented care. Throughout the studies, we learned that there is no golden rule to apply goal-oriented care. Especially from the studies conducted by primary care providers, we learned that each provider applies goal-oriented care differently, depending on the context wherein they work. As such, it is better to present a family of interventions that comprises a set of building blocks to inform interventions.

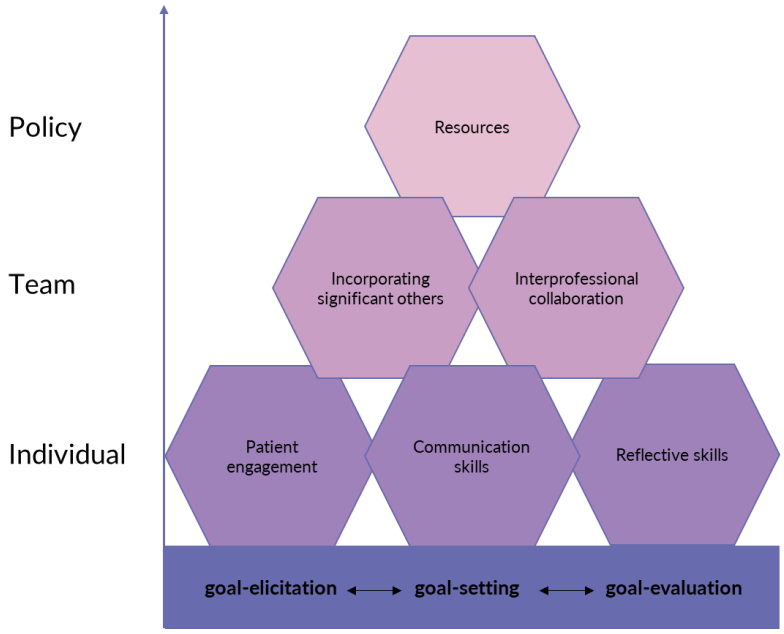

Figure 2 Building blocks of goal-oriented care

Goal-oriented process of care	Goal-oriented care is characterized by its multifaceted and iterative process. It goes beyond a single patient-provider conversation and represents an approach that should underpin the entire process of care. Three phases within this process are attributed to goal-oriented care and should guide interventions aimed at successful implementation.
Goal-elicitation	aims to foster a shared understanding and establish a trusting relationship between patients and providers based on the six defined key principles. Within goal-elicitation, special attention is given the patients' narratives, ensuring their lived experiences are acknowledged and respected.
Goal-setting	involves the sharing, discussion, and formulation of patients' and providers' goals to be integrated into the care plan or trajectory. The patients' personal goals become the driving force behind care delivery, and goal-oriented care.
Goal-evaluation	pays attention to reassessing patients' personal goals, considering that their care or life situations can evolve over time. This practice is captured in goal-evaluation and promotes reflection and adaptability throughout the care process.
Patient engagement	is the active involvement of patients throughout their care and the recognition of patients as experts in their own lives and experiences. It emphasizes the central role patients can take in defining their own personal goals and actions they can undertake to pursue those goals.
Communication skills	should encourage providers to change their conversation with patients. Rather than focusing on patients' health issues, providers should begin by understanding what matters most to patients. This requires possessing active listening skills and encouraging patients to open up.
Reflective skills	engages providers in critical thinking regarding their interactions with patients and the care they deliver, embodying the role of a "reflexive practitioner".
Incorporating significant others	helps in developing a shared understanding of the patients' situation and fosters a collaborative approach to care planning. It emphasizes that goal-oriented care extends beyond patient-provider interactions.

Interprofessional collaboration	encourages to coordinate care by patients' personal goals to ensure an integrated approach to working towards those goals.
Resources	involves dedicated time, education, financial incentives, etc. to support providers in having meaningful conversations with their patients.

As previously mentioned, the building blocks serve as essential elements that provide a framework to guide the development and execution of goal-oriented care interventions. They are specifically intended for organizations and primary care stakeholders aiming to create such interventions. Additionally, these building blocks should be tailored and adapted to the unique context in which one is operating or collaborating.

The development and implementation of goal-oriented care are not confined to specific professions but require collaboration among stakeholders to ensure its success. Although various professions play essential roles, Mold highlights that occupational therapists are considered best placed to implement goal-oriented care and can serve as champions to drive further implementation efforts [60]. Their specialization lies in assessing patients' personal goals and developing personalized plans to improve the patients' ability to engage in occupations that are meaningful for them and participate in daily life. He suggests that every primary care team should include an occupational therapist [60]. While there are arguments to promote occupational therapists' involvement in the implementation of goal-oriented care, it is crucial to emphasize that other professions, including family physicians, nurses, socials workers, and more, can also actively engage in goal-oriented care. The main reason therefore is that goal-oriented care is foremost a way of thinking and conversing with patients, making it applicable across various professions.

Goal-oriented care and other concepts

As previously stated in the general introduction, goal-oriented care can be situated on a continuum of care approaches that move beyond the disease-oriented paradigm and prioritize "what matters most to patients". With the current knowledge derived from the studies and the identified building blocks, we can make the exercise to see how goal-oriented care relates to other concepts. Two examples will be given: personalized care planning and advanced care planning.

Personalized care planning

Personalized care planning involves a series of conversations between patients and providers, where they collaboratively agree upon goals and actions to effectively address the patients' health challenges [61]. Goal-oriented care and personalized care planning have in common that they both emphasize a collaborative process of care between providers and patients wherein they jointly agree on goals and actions to manage them. Coulter et al. describe seven steps in personalized care planning: preparation, goal-setting, action planning, documenting, coordinating, supporting, and reviewing [61]. Bolton et al. affirms that personalized care planning is a process that centers care around patient priorities with follow-up conversations that respond to the patients' changing needs over time [62]. Although goal-oriented care and personalized care planning may appear similar,

there are two key differences. Firstly, goal-oriented care starts discussions from the patients' personal goals and their illness narratives, while personalized care planning begins with addressing patients' health issues. Secondly, goal-oriented care aims to improve meaningful outcomes for patients by underpinning care process by patients' personal goals while personalized care planning aims to improve health outcomes by focusing on enhancing patients' self-management skills [63].

Despite these key differences, some valuable lessons learned from personalized care planning can be applied to goal-oriented care. One crucial insight from personalized care planning interventions, which likely applies to goal-oriented care as well, is the need of a team-based approach in developing care plans or outlining trajectories. Another insight is that patients require sufficient time and support to adapt new perspectives on their health, enabling active participation in the decision-making process [64]. Additionally, a culture change or paradigm shift needs to happen to either focus on goal-oriented care or personalized care planning [65].

Advanced care planning

Advanced care planning is a complex process that allows individuals to establish and communicate their preferences for future medical treatment and care, including end-of life. It involves open discussions with family and providers regarding these goals and preferences, documenting, and reviewing these preferences when deemed appropriate [66]. These discussions can result in advanced directives which serve to articulate care preferences for situations wherein the patient may be less capable of making decisions concerning their own health and life circumstances [67].

Goal-oriented care and advanced care planning are closely related to each other as they both share the common ground of integrating patients' personal goals and values to guide care [68, 69]. Furthermore, both approaches place a strong emphasis on a communication process that involves not only the persons' significant others, but also providers [69]. However, the main difference between both concepts lies in their application. Goal-oriented care is primarily employed in providing immediate care in people with chronic conditions or multimorbidity, whereas advanced care planning is predominantly used for future care decisions and end-of life [68].

Similar to goal-oriented care, advanced care planning can be facilitated through various instruments or guidance methods. However, successful interventions in advanced care planning point to the development of effective communication skills and provider confidence to engage in these discussions [68]. The importance of addressing communication skills is emphasized in goal-oriented care interventions, as it is one of the building blocks and likely plays a pivotal role to succeed in goal-oriented care.

In summary, personalized care planning and advanced care planning are two illustrative examples that demonstrate both similarities and differences from goal-oriented care. All three concepts share a patient-centered approach and recognize the vital role of communication. Nevertheless, variations emerge in their specific focus and application. Hence, it becomes important to assess the context and purpose of the patient interaction to determine the most suitable approach.

Contribution of goal-oriented care to primary health care

The first pages of this dissertation were devoted to setting the stage of primary health care, its core values, and its importance in the context of people with moderate complex care needs. We then continued by stating that alternative strategies of caregiving in multimorbidity should be considered as a counter for the disease-oriented paradigm. This led us to the concept of goal-oriented care. Now, nearly at the end of this general discussion, still one question remains: how does goal-oriented contribute to strengthening primary health care?

To answer this question, the third part of this general discussion will address two different topics: the quintuple aim and person-centered integrated care.

Quintuple aim

The quintuple is a framework for improving healthcare that expands upon the well-known triple aim. In 2008, the Institute for Healthcare Improvement introduced the triple aim by stating that three aims should be pursuit to optimize healthcare: (1) improving patients' experiences, (2) improving population health, and (3) reducing costs. The triple aims were used as a compass to guide healthcare improvements for many years. In 2014, Bodenheimer and Sinksy observed that more and more providers were struggling with exhausting and burn-out [70]. They recognized that provider well-being is crucial to achieving better patient outcomes and lowering healthcare costs. For this reason, they added a fourth aim 'improving provider well-being' and, as such, presented the quadruple aim. More recently, in 2022, Nundy, Cooper and Mate, added the fifth aim of 'advancing health equity' [71]. Some might say that health equity was already addressed in the other aims, however it was not guaranteed so far.

To date, the quintuple aim has emerged as a guiding framework for stakeholders to enhancing healthcare. While we have previously discussed certain aspects that could be linked to the quintuple aim, we have not made an explicit connection. Hence, we will revisit our main findings to discuss whether goal-oriented care can effectively pursue the five aims.

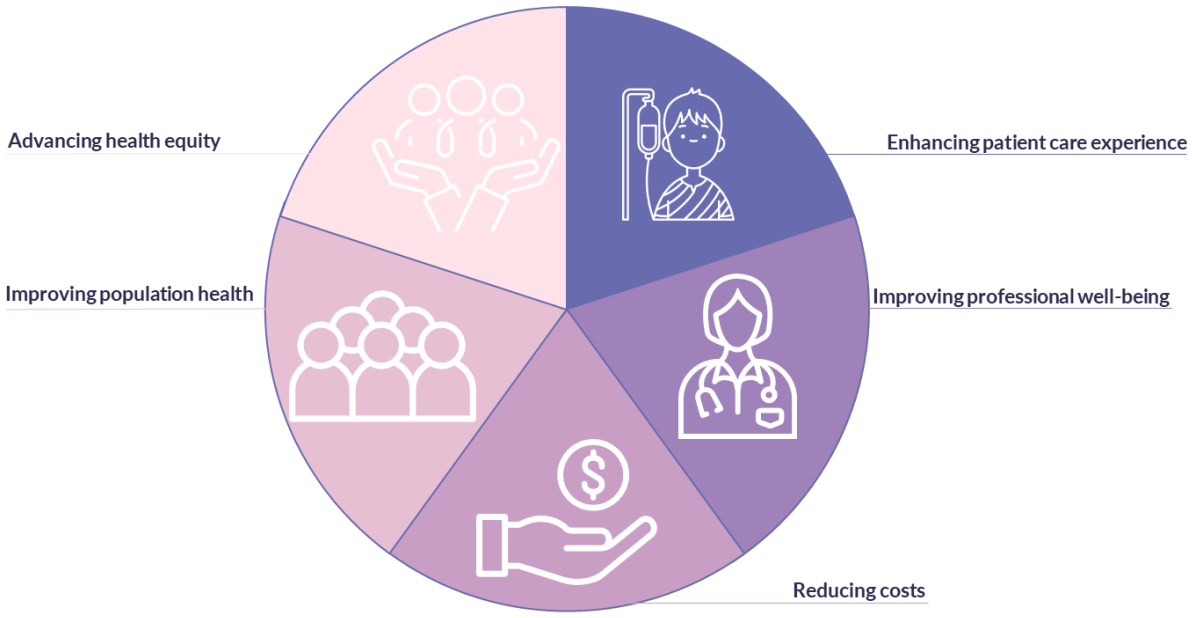

Figure 3 Quintuple aim

Enhancing patient care experience

Study four and five learned us that goal-oriented care can **enhance patient care experience.** In study four we identified the consequences of goal-oriented care through the literature and found that by taking into account the patients' values, preferences, knowledge, and opinions, patient satisfaction could increase and patients' quality of life could improve. As written in study five, patients shared that if they were more involved and engaged in their care, which can be supported by goal-oriented care, they would have a better understanding of their care and experience less frustration. Vice versa, when patients learned more about themselves and reflect on their personal goals, they were feeling more engaged in decision-making. It thus seemed that, based on the findings of study four and five, goal-oriented care could succeed in achieving a first, enhancing patient care experience, of five aims.

Reducing costs

Regarding the second aim, **reducing costs**, no firm conclusions could be drawn from our studies. Study two, four, five, and six did point out that goal-oriented care might result in less care fragmentation. Mainly because it allows providers to integrate different care plans into one shared plan. For patients, this also contributed to care continuity. In addition, the primary care stakeholders in study two mentioned that applying goal-oriented care could save time on the long term as patients would show less resistance, however the underlying mechanism are not yet clear. In our fourth study, we also described that one of the consequences of goal-oriented care might be that less tests and treatments would be prescribed. Although we have no proof, we can hypothesize that by integrating care plans, improving care continuity, prescribing less tests and treatments, goal-oriented care could pursue the second aim '**reducing costs**' of the quintuple aim.

Improving population health

More questions could be asked concerning the fourth aim, **improving population health**. The main concern will be that goal-oriented care individualizes care whereas population health actually shift the focus from the individual patient to the entire population. Moreover, in our fourth study we mentioned that one of the pitfalls of goal-oriented care is that it could even worsen population health. Despite our findings do not provide conclusive evidence, there are reasons to assume that goal-oriented care could contribute to population health by improving patient outcomes, increasing patient engagement, and improving healthcare delivery. As such, goal-oriented care can potentially achieve the third aim, **improving population health.**

Improving provider well-being

In study two and four we found that providers felt that, by applying goal-oriented care, they contributed more to improving patients' quality of life. For them, this gave more meaning to the relationship they have with their patients and decision-making. Providers experienced that the patient return they got from centering care around their personal goals was greater compared to applying a disease-oriented approach. This, on turn, increased the level of job satisfaction of providers. In conclusion, goal-oriented care could indeed contribute to **improving provider well-being**, and thus a fourth aim.

Advancing health equity

Lastly, concerning the fifth aim, we hypothesize that goal-oriented care could **advance health equity**. Specifically in our sixth study we found that goal-oriented care was more often been applied in vulnerable populations. One of the main underpinning attributes in goal-oriented care, we identified in study four, is that the patients' context is continuously been taken into account. This means that providers get an understanding of the patients' background, including cultural beliefs, values, and living situation. By identifying these context factors, providers can help to overcome potential barriers and tailor care to the individual and the unique needs. This might **advance health equity** and thus succeed in the fifth aim of the quintuple aim.

To conclude, goal-oriented care seems to succeed in achieving the five aims of the quintuple aim at a first glance. Nevertheless, it is essential to maintain a critical perspective, as our findings are primarily based on assumptions, and the conclusive evidence needed to prove these assumptions is lacking.

Person-centered integrated care

The WHO recommends to follow a person-centered integrated care approach for strengthening primary health care. With their 'Framework on integrated people-centered health services' they call for a shift in how health services are funded, managed, and delivered [72]. Two main fundaments underline this shift; integrated health services and people-centered care which appears meaningful for patients with multiple care needs [73]. Integrated services are regarded key for strong primary health care. As such, having strategies to work towards an integrated health service is crucial for strengthening primary health care [74]. We believe that goal-oriented care can provide such strategy. An often used framework to describe integrated care is the Rainbow Model of Valentijn. This framework consists of six integration dimensions: clinical, professional, organizational, system, functional, and normative integration [74]. Previous work has already hypothesized the relation between integrated care and goal-oriented care [75]. Based on our findings and the discussions we held at the micro, meso, and macro level we can add to this exercise.

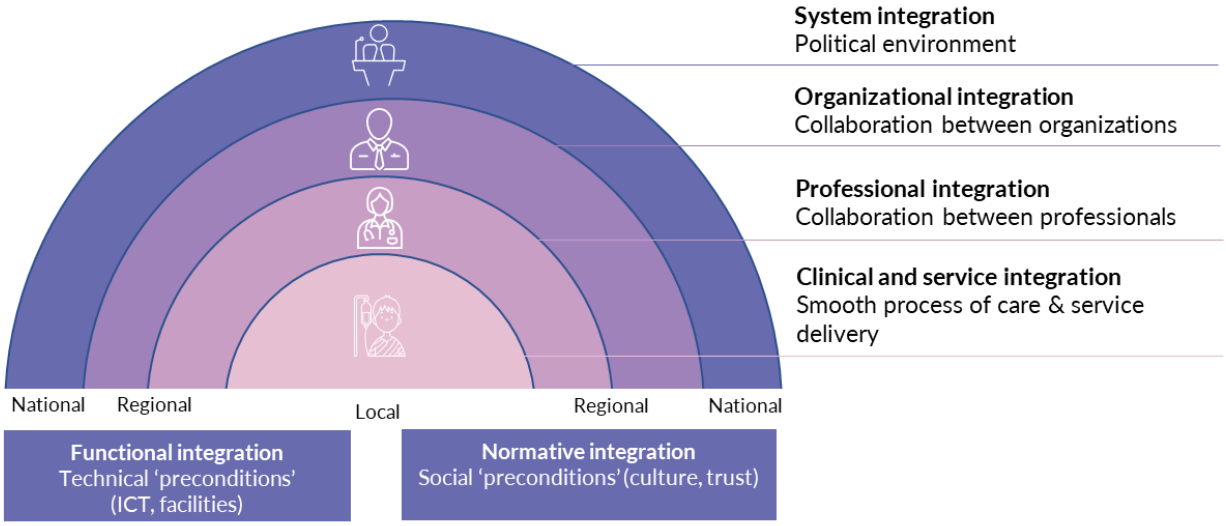

Figure 4 Rainbow model of Valentijn

Clinical integration

"The coordination of person-focused care in a single process across time, place, and discipline."

In goal-oriented care, the process of care is underpinned by the patients' personal goals that are continuously monitored. Furthermore, both patients and providers must be prepared to actively participate in the goal-oriented process of care.

Professional integration

"*Interprofessional partnerships based on shared competencies, roles, responsibilities, and accountability to deliver a comprehensive continuum of care to a defined population."*

Interprofessional collaboration has been identified as a component of goal-oriented care. Patients' personal goals can provide guidance to a care team to integrated their individual care plans and as such develop a shared plan. In addition, goal-oriented care allows care teams to develop common philosophy to work towards the patients' personal goals.

Organizational integration

"Inter-organizational relationships including common governance mechanisms, to deliver comprehensive services to a defined population."

Organizations should encourage providers to develop a common philosophy on goal-oriented care. Providers should also be encouraged to transfer goal-oriented care across organizations, by for example, entering patients' personal goals into an electronic health record.

System integration

"A horizontal and vertical integrated system, based on a coherent set of rules and policies between care providers and external stakeholders for the benefit of people and populations."

Goal-oriented care can be used as an alternative way to guide caregiving and make the shift away from disease-oriented guidelines. Rules and policies should be described in such way that they support providers in applying a more qualitative way of caregiving and encourage reflexive practice. In addition, measuring quality of care should be adapted so it can acknowledge the patients experiences throughout the entire care process.

Functional integration

"Key support functions and activities structured around the primary process of service delivery to coordinate and support accountability and decision-making between organizations and professionals in orde to add overall value to the system."

Patients and providers could learn to use instruments as guidance and structure to engage in a goal-oriented process of care. Shared care plans based on the patients' personal goals should also made available across organizations and providers via the electronical medical record.

Normative integration

"The development and maintenance of a common frame of reference between organizations, professionals, groups, and individuals."

Goal-oriented care is in essence developing a common philosophy about what matters most to patients in both one-on-one patient-provider interactions, but also within and across organizations.

In conclusion, goal-oriented care could indeed be linked to the dimensions of integrated care and as such be proposed as a potential strategy to facilitate person-centered integrated care. So, goal-oriented care should be taken into consideration when outlining the future of primary health care and when thinking about how primary health care can be strengthened.

To end, a critical stance towards goal-oriented care

Goal-oriented care emerges as a promising strategy for managing multimorbidity for people with multimorbidity and strengthening primary health care. Especially its alignment with the quintuple aim and its potential to inform the transition towards person-centered integrated care, goal-oriented care becomes an important subject for further research.

Nonetheless, it is essential to acknowledge that, without undermining our research, goal-oriented care can also be subject to a critical perspective. Certain aspects and points of attention in goal-oriented care warrant consideration. First, based on our studies it initially seems that goal-oriented care could be beneficial for all patients. However, more likely is that a significant number of patients will exhibit reluctance when it comes to identifying their own goals. This subset of patients may feel that being open about their personal goals could lead to the medicalization of their everyday life. Second, as we previously discussed, while goal-oriented care has the potential to improve health equity, it may also inadvertently perpetuate inequities. This could be due to the fact that individuals in vulnerable situations, such as those with low health literacy, may set less ambitious goals and therefore not feel compelled to make necessary lifestyle changes to maintain their health. Third, organizing care around patient's personal goals could give the impression that goal-oriented care places more responsibility on patients, potentially leading to a lackadaisical attitude among providers. Fourth, providers may experience that they are not improving the health status of their patients in the strictest sense of the word, and as such create a feeling that they are not doing good for their patients. Fifth, implementing goal-oriented care may reduce the likelihood of achieving aggregated health outcomes, potentially leading to the perception that the quality of care has decreased.

Notwithstanding these points of discussion, it can undoubtedly be concluded that goal-oriented care holds the potential to drive meaningful outcomes for patients. The research findings provide a stepping stone for further exploring the possibilities and potential of goal-oriented care.

STRENGTHS AND LIMITATIONS

In addition to the strengths and limitations that we have already addressed for each individual study, this dissertation also comes with some general strengths and limitations. In this part we will focus on the application of the Medical Research Council Framework in developing complex interventions, the use of qualitative research methodologies, and the role of patients in research on goal-oriented care.

Medical Research Council Framework

The MRC Framework gave us a starting point to initiate the development of a goal-oriented care intervention. However, during the research process we came to the realization that the framework was insufficient in fully addressing our research aim. In particular, the 'development phase' has been subject for discussions among researchers because limited guidance is provided [76, 77]

One of the main concerns with the MRC development phase is the lack of attention for the context in which the intervention has to be implemented. Not only do other researchers commented on this shortcoming in the MRC-framework, but it has also been remarked in other implementation frameworks. Multiple frameworks already pointed to the importance of finding 'a fit' with the context in which a new intervention has to be implemented [1, 78]. Often, newly developed interventions remain at an 'evidence-based surface' and lack practice-based roots. Though, when looking at more recent revisions of the MRC Framework, more attention is being given to assessing the context for developing interventions [77, 78]. Having an understanding about the context in which the intervention is supposed to be implemented, is a crucial indicator for success. The context gives insight into the real world and abstracts from the, sometimes, linear approaches and set structures in which research is conducted. A more profound search led to a study of Bleijenberg et al. who recognized the gap between an intervention and implementation context [76]. To overcome this gap, they combined the stages of the MRC development phase with existing development models to enhance the intervention design [76]. The result was an enriched development phase, extended by 'problem identification and definition', 'determine the needs', and 'examine practice' in the light of reducing research waste. A study of Skivington et al., that is considered as the most recent revision of the MRC Framework, formulates six core elements that have to be taken into account throughout all phases of the MRC Framework [78]. They refer to the consideration of the context, development, refinement, and testing of the program theory, engagement of stakeholders, identification of key uncertainties, refinement of the intervention, and economic considerations [78].

Thinking about how we have outlined our studies following the original MRC development phase, and comparing this with the more recent additions, more commonalities could be found with the latter ones. Whereas, the original MRC development phase prescribes to first asses the evidence base by describing the expected effects of the intervention, we have chosen to explore the potential and openness of primary care stakeholders, including people with complex care needs in the first three studies. This is in line with what Bleijenberg called 'problem identification and

definition' and what Skivington describes as stakeholder engagement [76, 78]. This allowed us to identify the current problems, the stakeholders' needs, and the desired situation for goal-oriented care. Furthermore, Bleijenberg also recommends to perform this first step by applying a phenomenological approach as this allows to explore a phenomenon, in this dissertation "experiences with primary care, "experiences with putting patients' goals first, and "experiences with goal-oriented care", more in depth. The second stage of the MRC development phase 'identifying and developing the theory' should give an understanding about the process of change. Therefore, a theoretical understanding should be drawn on existing evidence and theory [79]. We have formulated this theoretical understanding by using the methodology of a concept analysis in study four that integrated the existing knowledge in literature of goal-oriented care. This fourth study could also be considered as a first step towards program theory development, as described by Skivington et al.. Lastly, the stage of 'modelling processes and outcomes' is recommended before piloting a full scale intervention [79]. The MRC development phase points to a trial to identify weaknesses and conduct refinements to the intervention. In the last two studies we have adapted the theoretical understanding of goal-oriented care with a practice-based understanding grounded in experiences of patients and primary care providers. This allowed us to further refine the programme theory of goal-oriented care, engage stakeholders, and examine the theory we have identified in literature through a practice-based lens. Overall, throughout all our studies, attention was being paid to the context in which goal-oriented care should be implemented.

This brief comparison with our own interpretation of the different stages, the MRC development phase and its revised versions led to our conclusion that no standardized structure can be followed. Looking back and based on our current understanding, we would suggest to use the steps as a non-limitative structure that can be adapted in regard to the research aim. For example, the adaption of an existing intervention would require other focal points then an intervention that has to be developed from scratch.

Qualitative research methodologies

Most studies were grounded in qualitative research methodologies. Specifically for research on goal-oriented care, qualitative research methodologies are the best fit. The main reason is that they allowed us to get an understanding of the experiences of primary care stakeholders, including patients with goal-oriented care. Another reason is that, to date, no surveys or assessments are available, and thus, for example how goal-oriented care is experienced by patients cannot be answered by a quantitative lens. Furthermore, the answers we sought by each study required a thick description and could not be reduced to facts and numbers and the use of quantitative research methodologies [80]. However, qualitative research methodologies do not come without limitations. More than in quantitative research, qualitative researchers have to persuade other researchers and their readers that their findings are trustworthy. To guarantee trustworthiness, four criteria are considered applicable in every research paradigm: credibility, transferability, dependability, and confirmability [81]. However, it is important to address those criteria from the two paradigms we have used, phenomenological-hermeneutics and descriptive phenomenology,

as the techniques to improve trustworthiness are applied differently. If needed, differences are described.

Credibility refers to the meaningfulness of the findings and whether these are well presented [82]. It indicates the confidence to the truth of the data and its interpretation [83]. In phenomenological-hermeneutics this means having reflexivity as researcher about your preconceptions and preunderstanding about the phenomenon under investigation and that the researcher can possibly interpret too early in the research process. Researcher triangulation is a technique to counter this. Research triangulation was guaranteed in study one and two as those studies were performed by an interprofessional team of researchers. In descriptive phenomenology, Sundler et al. stresses that, to strive for credibility, the analysis need to be transparent which means that the researcher should present it thoroughly as possible [84]. This can be done by presenting the themes with illustrative quotes to ensure that the content and meaning are consistent. In study five and six, examples of data extraction are given and themes are exemplified by illustrative quotations to improve credibility.

Transferability refers to the extent that research findings apply to other settings, populations, or situations [85]. One of the main limitations of qualitative research is the lack of the transferability of the research findings. However, the main aim in phenomenological-hermeneutics is to provide a thick description of the phenomenon 'primary care' (study 1) or 'putting patients' personal goals first' (study 2) and not to transfer the findings to other settings. Thick description means that data is described in detail up to a contextual level and readers can lively visualize the participants' experiences or situation. Sundler et al. describes in her methodology paper on descriptive phenomenology that transferability is a *'a measure of whether the findings are sound and if the study adds to new knowledge to what is already known.'* [84]. In study five and six, we included samples that represent stakeholders of all primary care settings and even different countries. This allows researchers and readers to judge for their own setting, population, or context if these findings are transferable.

Dependability ensures that the research process is logical, traceable, and clearly documented so the studies are repeatable by others [86]. Techniques to improve dependability are having peers to participate in the analyzing process and providing a detailed description of research methods. As written in the previous paragraphs, each of the studies is performed by an interprofessional team and the data analysis has been conducted by at least two researchers. We have also tried to be as transparent as possible by providing a profound description of how the data collection and analyzing process has been completed.

Confirmability refers to the objectivity of research during data collection and data analysis and is established when credibility, transferability, and dependability are achieved [87]. In phenomenological-hermeneutics, confirmability refers to whether the findings reveal the essence of meaning from the perspectives of the participants and not that of the researcher [88]. Data triangulation is presented as one of the main techniques to establishing confirmability. In study one and two, data triangulation has been assured by striving for a maximal variation sampling shown by the criteria for moderate complex care needs applied, or the inclusion of a broad range

of primary care stakeholders and multi perspective lens used. Sundler et al. does not specifically mention techniques to establish confirmability in descriptive phenomenology, but a general recognized technique is an audit trail. An audit trail is the detailed description of the data collection process, data analyzing, and data interpretation [89]. For all of our studies we have made the raw data and transcripts available upon request and provided a detailed description of the research process.

Summarizing this section about the use of a qualitative lens, we can conclude that we overall succeeded in establishing trustworthiness in this dissertation which is one of our main strengths.

Final reflections on dyadic interviews

The strengths and limitations of each study can be found in the relevant publication. However, it is important to note that conducting dyadic interviews, as has been done in study one, deserves some extra attention as limited information is available on this particular interviewing approach.

In study one, we interviewed patient-informal caregiver dyads (abbreviated as 'PCDs) and the data were analyzed together as this allowed us to gain rich data regarding their experiences with primary care. We already mentioned that "*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* [90]*."*Especially in dyadic interviews, it is important that sensitive material is handled with care and confidentiality is guaranteed. This is not always that easy in this context as some of the dyad member can have some prejudgments [91]. We countered this limitation by stating that patients had the freedom of choosing their informal caregiver by which they felt most comfortable with. However, some more methodological and ethical considerations could be mentioned. Dyads' analysis allowed us to better understand and find overlap in the experiences of PCDs regarding primary care, or maybe find contrasts. A strength of this approach is that it enabled us to go beyond the individual perspectives of patients or informal caregivers, and stress that they are interchained [92]. However, a major problem can be that one participant dominates the other in, for example, cases were experiences or reflections on the topic differ, or when one participant has more confidence to speak up [93]. When we, as interviewers, noticed that one participant took control, we tried to encourage the other to open-up by specifically asking if they have something to add to the answer or share the same experience.

Some lessons learned could be derived from our own experiences in performing dyadic interviews. The first lessons learned is the importance of selecting compatible participants for the dyad, as this fosters a sense of ease and comfort, encouraging openness during the interview. Secondly, it is crucial to handle confidentially carefully as participants may hesitate to share their true experiences and feelings. Thirdly, the interview guide should be thoughtfully developed to accommodate the perspectives of both participants. Lastly, active encouragement should be given to both participants to ensure equal participation and contribution throughout the interview process.

Role of patients in research on goal-oriented care

In this dissertation we have focused on goal-oriented care as a strategy to organize care for people with moderate complex care needs, framed as 'the patient'. Those patients are one of the main actors to determine if the implementation of goal-oriented care would be a success. It is therefore important to capture their perspectives as this will lead to research findings that are more in line with patients' needs and have higher credibility [94]. Despite we succeeded to include patients in two out of six studies, some limitations are to be discussed.

It is becoming more common to engage patients throughout the entire research process. Patient engagement in research ranges from passive (e.g., patient is a data sources) to active (e.g., patient as a researcher). In this dissertation patients are only approached as data sources and were not actively involved in, for example, formulating research questions or outlining interview guides. In regard to the research aim to develop a goal-oriented care intervention, it might have been better to involve patients as active researchers from the start. A method that could have underpinned our studies, is Participatory Action Research (PAR) [95]. A PAR approach is characterized by three main elements: it focuses on research enabling action wherein action is created by a reflective cycle, it blurs the line between researchers and the participants, and those being researched should be actively involved in the process [95]. It would have allowed us to think together with patients about how goal-oriented care should take shape. PAR can also go hand in hand with phenomenology as it enables participants to engage with their own world, and thus not isolate the 'research objects' from their lived experiences [96]. This combination would have led to more profound insights into the lived experiences of patients, and by extension all primary care stakeholders. In terms of strengths and limitations regarding this dissertation we can conclude that we have paid attention to incorporate the patients' perspectives but that the extent could be more comprehensive.

The above paragraphs handled specifically about the patients, but the reflections are also applicable to the other stakeholders we have included in our studies. Having representatives of all sections that are important in the eventual implementation of goal-oriented care would have contributed to the credibility and applicability of our research findings.

RECOMMENDATIONS AND IMPLICATIONS

Throughout the general discussion, we have already pointed to some recommendations and implications for clinical practice, education, policy, and further research. In this final part, we will specifically pay attention to the lessons learned from our studies and what they can mean for all these domains.

Current implications

Before we formulate future directions, we will describe how the findings of our studies have already served as the foundation for ongoing initiatives at different levels in primary care.

Initiatives for implementing goal-oriented care

The King Baudouin Foundation, and more specifically Fund Daniël De Coninck launched a project call specially targeted at organizations in primary care that aim to implement goal-oriented care. The selected projects were awarded a grant of up to €25 000 each to develop strategies for implementing goal-oriented care within a one-year time frame. A launch event was arranged to bring together all the selected projects of Flanders and Wallonia, enabling them to share and learn from their understanding on goal-oriented care and implementation strategies. Additionally, a closing day was organized to reflect on the progress made during the process and formulate lessons learned for the future. Throughout the year, project leaders had the option to participate informative sessions on, for example, the fundaments of goal-oriented care and project evaluation.

More information:

https://kbs-frb.be/nl/doelgerichte-zorg-de-eerste-lijn-bevorderen-fonds-dr-daniel-de-coninck

Interprofessional training program goal-oriented care

On behalf of the Flemish Institute of Primary Care (in Dutch: VIVEL), a training package on goal-oriented care was developed in a co-creation process with innovators in goal-oriented care and the Flemish Patients Representatives Platform. This package includes a widely accessible online training for all citizens, and a specialized training for primary care providers. This specialized training allows providers to acquire the competences to put goal-oriented care into practice by means of four theoretical courses: 1) changing the patient-provider conversation, 2) patient-provider relationship, 3) the role of interprofessional collaboration, and 4) realization and evaluation of patients' personal goals. These theoretical courses alternate with groups discussions at which also, in addition to a moderator, a patient partner is represented. These discussions not only encourage providers to reflect on complex cases and share experiences with goal-oriented care, but also foster interprofessional collaboration among providers.

More information:

https://www.vivel.be/nl/interprofessionele-training-doelgerichte-zorg/

Digital care and support plan

On behalf of the Flemish Agency for Care and Health, a digital care and support plan, named ALIVIA, is developed in a co-creation process by primary care stakeholders, including informal caregivers and individuals with (moderate) complex care needs. ALIVIA will provide an added value for all individuals with (moderate) complex care needs and providers involved in their care support. It aims to smoothen task assignments, planning, coordination, and communication among these providers, and improve transparency. Most importantly, individuals will gain a better overview of their overall care and support plan. ALIVIA is informed by goal-oriented care as the tenet are the personal goals of the individuals with (moderate) complex care needs. The central question is "What does the person with the care need find important in his daily life" by focusing on five main components: life goals (e.g., autonomy), care and support goals (e.g., life independently at home), care and support tasks (e.g., home nurse who is coming every evening to wash the person), care and support team (e.g., informal and formal providers), and communication (e.g., diary or journal).

More information:

https://www.zorg-en-gezondheid.be/alivia-wordt-het-digitale-instrument-voor-geintegreerde-zorg-in-vlaanderen-en-brussel-300323

Future directions

While goal-oriented care has gained momentum in Belgium over the past few years, illustrated by the various initiatives, there is still room for improvement. Recommendations and implications for further uptake in primary care could be formulated.

Recommendations and implications for clinical practice

Five recommendations and implications for clinical practice are proposed. They are formulated in such way they are practical and actionable so providers can promptly implement goal-oriented care in their practice.

1. Change the patient-provider conversation
2. Integrate patients' personal goals and values into the care plan
3. Engage patients in their care process
4. Involve patients' significant others
5. Foster interprofessional collaboration

Box 1 Recommendations for clinical practice

Change the patient-provider conversation so it prioritizes what matters most to patients, rather than focusing solely on a lengthy list of treatment restrictions or medication regimens that patients must adhere to. Shifting from "what is the matter with the patient" to "what matters most to patients" exemplifies this change. "Changing the conversation" not only pertains to the content of the consultation, but also directs the context in which it should occur. This context should create a psychologically safe environment that fosters the development of a patient-provider relationship based on the key principles we have previously described. Some sample questions that can support providers in changing the conversation are: 'What gives you energy', 'How do you define a good day?', 'What motivates you to get out of your bed in the morning?'.

Integrate patients' personal goals and values into the care plan to ensure that care is aligned with those goals and values. To facilitate this integration, it is recommended to translate patients' personal goals into goals of care and corresponding strategies (Figure 4). By writing them down, patients and providers have a constant reminder of what they are striving for. It is also the focus on those goals and values that will characterize the shift to what matters most to patients.

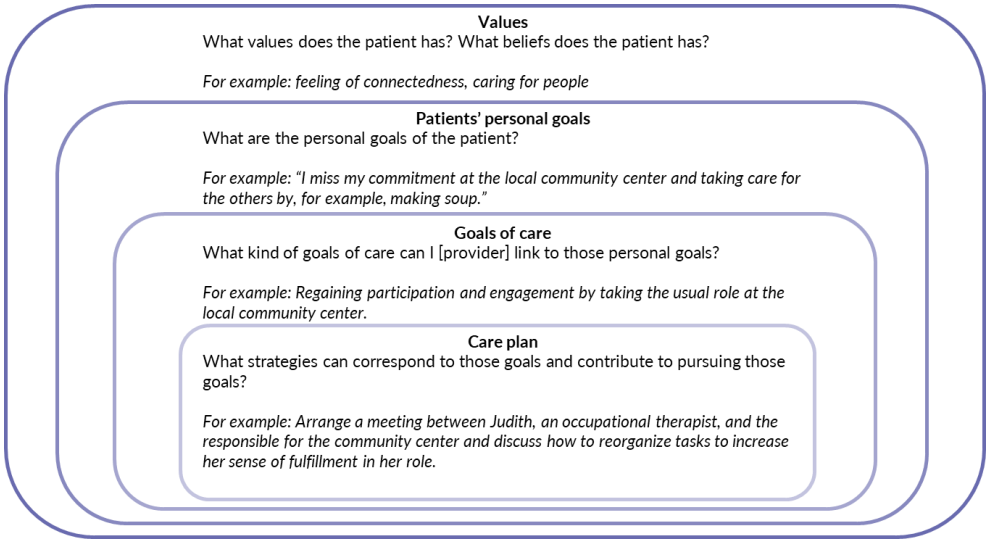

Figure 4 Integrating patients' personal goals into care plans - Judith's case

Engage patients in their care process so they can actively participate. Goal-oriented care hinges on a two-way communication between patients and providers with patients viewed as active participants rather than as passive subjects. To engage patients, we have suggested implementing self-management techniques that equip them to make informed choices about their personal goals and how to best pursue them.

Involve patients' significant others to provide an additional perspective on the patients' health status and living situation. Our studies have demonstrated that these significant others can have a supportive or hindering influence. They often possess valuable information that can inform the development of strategies to work towards the patients' personal goals, but can also have

conflicting goals with those of the patient. Furthermore, by involving patients' significant others, providers can get an idea of the level of support those significant others can offer to the patients.

Foster interprofessional collaboration to integrate different care plans into a shared plan based on patients' personal goals. The exact nature of interprofessional collaboration in goal-oriented care is still topic of debate, but based on our findings it should be regarded as one of the core components. Primary care providers should undertake efforts to participate in interprofessional collaboration.

Recommendations and implications for education

Two recommendations and implications are formulated concerning education. Investing in education is important for the long-term sustainability of goal-oriented care. Our studies have revealed that both patients and providers need to acquire competences to put goal-oriented care into practice. It is therefore recommended to incorporate our study findings into the curricula of future providers and inspire training programs for continuous learning.

1. Embed goal-oriented care in (under)graduate programs
2. Establish opportunities for continuous learning

Box 2 Recommendations for education

Embed goal-oriented in (under)graduate programs to enable students to embrace this approach of care from the beginning of their study trajectory and their career. Future providers need to acquaint the competences to change the patient-provider conversation and focus on "what matters most to patients" during their interactions. Integrating goal-oriented care early in the curricula is important so future providers view it not as a theoretical competency but as an inherent attitude of a providers' profile. It is suggested to invest in teaching methodologies that approach the reality as closely as possible and engage students to think aloud and reflect on real cases. This can be done by for example the use of simulated patients [97].

Establish opportunities for continuous learning so providers can invest in personal growth throughout their entire career. In terms of continuous learning, providers who are already practicing must also focus on developing their competences. However, a main hurdle might be that these providers have already established their own methods of interacting and engaging with patients. Therefore, in continuous learning programs, more attention should be paid to facilitating discussion groups that allow them to exchange best practices, difficult cases, and insights in goal-oriented care gained from one another. Ideally, continuous learning programs about goal-oriented care should involve an interprofessional setting that offers providers the opportunity to learn more about potential contributing roles of other disciplines in working towards the patients' personal goals.

Recommendations and implications for policy

Five recommendations and implications for policy are suggested. Policy might be considered as a gatekeeper for truly supporting the implementation of new care approaches, such as goal-oriented care. On the one hand, policy can encourage to embed goal-oriented care in clinical practice and offer resources to make this possible. On the other hand, policy can also inhibit the implementation of goal-oriented care and stay strong with known care approaches.

1. Provide sufficient resources
2. Support the implementation of goal-oriented care
3. Trust primary care providers
4. Rethink how quality of care should ideally be measured
5. Keep investing in strengthening primary health care

Box 4 Recommendations for policy

Provide sufficient resources to counter two of the main barriers providers experience to apply goal-oriented care, namely time restrictions in consultations and lack of financial remunerations. Providers should be given more flexibility to schedule consultations that take longer to have for example goal-setting discussions. At the same time, conversations about those personal goals should be recognized as a full-scale interventions for which remunerations should be provided.

Support the implementation of goal-oriented care at all domains in primary health care. By promoting a goal-oriented care approach from the policy level, primary care organizations and providers would likely be more convinced about its potential. Policy recommendations, worldwide, have already acknowledged that person-centered integrated care should be the guiding principle for further building a strong primary health care system. Therefore, further efforts should be made to operationalize such shift by goal-oriented care.

Trust primary care providers and what they consider as most important to provide quality care to their patients. This also implies assigning a certain level of responsibility to providers to ensure quality of care. Providers should be trusted in their actions they undertake in order to center care around patients. They should have the chance to determine, together with the patient, the actions that are most beneficial to the patients' situation. For example, if a home nurse is required to assist their patient morning routine, such as bathing, but the patient would prefer to have a meaningful conversation about their living situation and the organization of support, they should be supported to have such conversations.

Rethink how quality of care should ideally be measured and be critical towards the aim of achieving set outcomes. Policy makers have to be open to consider new methods to measure quality of care and adopt a more qualitative approach. More attention should be paid to recognizing that care

processes are dynamic and require a reflexive approach. In such more qualitative approach, patients' experiences on the process of care should be one of the main focal points.

Keep investing in strengthening primary health care to ensure quality of care for people with (multiple) moderate complex care needs. The first paragraphs of this dissertation were devoted to advocating for a strong primary health care system. We pleaded for a focus on goal-oriented care as a strategy to manage multimorbidity. While we do not want to assert that goal-oriented care is the sole strategy, we advocate for continued exploration of alternative approaches. Maintaining a critical mindset and fostering curiosity for the ongoing improvement of primary health care will be pivotal.

Recommendations and implications for further research

Three main recommendations and implications concerning further research are proposed. These further research plans should be in line with the aforementioned recommendations and implications for clinical practice, education, and policy.

1. Identify the needed competencies for patients and providers
2. Invest in developing an implementation strategy for goal-oriented care
3. Explore the potential of goal-oriented care across organizations

Box 5 Recommendations for further research

Identify the needed competencies for patients and providers to embody goal-oriented care. In further research on goal-oriented care, a first focus should be to identify the competencies that patients and providers must acquire to effectively integrate goal-oriented care into their daily practice. Second, the competencies identified should be translated into training programs to provide learning opportunities for both patients and providers. It seems important to think about strategies to further disseminate the interprofessional training on goal-oriented care into primary care.

Invest in developing an implementation strategy for goal-oriented care to guarantee sustainability on the long term. In this dissertation we have already identified some barriers and facilitators for implementing goal-oriented care. However, no sole study was specially performed to identify those barriers and facilitators. Because mapping those elements is crucial to overcome potential problems or identify missed gaps, and miss the opportunity to successfully implement goal-oriented care, further research should specifically focus on developing an implementation strategy. Preferably, these strategies are developed in a co-creation process by primary care stakeholders.

Explore the potential of goal-oriented care across organizations and does not limit to primary health care. This dissertation focused on primary health care, but the concept of goal-oriented care should not be restricted to this setting alone. Its application should extend to other settings,

including hospitals. Furthermore, there is a need to explore the potential of goal-oriented care in guiding care transitions.

CONCLUSION

A strong primary care system is key for managing the increasing number of people with moderate complex care needs (i.e., 'patients'). The current system, however, is mainly rooted in disease-oriented guidelines that are less appropriate in this context. A shift from a disease-oriented approach of care to goal-oriented care is proposed to manage care for those patients. Despite the rationale for goal-oriented care has already been described, there is still little known about what exactly goal-oriented care is and how it should be translated into primary health care. To overcome this gap, this dissertation aimed to identify building blocks of goal-oriented care interventions accordingly to the development phase of the Medical Research Council Framework. To identify those building blocks, viewpoints of patients, informal caregivers, primary care providers, scholars, policy makers, and the literature were captured in six qualitative studies. The first three studies intended to build an evidence base by capturing the needs of primary care stakeholders. The fourth study supported the identification and development of the theory by presenting a comprehensive understanding of goal-oriented care by means of a concept analysis. The final two studies expanded on this understanding through learnings from patients and primary care providers and their experiences with goal-oriented care. Based on the study findings, we found that goal-oriented care could not be limited to one strict intervention, but that it is better to present a family of interventions. To inform the development of interventions, we identified nine building blocks: goal-oriented process of care including goal-elicitation, goal-setting, and goal-evaluation, patient engagement, communication skills, reflective skills, incorporating significant others, interprofessional collaboration, and resources. These building blocks could inform the development of goal-oriented care interventions.

To conclude, this dissertation contributed to the body of knowledge on strategies aiming to manage care in people with moderate complex care needs. In doing so, it endeavored to provide input to the discussion on how primary health care should be strengthened to cope with the increasing of this population.

REFERENCES

(1) Huybrechts, I.; Declercq, A.; Verté, E.; Raeymaeckers, P.; Anthierens, S. The Building Blocks of Implementation Frameworks and Models in Primary Care: A Narrative Review. *Front Public Health* **2021**, *9*, 675171. DOI: 10.3389/fpubh.2021.675171 From NLM.
(2) Moullin, J. C.; Dickson, K. S.; Stadnick, N. A.; Albers, B.; Nilsen, P.; Broder-Fingert, S.; Mukasa, B.; Aarons, G. A. Ten recommendations for using implementation frameworks in research and practice. *Implement Sci Commun* **2020**, *1*, 42. DOI: 10.1186/s43058-020-00023-7 From NLM.
(3) Tierney, L.; Beattie, E. Enjoyable, engaging and individualised: A concept analysis of meaningful activity for older adults with dementia. *International journal of older people nursing* **2020**, *15* (2), e12306.
(4) Eakman, A. M. Relationships between meaningful activity, basic psychological needs, and meaning in life: test of the meaningful activity and life meaning model. *OTJR (Thorofare N J)* **2013**, *33* (2), 100-109. DOI: 10.3928/15394492-20130222-02 From NLM.
(5) White, C.; Lentin, P.; Farnworth, L. An investigation into the role and meaning of occupation for people living with on-going health conditions. *Aust Occup Ther J* **2013**, *60* (1), 20-29. DOI: 10.1111/1440-1630.12023 From NLM.
(6) Akaida, S.; Tabira, T.; Nakai, Y.; Maruta, M.; Taniguchi, Y.; Tomioka, K.; Sato, N.; Wada, A.; Makizako, H. Are satisfaction and performance of meaningful activities associated with frailty in older adults? *Arch Gerontol Geriatr* **2023**, *105*, 104845. DOI: 10.1016/j.archger.2022.104845 From NLM.
(7) Eakman, A. M.; Carlson, M. E.; Clark, F. A. The Meaningful Activity Participation Assessment: a measure of engagement in personally valued activities. *Int J Aging Hum Dev* **2010**, *70* (4), 299-317. DOI: 10.2190/AG.70.4.b From NLM.
(8) White, C.; Lentin, P.; Farnworth, L. 'I know what I am doing': A grounded theory investigation into the activities and occupations of adults living with chronic conditions. *Scand J Occup Ther* **2020**, *27* (1), 56-65. DOI: 10.1080/11038128.2019.1624818 From NLM.
(9) Kersey, J.; Kringle, E.; Rodakowski, J. An Expansive View of the Relationship Between Meaningful Activities and Health: A Call to Action. *J Am Med Dir Assoc* **2022**, *23* (7), 1266-1267. DOI: 10.1016/j.jamda.2022.01.074 From NLM.
(10) Higgins, T.; Larson, E.; Schnall, R. Unraveling the meaning of patient engagement: A concept analysis. *Patient Educ Couns* **2017**, *100* (1), 30-36. DOI: 10.1016/j.pec.2016.09.002 From NLM.
(11) James, J. Patient engagement. *Health Affairs Health Policy Brief* **2013**, *14* (10.1377).
(12) Protheroe, J.; Rogers, A.; Kennedy, A. P.; Macdonald, W.; Lee, V. Promoting patient engagement with self-management support information: a qualitative meta-synthesis of processes influencing uptake. *Implement Sci* **2008**, *3*, 44. DOI: 10.1186/1748-5908-3-44 From NLM.
(13) 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 From NLM.
(14) Timmermans, L.; Boeykens, D.; Sirimsi, M. M.; Decat, P.; Foulon, V.; Van Hecke, A.; Vermandere, M.; Schoenmakers, B. 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), 63. DOI: 10.1186/s12875-022-01652-8 From NLM.
(15) Dineen-Griffin, S.; Garcia-Cardenas, V.; Williams, K.; Benrimoj, S. I. Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. *PLoS One* **2019**, *14* (8), e0220116. DOI: 10.1371/journal.pone.0220116 From NLM.
Van Hecke, A.; Heinen, M.; Fernández-Ortega, P.; Graue, M.; Hendriks, J. M.; Høy, B.; Köpke, S.; Lithner, M.; Van Gaal, B. G. Systematic literature review on effectiveness of self-management

support interventions in patients with chronic conditions and low socio-economic status. *J Adv Nurs* **2017**, *73* (4), 775-793. DOI: 10.1111/jan.13159 From NLM.
(16) Mann, T.; de Ridder, D.; Fujita, K. Self-regulation of health behavior: social psychological approaches to goal setting and goal striving. *Health Psychol* **2013**, *32* (5), 487-498. DOI: 10.1037/a0028533 From NLM.
(17) Maes, S.; Karoly, P. Self-regulation assessment and intervention in physical health and illness: A review. *Applied psychology* **2005**, *54* (2), 267-299.
(18) Purkaple, B. A.; Mold, J. W.; Chen, S. Encouraging Patient-Centered Care by Including Quality-of-Life Questions on Pre-Encounter Forms. *Ann Fam Med* **2016**, *14* (3), 221-226. DOI: 10.1370/afm.1905 From NLM.
(19) Salter, C.; Shiner, A.; Lenaghan, E.; Murdoch, J.; Ford, J. A.; Winterburn, S.; Steel, N. Setting goals with patients living with multimorbidity: qualitative analysis of general practice consultations. *British Journal of General Practice* **2019**, *69* (684), e479-e488.
(20) Pakkonen, M.; Stolt, M.; Charalambous, A.; Suhonen, R. Continuing education interventions about person-centered care targeted for nurses in older people long-term care: a systematic review. *BMC Nurs* **2021**, *20* (1), 67. DOI: 10.1186/s12912-021-00585-4 From NLM.
(21) Fried, T. R.; Tinetti, M.; Agostini, J.; Iannone, L.; Towle, V. Health outcome prioritization to elicit preferences of older persons with multiple health conditions. *Patient Educ Couns* **2011**, *83* (2), 278-282. DOI: 10.1016/j.pec.2010.04.032 From NLM.
(22) Boeckxstaens, P.; Vandenbroeck, P. Goal-oriented care. A shared language and co-creative practice for health and social care. *Koning Boudewijn Foundation* **2020**.
(23) Conner, M.; Norman, P. Understanding the intention-behavior gap: The role of intention strength. *Front Psychol* **2022**, *13*, 923464. DOI: 10.3389/fpsyg.2022.923464 From NLM.
(24) Mather, M.; Pettigrew, L. M.; Navaratnam, S. Barriers and facilitators to clinical behaviour change by primary care practitioners: a theory-informed systematic review of reviews using the Theoretical Domains Framework and Behaviour Change Wheel. *Syst Rev* **2022**, *11* (1), 180. DOI: 10.1186/s13643-022-02030-2 From NLM.
(25) Michielsen, L.; Bischoff, E.; Schermer, T.; Laurant, M. Primary healthcare competencies needed in the management of person-centred integrated care for chronic illness and multimorbidity: Results of a scoping review. *BMC Prim Care* **2023**, *24* (1), 98. DOI: 10.1186/s12875-023-02050-4 From NLM.
(26) Frank, J. R.; Snell, L. S.; Cate, O. T.; Holmboe, E. S.; Carraccio, C.; Swing, S. R.; Harris, P.; Glasgow, N. J.; Campbell, C.; Dath, D.; et al. Competency-based medical education: theory to practice. *Med Teach* **2010**, *32* (8), 638-645. DOI: 10.3109/0142159x.2010.501190 From NLM.
(27) Cunliffe, A. L. Republication of "On becoming a critically reflexive practitioner". *Journal of management education* **2016**, *40* (6), 747-768.
(28) Rasiah, S.; Jaafar, S.; Yusof, S.; Ponnudurai, G.; Chung, K. P. Y.; Amirthalingam, S. D. A study of the nature and level of trust between patients and healthcare providers, its dimensions and determinants: a scoping review protocol. *BMJ Open* **2020**, *10* (1), e028061. DOI: 10.1136/bmjopen-2018-028061 From NLM.
(29) Hall, M. A.; Zheng, B.; Dugan, E.; Camacho, F.; Kidd, K. E.; Mishra, A.; Balkrishnan, R. Measuring patients' trust in their primary care providers. *Med Care Res Rev* **2002**, *59* (3), 293-318. DOI: 10.1177/1077558702059003004 From NLM.
(30) Khazen, M. Power dynamics in doctor-patient relationships: A qualitative study examining how cultural and personal relationships facilitate medication requests in a minority with collectivist attributes. *Patient Education and Counseling* **2022**, *105* (7), 2038-2044.
(31) Kuipers, S. J.; Cramm, J. M.; Nieboer, A. P. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-

morbidity in the primary care setting. *BMC Health Serv Res* **2019**, *19* (1), 13. DOI: 10.1186/s12913-018-3818-y From NLM.
(32) Murdoch, J.; Salter, C.; Ford, J.; Lenaghan, E.; Shiner, A.; Steel, N. The "unknown territory" of goal-setting: Negotiating a novel interactional activity within primary care doctor-patient consultations for patients with multiple chronic conditions. *Soc Sci Med* **2020**, *256*, 113040. DOI: 10.1016/j.socscimed.2020.113040 From NLM.
(33) Chipidza, F. E.; Wallwork, R. S.; Stern, T. A. Impact of the Doctor-Patient Relationship. *Prim Care Companion CNS Disord* **2015**, *17* (5). DOI: 10.4088/PCC.15f01840 From NLM.
(34) Stewart, M. Reflections on the doctor-patient relationship: from evidence and experience. *Br J Gen Pract* **2005**, *55* (519), 793-801. From NLM.
(35) Elwyn, G.; Frosch, D.; Thomson, R.; Joseph-Williams, N.; Lloyd, A.; Kinnersley, P.; Cording, E.; Tomson, D.; Dodd, C.; Rollnick, S. Shared decision making: a model for clinical practice. *Journal of general internal medicine* **2012**, *27*, 1361-1367.
(36) Elwyn, G.; Edwards, A.; Kinnersley, P.; Grol, R. Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. *Br J Gen Pract* **2000**, *50* (460), 892-899. From NLM.
(37) Kokorelias, K. M.; Gignac, M. A. M.; Naglie, G.; Cameron, J. I. Towards a universal model of family centered care: a scoping review. *BMC Health Serv Res* **2019**, *19* (1), 564. DOI: 10.1186/s12913-019-4394-5 From NLM.
(38) Blazer, D. G.; Hernandez, L. M. Genes, behavior, and the social environment: Moving beyond the nature/nurture debate. **2006**.
(39) Hsu, C.; Gray, M. F.; Murray, L.; Abraham, M.; Nickel, W.; Sweeney, J. M.; Frosch, D. L.; Mroz, T. M.; Ehrlich, K.; Johnson, B.; et al. Actions and processes that patients, family members, and physicians associate with patient- and family-centered care. *BMC Fam Pract* **2019**, *20* (1), 35. DOI: 10.1186/s12875-019-0918-7 From NLM.
(40) van Dongen, J. J. J.; de Wit, M.; Smeets, H. W. H.; Stoffers, E.; van Bokhoven, M. A.; Daniëls, R. "They are talking about me, but not with me": a focus group study to explore the patient perspective on interprofessional team meetings in primary care. *The Patient-Patient-Centered Outcomes Research* **2017**, *10*, 429-438.
(41) Szafran, O.; Kennett, S. L.; Bell, N. R.; Green, L. Patients' perceptions of team-based care in family practice: access, benefits and team roles. *Journal of Primary Health Care* **2018**, *10* (3), 248-257.
(42) van Dongen, J. J. J.; van Bokhoven, M. A.; Daniëls, R.; van der Weijden, T.; Emonts, W. W. G. P.; Beurskens, A. Developing interprofessional care plans in chronic care: a scoping review. *BMC Family Practice* **2016**, *17*, 1-9.
(43) Sirimsi, M. M.; De Loof, H.; Van den Broeck, K.; De Vliegher, K.; Pype, P.; Remmen, R.; Van Bogaert, P. Scoping review to identify strategies and interventions improving interprofessional collaboration and integration in primary care. *BMJ Open* **2022**, *12* (10), e062111. DOI: 10.1136/bmjopen-2022-062111 From NLM.
(44) Lau, R.; Stevenson, F.; Ong, B. N.; Dziedzic, K.; Treweek, S.; Eldridge, S.; Everitt, H.; Kennedy, A.; Qureshi, N.; Rogers, A. Achieving change in primary care—causes of the evidence to practice gap: systematic reviews of reviews. *Implementation Science* **2015**, *11* (1), 1-39.
(45) Nagykaldi, Z. J.; Tange, H.; De Maeseneer, J. Moving from problem-oriented to goal-directed health records. *The Annals of Family Medicine* **2018**, *16* (2), 155-159.
(46) Tange, H.; Nagykaldi, Z.; De Maeseneer, J. Towards an overarching model for electronic medical-record systems, including problem-oriented, goal-oriented, and other approaches. *Eur J Gen Pract* **2017**, *23* (1), 257-260. DOI: 10.1080/13814788.2017.1374367 From NLM.
(47) Sawatzky, R.; Kwon, J. Y.; Barclay, R.; Chauhan, C.; Frank, L.; van den Hout, W. B.; Nielsen, L. K.; Nolte, S.; Sprangers, M. A. G. Implications of response shift for micro-, meso-, and macro-level

healthcare decision-making using results of patient-reported outcome measures. *Qual Life Res* **2021**, *30* (12), 3343-3357. DOI: 10.1007/s11136-021-02766-9 From NLM.
(48) Danhieux, K.; Martens, M.; Colman, E.; Wouters, E.; Remmen, R.; van Olmen, J.; Anthierens, S. What Makes Integration of Chronic Care so Difficult? A Macro-Level Analysis of Barriers and Facilitators in Belgium. *Int J Integr Care* **2021**, *21* (4), 8. DOI: 10.5334/ijic.5671 From NLM.
(49) Huybrechts, I.; Declercq, A.; Verté, E.; Boeckxstaens, P.; Raeymaeckers, P.; Anthierens, S. Will the implementation process for goal-oriented primary care succeed? A qualitative study investigating five perceived attributes of goal-oriented care. *Soc Sci Med* **2023**, *331*, 116048. DOI: 10.1016/j.socscimed.2023.116048 From NLM.
(50) Bertakis, K. D.; Azari, R. Patient-centered care is associated with decreased health care utilization. *J Am Board Fam Med* **2011**, *24* (3), 229-239. DOI: 10.3122/jabfm.2011.03.100170 From NLM.
(51) Blom, J.; den Elzen, W.; van Houwelingen, A. H.; Heijmans, M.; Stijnen, T.; Van den Hout, W.; Gussekloo, J. Effectiveness and cost-effectiveness of a proactive, goal-oriented, integrated care model in general practice for older people. A cluster randomised controlled trial: Integrated Systematic Care for older People--the ISCOPE study. *Age Ageing* **2016**, *45* (1), 30-41. DOI: 10.1093/ageing/afv174 From NLM.
(52) Barbato, A.; D'Avanzo, B.; Cinquini, M.; Fittipaldo, A. V.; Nobili, A.; Amato, L.; Vecchi, S.; Onder, G. Effects of goal-oriented care for adults with multimorbidity: A systematic review and meta-analysis. *Journal of Evaluation in Clinical Practice* **2022**, *28* (3), 371-381.
(53) McGlynn, E. A.; Asch, S. M.; Adams, J.; Keesey, J.; Hicks, J.; DeCristofaro, A.; Kerr, E. A. The quality of health care delivered to adults in the United States. *N Engl J Med* **2003**, *348* (26), 2635-2645. DOI: 10.1056/NEJMsa022615 From NLM.
(54) Muth, C.; Kirchner, H.; Van Den Akker, M.; Scherer, M.; Glasziou, P. P. Current guidelines poorly address multimorbidity: pilot of the interaction matrix method. *Journal of clinical epidemiology* **2014**, *67* (11), 1242-1250.
(55) Valderas, J.; Gangannagaripalli, J.; Nolte, E.; Boyd, C.; Roland, M.; Sarria-Santamera, A.; Jones, E.; Rijken, M. Quality of care assessment for people with multimorbidity. Wiley Online Library: 2019; Vol. 285, pp 289-300.
(56) Porter, M. E.; Teisberg, E. O. *Redefining health care: creating value-based competition on results*; Harvard business press, 2006.
(57) Boeykens, D.; Boeckxstaens, P.; De Sutter, A.; Lahousse, L.; Pype, P.; De Vriendt, P.; Van de Velde, D. Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: A scoping review and concept analysis. *PLoS One* **2022**, *17* (2), e0262843. DOI: 10.1371/journal.pone.0262843 From NLM.
(58) *Person-centred value-based health care*. 2021. https://sprink.co.uk/files/2021_09_01_PCVBHC_Report.pdf (accessed.
(59) Baumhauer, J. F.; Bozic, K. J. Value-based Healthcare: Patient-reported Outcomes in Clinical Decision Making. *Clin Orthop Relat Res* **2016**, *474* (6), 1375-1378. DOI: 10.1007/s11999-016-4813-4 From NLM.
(60) Mold, J. Goal-Directed Health Care: Redefining Health and Health Care in the Era of Value-Based Care. *Cureus* **2017**, *9* (2), e1043. DOI: 10.7759/cureus.1043 From NLM.
(61) Coulter, A.; Entwistle, V. A.; Eccles, A.; Ryan, S.; Shepperd, S.; Perera, R. Personalised care planning for adults with chronic or long-term health conditions. *Cochrane Database Syst Rev* **2015**, *2015* (3), Cd010523. DOI: 10.1002/14651858.CD010523.pub2 From NLM.
(62) Bolton, R. E.; Bokhour, B. G.; Hogan, T. P.; Luger, T. M.; Ruben, M.; Fix, G. M. Integrating Personalized Care Planning into Primary Care: a Multiple-Case Study of Early Adopting Patient-Centered Medical Homes. *J Gen Intern Med* **2020**, *35* (2), 428-436. DOI: 10.1007/s11606-019-05418-4 From NLM.

(63) Whitehead, L. The effects of personalized care planning for adults living with chronic conditions. *Int J Nurs Pract* **2016**, *22* (2), 138-140. DOI: 10.1111/ijn.12429 From NLM.
(64) Kime, N.; Wright, A.; Heaven, A.; Hawkins, R.; Smith, J.; Cundill, B.; Foy, R.; Lawton, R.; Farrin, A.; Hulme, C.; et al. Implementing personalised care planning for older people with frailty: a process evaluation of the PROSPER feasibility trial. *BMC Geriatr* **2022**, *22* (1), 760. DOI: 10.1186/s12877-022-03426-4 From NLM.
(65) Fix, G. M.; Bolton, R. E.; Bokhour, B. G. Challenges in Implementing Personalized Care Planning. *Jama* **2017**, *318* (17), 1713. DOI: 10.1001/jama.2017.14254 From NLM.
(66) Sudore, R. L.; Lum, H. D.; You, J. J.; Hanson, L. C.; Meier, D. E.; Pantilat, S. Z.; Matlock, D. D.; Rietjens, J. A. C.; Korfage, I. J.; Ritchie, C. S.; et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage* **2017**, *53* (5), 821-832.e821. DOI: 10.1016/j.jpainsymman.2016.12.331 From NLM. Rietjens, J. A. C.; Sudore, R. L.; Connolly, M.; van Delden, J. J.; Drickamer, M. A.; Droger, M.; van der Heide, A.; Heyland, D. K.; Houttekier, D.; Janssen, D. J. A.; et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* **2017**, *18* (9), e543-e551. DOI: 10.1016/s1470-2045(17)30582-x From NLM.
(67) Martins, C. S.; Cadavez, E.; Nunes, R. Advance directives in palliative care-a new tool to improve the communication between patients and caregivers? *Int J Palliat Nurs* **2023**, *29* (7), 344-349. DOI: 10.12968/ijpn.2023.29.7.344 From NLM.
(68) Rosa, W. E.; Izumi, S.; Sullivan, D. R.; Lakin, J.; Rosenberg, A. R.; Creutzfeldt, C. J.; Lafond, D.; Tjia, J.; Cotter, V.; Wallace, C.; et al. Advance Care Planning in Serious Illness: A Narrative Review. *J Pain Symptom Manage* **2023**, *65* (1), e63-e78. DOI: 10.1016/j.jpainsymman.2022.08.012 From NLM.
(69) Stevens, J.; Deliens, L.; Pype, P.; De Vleminck, A.; Pardon, K. Complex advance care planning interventions for chronic serious illness: how do they work: a scoping review. *BMJ Support Palliat Care* **2021**, *12* (e3), e441-450. DOI: 10.1136/bmjspcare-2021-003310 From NLM.
(70) Bodenheimer, T.; Sinsky, C. From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med* **2014**, *12* (6), 573-576. DOI: 10.1370/afm.1713 From NLM.
(71) Nundy, S.; Cooper, L. A.; Mate, K. S. The Quintuple Aim for Health Care Improvement: A New Imperative to Advance Health Equity. *Jama* **2022**, *327* (6), 521-522. DOI: 10.1001/jama.2021.25181 From NLM.
(72) Organization, W. H. Framework on integrated, people-centred health services. *Geneva: World Health Organization* **2016**, *2019*.
(73) Berntsen, G.; Høyem, 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 services research* **2018**, *18*, 1-15.
(74) Valentijn, P. P.; Boesveld, I. C.; Van der Klauw, D. M.; Ruwaard, D.; Struijs, J. N.; Molema, J. J.; Bruijnzeels, M. A.; Vrijhoef, H. J. Towards a taxonomy for integrated care: a mixed-methods study. *International journal of integrated care* **2015**, *15*.
(75) Steele Gray, C.; Grudniewicz, A.; Armas, A.; Mold, J.; Im, J.; Boeckxstaens, P. Goal-Oriented Care: A Catalyst for Person-Centred System Integration. *Int J Integr Care* **2020**, *20* (4), 8. DOI: 10.5334/ijic.5520 From NLM.
(76) Bleijenberg, N.; de Man-van Ginkel, J. M.; Trappenburg, J. C. A.; Ettema, R. G. A.; Sino, C. G.; Heim, N.; Hafsteindóttir, T. B.; Richards, D. A.; Schuurmans, M. J. Increasing value and reducing waste by optimizing the development of complex interventions: Enriching the development phase of the Medical Research Council (MRC) Framework. *Int J Nurs Stud* **2018**, *79*, 86-93. DOI: 10.1016/j.ijnurstu.2017.12.001 From NLM.

(77) O'Cathain, A.; Croot, L.; Duncan, E.; Rousseau, N.; Sworn, K.; Turner, K. M.; Yardley, L.; Hoddinott, P. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open* **2019**, *9* (8), e029954. DOI: 10.1136/bmjopen-2019-029954 From NLM.
(78) Skivington, K.; Matthews, L.; Simpson, S. A.; Craig, P.; Baird, J.; Blazeby, J. M.; Boyd, K. A.; Craig, N.; French, D. P.; McIntosh, E.; et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *Bmj* **2021**, *374*, n2061. DOI: 10.1136/bmj.n2061 From NLM.
(79) 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*, a1655. DOI: 10.1136/bmj.a1655 From NLM.
(80) Cleland, J. A. The qualitative orientation in medical education research. *Korean J Med Educ* **2017**, *29* (2), 61-71. DOI: 10.3946/kjme.2017.53 From NLM.
(81) Nowell, L. S.; Norris, J. M.; White, D. E.; Moules, N. J. Thematic analysis: Striving to meet the trustworthiness criteria. *International journal of qualitative methods* **2017**, *16* (1), 1609406917733847.
(82) Kitto, S. C.; Chesters, J.; Grbich, C. Quality in qualitative research. *Medical journal of Australia* **2008**, *188* (4), 243-246.
(83) Lincoln, Y. S. Establishing trustworthiness. *Naturalistic inquiry* **1985**, *289* (331), 289. Patton, M. Q. Enhancing the quality and credibility of qualitative analysis. *Health services research* **1999**, *34* (5 Pt 2), 1189.
(84) Sundler, A. J.; Lindberg, E.; Nilsson, C.; Palmér, L. Qualitative thematic analysis based on descriptive phenomenology. *Nurs Open* **2019**, *6* (3), 733-739. DOI: 10.1002/nop2.275 From NLM.
(85) Slevin, E.; Sines, D. Enhancing the truthfulness, consistency and transferability of a qualitative study: utilising a manifold of approaches. *Nurse Researcher (through 2013)* **1999**, *7* (2), 79.
(86) Golafshani, N. Understanding reliability and validity in qualitative research. *The qualitative report* **2003**, *8* (4), 597-607.
(87) Drisko, J. W. Strengthening qualitative studies and reports: Standards to promote academic integrity. *Journal of social work education* **1997**, *33* (1), 185-197.
(88) Ramsook, L. A methodological approach to hermeneutic phenomenology. *International journal of humanities and social sciences* **2018**, *10* (1), 14-24.
(89) Wolf, Z. R. Exploring the audit trail for qualitative investigations. *Nurse educator* **2003**, *28* (4), 175-178.
(90) Boeykens, D.; Sirimsi, M. M.; Timmermans, L.; Hartmann, M. L.; Anthierens, S.; De Loof, H.; De Vliegher, K.; Foulon, V.; Huybrechts, I.; Lahousse, L.; et al. How do people living with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. *J Clin Nurs* **2023**, *32* (3-4), 422-437. DOI: 10.1111/jocn.16243 From NLM.
(91) Lowton, K. He said, she said, we said: ethical issues in conducting dyadic interviews. *The Sage handbook of qualitative research ethics* **2018**, 133-147.
(92) Collaço, N.; Wagland, R.; Alexis, O.; Gavin, A.; Glaser, A.; Watson, E. K. Using the framework method for the analysis of qualitative dyadic data in health research. *Qualitative Health Research* **2021**, *31* (8), 1555-1564.
(93) Szulc, J.; King, N. The practice of dyadic interviewing: Strengths, limitations and key decisions. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research*, 2022; Vol. 23.
(94) Domecq, J. P.; Prutsky, G.; Elraiyah, T.; Wang, Z.; Nabhan, M.; Shippee, N.; Brito, J. P.; Boehmer, K.; Hasan, R.; Firwana, B.; et al. Patient engagement in research: a systematic review. *BMC Health Serv Res* **2014**, *14*, 89. DOI: 10.1186/1472-6963-14-89 From NLM.
(95) Baum, F.; MacDougall, C.; Smith, D. Participatory action research. *J Epidemiol Community Health* **2006**, *60* (10), 854-857. DOI: 10.1136/jech.2004.028662 From NLM.

(96) Bush, E. J.; Singh, R. L.; Kooienga, S. Lived Experiences of a Community: Merging Interpretive Phenomenology and Community-Based Participatory Research. *International Journal of Qualitative Methods* **2019**, *18*, 1609406919875891. DOI: 10.1177/1609406919875891 (acccessed 2023/03/17).
(97) Gorski, S.; Prokop-Dorner, A.; Pers, M.; Stalmach-Przygoda, A.; Malecki, Ł.; Cebula, G.; Bombeke, K. The Use of Simulated Patients Is more Effective than Student Role Playing in Fostering Patient-Centred Attitudes during Communication Skills Training: A Mixed Method Study. *BioMed Research International* **2022**, *2022*, 1498692. DOI: 10.1155/2022/1498692.

SAMENVATTING
SUMMARY

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De eerstelijnszorg staat voor grote uitdagingen om met de negatieve gevolgen van het toenemend aantal personen met (meerdere) problemen op medisch en/ of (psycho)sociaal domein om te gaan (cfr. personen met een zorg- en ondersteuningsvraag, ofwel 'PZOV). Dit toenemend aantal, mede in stand gehouden door de vergrijzing en innovatie in gezondheidstechnologieën, resulteert in vraagstukken over hoe de hulpverlening voor deze populatie moet georganiseerd worden. De zoektocht naar geschikte strategieën leidde eerder al tot de conclusie dat een ziektegerichte benadering, waarin het huidige zorgsysteem is ingebed, ontoereikend is in deze context. Wanneer een persoon te maken heeft met verschillende medische of sociale problemen zal een ziektegerichte benadering, gegrond in gestandaardiseerde richtlijnen, een versnippering in hulpverlening veroorzaken. Met deze conclusie kwam ook de vaststelling dat strategieën zich moeten bedden op hetgeen als waarde- en betekenisvol voor de PZOV wordt aanzien. Door het centreren van hulpverlening op de PZOV en rekening te houden met de persoonlijke doelen, zal het mogelijk zijn om de relatie tussen de PZOV en de hulpverlener te versterken, wat zal resulteren in een betere samenwerking en een betere ervaring met de hulpverlening. Om de hulpverlening af te stemmen op de persoonlijke doelen van de PZOV lijkt doelgerichte zorg de aangewezen strategie. Hoewel het potentieel van doelgerichte zorg is aangetoond, komt het voorstel om hierop in te zetten met heel wat vraagstukken. Die vraagstukken zitten zowel vervat in een conceptueel luik als het luik om de vertaalslag naar de praktijk te maken. Met als doelstelling om alle belanghebbenden in de eerstelijnszorg van de nodige handvaten te voorzien om doelgerichte zorg naar de praktijk te vertalen, tracht dit proefschrift de bouwstenen van doelgerichte zorg te identificeren.

Om dit onderzoeksproces te onderbouwen, wordt het Medical Research Council Framework gebruikt. Dit Framework biedt een kader dat toelaat om op een stapsgewijze manier na te gaan wat 1) de draagkracht is van een nieuwe interventie, 2) welke theorie een interventie onderbouwt en 3) hoe die theorie verder kan verfijnd worden om tegemoet te komen aan de noden in de praktijk. In dit proefschrift heeft dit ontwikkelingsproces vorm gekregen op basis van zes, voornamelijk kwalitatieve, studies die de verschillende perspectieven van belanghebbenden in de eerstelijnszorg in kaart brengen .

De eerste drie studies hadden als doelstelling om de draagkracht voor een doelgerichte zorg interventie te identificeren. Hiervoor werden zowel PZOVs en hun mantelzorgers, eerstelijnshulpverleners, onderzoekers als beleidsmakers bevraagd.

De **eerste studie** ging na wat de ervaringen van de PZOVs en hun mantelzorger (duo's) zijn met de eerstelijnszorg. De gesprekken leverden waardevolle informatie op waarbij inzichten werden verkregen in hoe eerstelijnszorg kan tegemoet komen aan hun noden. De noodzaak voor een meer persoonlijke benadering in hulpverlening was sprekend. Die persoonlijke benadering dient vorm te krijgen op basis van hetgeen betekenisvol is voor de duo's, vaak uitgedrukt in betekenisvolle activiteiten. Daarnaast dient een meer persoonlijke benadering ook de relatie tussen de duo's en hulpverleners te onderbouwen. Door de wens uit te drukken voor hulpverlening die gegrond is in hetgeen betekenis en waarde geeft in hun dagelijkse leven, uitten de duo's onbewust de nood voor doelgerichte zorg.

Een tweede studie schetste de ervaringen van belanghebbenden (o.m. hulpverleners, onderzoekers en beleidsmakers) in de eerstelijnszorg met het voorop plaatsen van persoonlijke doelen van de PZOV in hulpverlening doormiddel van focusgroepen. Meer specifiek werden strategieën die ze hiervoor gebruikten en de belemmeringen waarmee ze kampten in kaart gebracht. Hieruit bleek dat belanghebbenden de neiging hebben om doelen voorop te plaatsen in hulpverlening. Enerzijds deden ze dit door ruimte te creëren om persoonlijke doelstellingen van de PZOV te bevragen en te integreren met het hun eigen, veelal medisch georiënteerde doelen. Anderzijds kregen persoonlijke doelen van de PZOV een plaats in interprofessionele samenwerking als leidraad om de zorg op elkaar af te stemmen. Hoewel hulpverleners hun best deden om doelen voorop te plaatsen, ervaarden ze twee belemmeringen. Een eerste belemmering richt zich naar de noodzaak om over de geschikte vaardigheden te beschikken om doelen te bevragen en bespreken. Een tweede belemmering situeert zich op het organisatorische niveau waarbij veranderingen moeten doorgevoerd worden zodat hulpverleners de nodige middelen, in termen van tijd en financiën, krijgen. Deze tweede studie leidt tot de conclusie dat doelgerichte zorg voor hulpverleners niets nieuw is aangezien ze al rekening houden met de persoonlijke doelen, maar er nog wel meer ingezet kan worden in het aanbieden van de nodige ondersteuning.

Waar de tweede studie naging op welke manier persoonlijke doelen nu al een plaats krijgen in hulpverlening, bracht de derde studie het implementatiepotentieel van doelgerichte zorg in de eerstelijnszorg in kaart. Door eerstelijnshulpverleners de NoMad Survey te laten invullen na het volgen van een twee uur durende buurtbijeenkomst over doelgerichte zorg, werd nagegaan hoe doelgerichte zorg genormaliseerd kan worden in de praktijk en wat mogelijke hiaten voor een succesvolle implementatie zijn. In lijn met de bevindingen uit de tweede studie, gaven hulpverleners aan dat ze een initieel begrip hebben van doelgerichte zorg. Daarnaast erkenden ze het potentieel en gaven ze aan dat het gemakkelijk kan geïntegreerd worden in de dagelijkse werking. Terwijl de tweede studie voornamelijk duidde op het gebrek aan middelen voor doelgerichte zorg, bleek in de derde studie dat hulpverleners aangemoedigd moeten worden om van elkaar te leren over doelgerichte zorg door het uitwisselen van ervaringen.

De eerste drie studies toonden aan dat er draagkracht is om doelgerichte zorg te vertalen naar een strategie om de hulpverlening voor PZOVs te organiseren. Enerzijds is er nood voor het ontwikkelen van vaardigheden om doelen te bespreken en op zoek te gaan naar opportuniteiten om te leren van en met elkaar over doelgerichte zorg. Anderzijds, moeten er voldoende middelen worden voorzien om doelgerichte zorg mogelijk te maken.

Hoewel er onderliggend aan de eerste drie studies sleutelelementen van doelgerichte zorg naar boven blijken te komen, bleef een duidelijk begrip uit. De vierde studie had als doel om door gebruik te maken van een conceptanalyse een dergelijk begrip te formuleren. Een conceptanalyse laat toe om in de literatuur op zoek te gaan naar antecedenten, attributen en consequenties van een bepaald concept, in dit geval doelgerichte zorg. Hieruit bleek dat doelgerichte zorg een dynamisch proces is bestaande uit drie iteratieve fases: verkennend gesprek, bespreken en bepalen van doelen, reflectie op het proces. Onderliggend aan dit proces ligt het belang van rekening te houden met de leefomgeving van de PZOV en de persoonlijke doelstellingen. Daarnaast bleek dat zowel PZOVs als hulpverleners moeten voorbereid worden om doelgerichte zorg mogelijk te maken. Indien doelgerichte zorg succesvol werd toegepast, is er het potentieel om zowel de

ervaringen van de PZOV en hulpverlener met hulpverlening te verbeteren, in te spelen op de gezondheid van de populatie en zelfs het verminderen van gezondheid gerelateerde kosten.

De attributen, geïdentificeerd in de conceptanalyse, werden vervolgens gebruikt als voedingsbodem voor studie vijf en zes. Dit liet toe om het doelgerichte zorgproces verder te verfijnen met ervaringen van PZOVs en hulpverleners met doelgerichte zorg.

Uit studie vijf bleek dat PZOVs enkel ervaring hadden met een verkennend gesprek, het bespreken van doelen en het reflecteren over het proces van hulpverlening bleek naar de achtergrond te zijn verschoven. In aanvulling tot de attributen die in de conceptanalyse werd geïdentificeerd, duidden de PZOVs enerzijds naar het belang van het verkrijgen van voldoende informatie over hun aandoeningen om doordachte keuzes te maken in functie van hun persoonlijke doelen en anderzijds naar het belang van interprofessionele samenwerking.

Studie zes belichtte het perspectief van de eerstelijnshulpverleners. In de neerslag van hun ervaringen met doelgerichte zorg konden alle attributen, zoals neergeschreven in de conceptanalyse, geïdentificeerd worden. Hun ervaringen toonden aan dat doelgerichte zorg eerder duidt op een reflexief proces van hulpverlening wat betekent dat de verschillende fases van het proces niet op een gestructureerde manier werden doorlopen, maar er attributen van doelgerichte zorg vervlochten zitten doorheen het hele proces van hulpverlening. Om dit mogelijk te maken en hen hierin te ondersteunen maakten ze gebruik van sleutelvragen en instrumenten. In lijn met de vijfde studie duidden de hulpverleners naar het belang van interprofessionele samenwerking. Dit liet hen toe om, op basis van de persoonlijke doelen van de PZOV, zorg op elkaar af te stemmen.

Hoewel dit overzicht van de belangrijkste bevindingen wijzen naar belangrijke sleutelelementen van doelgerichte zorg voor belanghebbenden in de eerstelijnszorg (inclusief PZOVs en mantelzorgers), kan het een ontnuchterende conclusie zijn dat er geen concrete acties voor een interventie zijn geformuleerd. Dit hoeft echter niet te verwonderen aangezien er uit verschillende studies naar voor komt dat doelgerichte zorg voornamelijk een benadering van zorg is die hulpverleners zichzelf eigen moeten maken. Dit betekent een zekere mate van reflexiviteit over je houding als hulpverlener en reflexiviteit over het verloop van het hulpverleningsproces. Dergelijke benadering van zorg is moeilijk te vatten in een gestructureerde interventie. Op basis van deze conclusie is het beter om bouwstenen te presenteren die de ontwikkeling van interventies voor doelgerichte zorg kunnen informeren. Deze bouwstenen zijn: doelgerichte zorg proces bestaande uit de drie geïdentificeerde fases, patiënt engagement, communicatievaardigheden, reflectieve vaardigheden, betrekken van belangrijke anderen, interprofessionele samenwerking en middelen.

Tot slot, doelgerichte zorg biedt heel wat potentieel om de hulpverlening voor personen met (meerdere) medische en (psycho)sociale problemen te organiseren. Door de hulpverlening te laten starten vanuit de persoonlijke doelstellingen van de PZOV is het mogelijk om de negatieve gevolgen van dergelijke problemen aan te pakken. Dergelijke benadering van hulpverlening biedt zowel voordelen voor de PZOV, hulpverleners als het zorgsysteem. Het is dus van belang om blijvend in te zetten om een verschuiving naar doelgerichte zorg mogelijk te maken.

SUMMARY

Primary health care faces great challenges in dealing with the negative consequences of the increasing number of people with (multiple) problems in the medical and/or (psycho)social domain (i.e., 'patients'). This increasing number, partly maintained by the aging population and innovation in health technologies, results in questions about how to manage care for this population. The search for appropriate strategies led already to the conclusion that a disease-oriented approach, in which the current healthcare system is embedded, is inadequate in this context. When a person is dealing with different medical or social problems, a disease-oriented approach, grounded in standardized guidelines, will cause fragmentation in care. Together with this conclusion, came the observation that strategies need to be oriented on what is perceived to be of value and meaningful to the person. By centering care on the person and taking into account personal goals, it will be possible to strengthen the patient-provider relationship, resulting in better cooperation and a better experience of care. To align care delivery with the person's personal goals, goal-oriented care seems to be the appropriate strategy. Although the potential of goal-oriented care has been proven, its implementation comes with various conceptual and practical issues. With the objective of providing all primary care stakeholders with the tools necessary to translate goal-oriented care into practice, this dissertation seeks to identify building blocks underpinning goal-oriented care.

To inform the development process of such an intervention, the Medical Research Council Framework is used. This Framework presents a step-by-step approach to assessing 1) the evidence base for an intervention, 2) the development and identification of a theory, and 3) the modelling of processes and outcomes of the theory. In this dissertation, this development process has taken shape based on six, mainly qualitative, studies that capture the different perspectives of primary care stakeholders.

The first three studies aimed to identify the evidence base for a goal-oriented care intervention. For this purpose, both patients and their informal providers, primary care providers, researchers, and policy makers were interviewed.

The first study explored the experiences of patients and their providers (i.e., 'dyads')with primary care. The interviews yielded valuable information that provided insight into how primary care can meet their needs. The need for a more personalized approach in care was telling. This personal approach should take shape on the basis of what is meaningful to the dyads, often expressed in meaningful activities. In addition, a more personal approach should also underpin the relationship between the dyads and providers. By expressing a desire for care that is grounded in what gives meaning and value in their daily lives, the dyads implicitly expressed a need for goal-oriented care.

A second study outlined the experiences of primary care stakeholders (including social workers, researchers and policy makers) care with putting patients' goals first in care. More specifically, strategies they used to do this and the barriers they faced were identified. This showed that stakeholders have the intrinsic nature to put goals first. On the one hand, they did this by creating room to question and integrate patients' personal goals with their own, mostly medically oriented goals. On the other hand, patients' personal goals were given a place in interprofessional collaboration as a guide to integrate care. Although providers did their best to put goals first, they experienced two barriers. A first barrier focuses on the need to have the appropriate competences

to question and discuss goals. A second barrier is at the organizational level where changes must be made so that providers have the necessary resources, in terms of time and finances. This second study leads to the conclusion that goal-oriented care is nothing new for providers since they already take personal goals into account, but more effort can be put into offering the necessary support.

Whereas the second study examined the ways in which patients' personal goals already have a place in caregiving, the third identified the implementation potential of goal-oriented care in primary care. By having primary care providers complete the NoMad Survey after attending a two-hour community meeting on goal-oriented care, it examined how goal-oriented care can be normalized in practice and what potential gaps for successful implementation exist. In line with the findings from the second study, providers indicated an initial understanding of goal-oriented care. In addition, they recognized its potential and indicated that it can be easily integrated into daily working. While the second study primarily indicated the lack of resources for goal-oriented care, the third study found that providers should be encouraged to learn from each other about goal-oriented care by sharing experiences.

The first three studies showed that there is a base for translating goal-oriented care into a strategy for organizing care for patients with multiple problems. On the one hand, there is a need for developing competences to discuss goals and look for opportunities to learn from and with each other about goal-oriented care. On the other hand, sufficient resources must be provided to enable goal-oriented care.

Although the first three studies underlined key elements of goal-oriented care, a comprehensive understanding was lacking. The fourth study aimed to formulate such understanding by means of a concept analysis. A concept analysis allows one to search the literature for antecedents, attributes and consequences of a particular concept, in this case goal-oriented care. It appeared that goal-oriented care is a dynamic process consisting of three iterative phases: goal-elicitation, goal-setting, and goal-evaluation underpinned by the patients' context and patients' needs and preferences. In addition, it was found that both patients and providers must be prepared to enable goal-oriented care. If goal-oriented care was successfully implemented, it has the potential to improve both the patients' and providers' experiences with care, respond to enhancing population health, and even reduce health-related costs.

The attributes, identified in the concept analysis, were then used to feed into studies five and six. This allowed for further modelling the goal-oriented process of care through experiences of patients and providers with goal-oriented care.

Study five showed that patients only experienced goal-elicitation while goal-setting and goal-evaluation were relegated to the background. In addition to the attributes identified in the concept analysis, patients indicated, on the one hand, the importance of obtaining enough information about their conditions to make thoughtful choices according to their personal goals and, on the other hand, the importance of interprofessional collaboration.

Study six highlighted the perspective of primary care providers. All attributes, as outlined in the concept analysis, could be identified in their experiences with goal-oriented care. Based on their experiences, it seemed that goal-oriented care is a reflexive process of care meaning that the phases are not followed as a set structure and are rather interwoven. To enable and support them

in this way of thinking, they used key questions and instruments. In line with the fifth study, providers pointed to the importance of interprofessional collaboration. This allowed them to integrate care based on the patients' personal goals.

Although this overview of the findings points to important key elements of goal-oriented care for primary care stakeholders (including patients and informal providers), it may be a sobering conclusion that no concrete actions for an intervention have been formulated. However, this should not be surprising since several of our studies suggest that goal-oriented care is primarily an approach to care that providers must make their own. This means a certain amount of reflexivity about one's attitude as a caregiver and reflexivity about the course of the caregiving process. Such an approach to care is difficult to capture in a structured intervention. Based on this conclusion, it is better to present building blocks that can inform the development of goal-oriented care interventions: goal-oriented process of care, patient engagement, communication skills, reflective skills, incorporating significant others, interprofessional collaboration, and resources.

In conclusion, goal-oriented care has a lot of potential to organize care for people with multiple medical and social challenges. By starting caregiving from patients' personal goals, burden for patients, providers, and the system might be overcome. It is thus important to make sustained efforts to enable a shift to goal-oriented care.

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CURRICULUM VITAE

About the author

Dagje Boeykens (°28 October 1994, Hingene) obtained a Master's degree in Health Promotion and Education at Ghent University in 2019 and a Bachelor's degree in Occupational Therapy in 2018. In 2019 she started a PhD entitled 'Goal-oriented care: from a theoretical concept to an intervention for primary care' that is currently coming to an end. This PhD is embedded in the consortium of the Primary Care Academy, funded by Fund Dr. Daniël De Coninck of the King Baudouin Foundation. The Academy aims to strengthen primary care in Flanders by means of research and education. During this PhD a close connection with primary care stakeholders is maintained. During her PhD, she spent four months abroad at Lanenfeld-Tanenbaum Research Institute in Toronto, Canada. Dagje is first author of five A1 publications which she presented at (inter)national conferences, was invited to several (inter)national events to present her work, and was guest lecturer within the bachelor and master programs of occupational therapy and advanced master in global health. She is also conducting research on behaviors related to antibiotics and biocides in Belgium on behalf of the FDS Public Health, Food Chain Safety and Environment at the University of Antwerp.

Education

2019 – current	PhD Candidate in Health Sciences Ghent University
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Professional experience

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September 2021 – April 2022	Coordinator project networks occupational therapy

Publications

How do people with chronic conditions and their informal caregivers experience primary care? A phenomenological-hermeneutical study. *Journal of Clinical Nursing.* **Dagje Boeykens**, Muhammed Mustafa Sirimsi, Lotte Timmermans, Maja Lopez Hartmann, Dominique Van de Velde, Patricia De Vriendt & on behalf of the Primary Care Academy. 2023;32(3-4):422-437

Creating space to talk about patients' personal goals: experiences from primary care stakeholders. *BMC Primary Care.* **Dagje Boeykens**, Reini Haverals, Muhammed Mustafa Sirimsi, Lotte Timmermans, Dominique Van de Velde, Patricia De Vriendt, Pauline Boeckxstaens & on behalf of the Primary Care Academy. 2023; 24(11)

Exploring readiness for implementing goal-oriented care in primary care using Normalization Process Theory. *Primary Health Care Research and Development.* Ine Huybrechts, **Dagje Boeykens**, Agnes Grudniewicz, Carolyn Steele Gray, An De Sutter, Peter Pype, Dominique Van de Velde, Pauline Boeckxstaens, Sibyl Anthierens & on behalf of the Primary Care Academy. 2023; 8(24):e12

Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: a scoping review and concept analysis. *PlosOne.* **Dagje Boeykens**, Pauline Boeckxstaens, An De Sutter, Lies Lahousse, Peter Pype, Patricia De Vriendt, Dominique Van de Velde & on behalf of the Primary Care Academy. 2022; 17(2):e0262843

Building an understanding of goal-oriented care through the experiences of people living with chronic conditions. *Patient Education and Counseling.* **Dagje Boeykens**, Lara Decoster, Dorine Lenoir, An De Sutter, Reini Haverals, Lies Lahousse, Peter Pype, Dominique Van de Velde, Pauline Boeckxstaens, Patricia De Vriendt & on behalf of the Primary Care Academy. 2023; 107:107567

Self-management in Flemish primary care practice: the development of a preliminary conceptual model using a qualitative approach. *BMC Primary Care.* Lotte Timmermans, **Dagje Boeykens,** Mustafa Muhammed Sirimsi, Peter Decat, Veerle Foulon, Ann Van Hecke, Mieke Vermandere, Birgitte Schoenmakers & on behalf of the Primary Care Academy. 2022; 23(1):63

Publications – others

Goal-oriented care: a shared language and co-creative practice for health and social care. *Koning Boudewijnstichting*. Pauline Boeckxstaens, **Dagje Boeykens**, Jean Macq, Philippe Vandenbroeck, 2020

Persoonsgerichte zorg bij patiënten met multimorbiditeit. *Minerva.* **Dagje Boeykens,** Dominique Van de Velde, Patricia De Vriendt, An De Sutter, Peter Pype, Pauline Boeckxstaens. 2021

Inspirerende bijdragen voor een sterke eerste lijn in Vlaanderen. *Academie Voor De Eerste Lijn.*

Integratie van persoonlijke patiëntdoelen in het geneesmiddelenbeleid van de huisarts. *Minerva*. Reini Haverals, **Dagje Boeykens**, Pauline Boeckxstaens. 2022

Oral presentations – international conferences

Goal-oriented care in primary care: a concept analysis. *92nd EGPRN Meeting.* **Dagje Boeykens,** Pauline Boeckxstaens, An De Sutter, Lies Lahousse, Peter Pype, Patricia De Vriendt, Dominique Van de Velde. 2021; virtual

Goal-oriented care: from a conceptual model to a practice-based intervention for primary care: a concept analysis. *Joint International Project for Occupational Therapy.* 2021; virtual

Goal-oriented care: an understanding on how primary healthcare professionals operationalize goal-oriented care in three international settings (Ghent, Vermont, and Ottawa). *International Conference on Integrated Care.* **Dagje Boeykens,** Patricia De Vriendt, An De Sutter, Agnes Grudniewicz, Lies Lahousse, Peter Pype, Carolyn Steele Gray, Dominique Van de Velde, and Pauline Boeckxstaens. 2022; Odense

"It's about telling my story in a trustful relationship": learning about goal-oriented care through the experiences of patients with chronic conditions or multimorbidity. *International Conference on Integrated Care.* **Dagje Boeykens,** Pauline Boeckxstaens, Dominique Van de Velde, Patricia De Vriendt. 2022; Odense

Redesigning healthcare in Flanders to meet the needs of patients with chronic conditions: how to implement goal-oriented care? *World Federation of Occupational Therapy.* **Dagje Boeykens,** Reini Haverals, Muhammed Mustafa Sirimsi, Lotte Timmermans, Dominique Van de Velde, Patricia De Vriendt, and Pauline Boeckxstaens. 2022; Paris

Experiences of people living with chronic conditions and their informal caregiver towards primary care in Flanders. *EFPC.* Dominique Van de Velde, **Dagje Boeykens,** Lotte Timmermans, Muhammed Mustafa Sirimsi, Maja Lopez Hartmann, and Patricia De Vriendt. 2022; Ghent

Oral presentations – national conferences

Een blik vanuit drie brillen naar doelgerichte zorg. *Eerstelijnsconferentie Academie Voor de Eerste Lijn.* **Dagje Boeykens**, Pauline Boeckxstaens, Patricia De Vriendt, and Dominique Van de Velde. 2021; virtual

Poster presentations – international conferences

From theory to an understanding on how primary care providers and managers operationalize goal-oriented care in three international primary care setting. *94th EGPRN Meeting.* **Dagje Boeykens,** Patricia De Vriendt, An De Sutter, Agnes Grudniewicz, Lies Lahousse, Peter Pype, Carolyn Steele Gray, Dominique Van de Velde, and Pauline Boeckxstaens. 2022; Istanbul

Are primary care providers ready to implement goal-oriented care? An explorative study using the Normalization Process Theory. *94th EGPRN Meeting.* Ine Huybrechts, **Dagje Boeykens,** Agnes Grudniewicz, Carolyn Steele Gray, An De Sutter, Peter Pype, Dominique Van de Velde, Pauline Boeckxstaens, and Sibyl Anthierens. 2022; Istanbul

Putting patients' goals first: learning from primary care stakeholders about their perspectives, strategies they use, and challenges they encounter. *NAPCRG Annual Meeting.* **Dagje Boeykens,**

Reini Haverals, Mustafa Muhammed Sirimsi, Lotte Timmermans, Dominique Van de Velde, Patricia De Vriendt, and Pauline Boeckxstaens. 2022; Phoenix

Goal-oriented care: operationalizing the theoretical concept by insights of cases in Ghent, Vermont, and Ottawa. *NAPCRG Annual Meeting.* **Dagje Boeykens,** Patricia De Vriendt, An De Sutter, Agnes Grudniewicz, Lies Lahousse, Peter Pype, Carolyn Steele Gray, Dominique Van de Velde, and Pauline Boeckxstaens. 2022; Phoenix

Poster presentations – national conferences

"Let's hope they do not put me in a nursing home" Experiences of community dwelling patients and their informal caregivers towards primary care. *Wintermeeting gerontologie.* **Dagje Boeykens**, Muhammed Mustafa Sirimsi, Lotte Timmermans, Maja Lopez Hartmann, Dominique Van de Velde, Patricia De Vriendt. 2022; Ostend

Goal-oriented care: bridging the gap between theory and practice with learnings from primary healthcare professionals. *Wintermeeting gerontologie.* **Dagje Boeykens,** Patricia De Vriendt, An De Sutter, Agnes Grudniewicz, Lies Lahousse, Peter Pype, Carolyn Steele Gray, Dominique Van de Velde, Pauline Boeckxstaens. 2022; Ostend

Invited talks

An introduction on the implementation process of goal-oriented care in Flanders. *Scirocco Research Project.* 2021; virtual

Experiences with goal-oriented care: example of Belgium. *ART² Conference.* 2022; Denver

Goal-oriented care: from a conceptual framework towards a practice-based understanding. *Building Research for Integrated Primary Healthcare in Nova Scotia*. 2023; virtual

Patient-centered care and implementation of goal-oriented care. *Sciensano.* 2023; Brussels

Teaching activities

(guest) lecturer
Advanced master in global health, University of Antwerp
Master of Science in Occupational Therapy, Ghent University
Bachelor of Occupational Therapy, Artesis Plantijn University of Applied Sciences

Co-supervisor bachelor and master theses

International research stay

September 2022 – December 2022

Research stay
Lunenfeld – Tanenbaum Research Institute
Sinai Health
Toronto, Canada

Extra activities

Member of the Knowledge Centre of Occupational Therapy (OKE)

Member of the Advisory Group ‘Grondslagen in de Ergotherapie’