IMPROVING THE QUALITY OF CARE FOR OLDER ADULTS

Towards person-centred integrated care supported by digital health technology

Esmée Bally

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Towards person-centred integrated care supported by digital health technology

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Copromotoren: Dr. A. van Grieken
Dr. B. Roozenbeek

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CHAPTER 1

General Introduction

BACKGROUND

In the European Union (EU), the proportion of older adults - defined in this thesis as those aged 65 years and over -is expected to rise from 21% in 2020 to 29% in 2050 (1). Moreover, the number of persons who are 80 years and older is projected to more than double in the next 30 years (1). Ageing is associated with an increased risk of chronic conditions (2). Multimorbidity, the coexistence of two or more chronic conditions in one person, is common among older adults (3). Approximately one-third of European citizens aged 50 years and older have multimorbidity (4), which increases with age, estimated at 30% for those aged 60-69 years, 44% for those aged 70-79 years and 51% for those aged ≥80 years (5).

Multimorbidity is associated with reduced functional status (6), reduced quality of life (7), and increased use of health care (8). Consequently, multimorbidity has become a considerable challenge to health and social care provision and funding (8). Service provision based on disease-specific guidelines can be inappropriate for patients with multimorbidity (7). If each condition is considered in isolation, care can become duplicative and inefficient due to poor coordination and integration (3). With this challenge in mind, organisations in Europe have endorsed the Chronic Care Model (9) to deliver high-quality care to patients with multiple chronic conditions (10). The Chronic Care Model sets out the design of chronic care initiatives to improve quality and outcomes, which is shown in **Figure 1**.

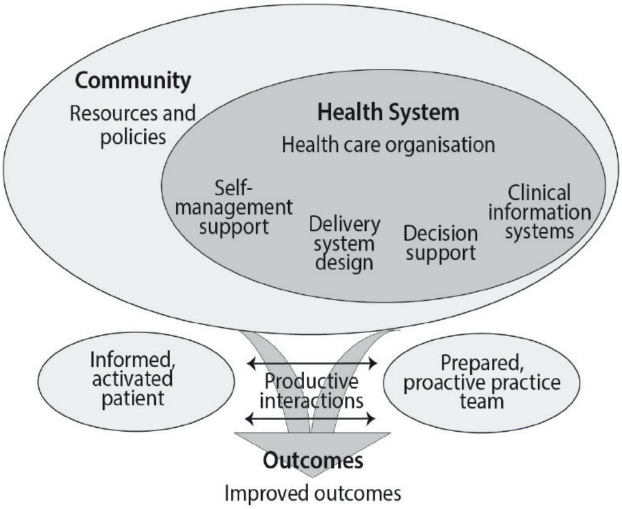

Figure 1 The Chronic Care Model (9)

In the Chronic Care Model, the health system is portrayed as part of the larger community and the practice as part of a health care organisation. The Chronic Care Model aims to achieve productive interactions between informed, activated patients and prepared, proactive care teams to improve outcomes. These two spheres are illustrated in the bottom half of the model. Quality improvement focuses on the four areas contained in the health system oval: self-management support, delivery system design, decision support and clinical information systems. **Table 1** provides an overview of efforts and interventions related to the components of the Chronic Care Model.

Table 1 Components of the Chronic Care Model, adapted from Wagner et al. 1999 (9)

MODEL COMPONENT	GOAL
Health system – Health care organisation	Program planning including measurable goals to improve chronic care
Self-management support	Support patients in increasing their confidence and skills to manage their health and care
Delivery system design	Reorganise care team function and practice systems (e.g., care delivery, follow-up) to meet the needs of chronically ill patients
Decision support	Integrate evidence-based guidelines into daily clinical practice
Clinical information systems	Establish information systems that facilitate improved care delivery (e.g., tracking systems, disease registries, monitoring performance)
Community - Resources and policies	Increase access to effective programs in the community and implement policies improving population health
Outcomes – Improved outcomes	Improve individual functional and clinical outcomes as well as population health outcomes

This thesis is guided by the Chronic Care Model. First, determinants of health and health outcomes among older adults are explored. Studies presented in Part I of this thesis used self-reported questionnaires to measure and analyse specific aspects of health and well-being, including falls and health-related quality of life (HRQOL). Identifying older adults at risk of poor outcomes can help clinicians and policymakers determine optimal resource allocation for prevention and care, which relates to the community component of the Chronic Care Model. Second, there is a need to explore stakeholder perspectives to improve the quality of care. In Part II of this thesis, the focus is on self-management support, delivery system design and clinical information systems as part of the health system component. Needs and preferences regarding self-management support were examined from the patients' perspective. In addition, Part II studied how different types of care delivery (e.g., person-centred care, integrated care) can contribute to productive interactions between patients and providers, which corresponds with the delivery system design element.

Furthermore, stakeholder perspectives regarding information systems (i.e., digital health technology) to support individual health and care were explored. Finally, in Part III, the design of a study to evaluate person-centred integrated care supported by digital health technology for older adults is described that aimed to improve health outcomes, enhance the experience of care, and use resources more efficiently.

HEALTH OUTCOMES IN OLDER ADULTS

Falls

Falls are a leading cause of injury among older adults. One in three community-dwelling older adults fall each year (11). After a fall, 20 to 30% of older adults have moderate to severe injuries (12) and in 10% of all cases hospitalisation is required (11). Falling affects the health of an older person, as well as health care costs. In the Netherlands, the estimated direct medical costs were 1.5 billion euros (13) in 2021 which is expected to increase to 2.7 billion by 2040 as the population ages (14).

Previous studies among community-dwelling older adults have identified several risk factors for falls such as high age (15), being female (16), the presence of multiple health conditions (17), experiencing frailty (15) and having mobility limitations (18). However, differences may exist between hospitalised and community-dwelling older adults. Studying the factors associated with falls enables the identification of older adults who are at increased risk of falling. This information can be used to design tailored fall prevention interventions for various groups at risk (19).

Health-related quality of life

The World Health Organization defines quality of life as “an individual’s 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” (20). Health-related quality of life (HRQOL) refers to those aspects of quality of life that relate to a person’s perception of health (21). It includes various domains of health such as general health, physical functioning, mental health, social functioning and role function (22). HRQOL can be used to assess the impact of disease on a person’s life as well as within the general population (21).

Measuring HRQOL is an important component of public health surveillance and can be considered a valid indicator of unmet needs and intervention outcomes (21). Analysis of HRQOL data may support the identification of subpopulations with relatively poor self-reported health. Interpretation and publication of these data can help to allocate resources more efficiently and to monitor the effectiveness of interventions (20). Previous studies have identified several factors associated with HRQOL such as gender (23), lower education (24) and chronic conditions (25). However, most studies have focused on HRQOL regarding specific diseases or subpopulations. There is a need for a comprehensive view by studying the determinants of HRQOL in the general older adult population.

PERSON-CENTRED INTEGRATED CARE SUPPORTED BY DIGITAL HEALTH TECHNOLOGY

There is wide consensus that re-design of care could support people living with chronic conditions (26). This requires a shift away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive, in which people with chronic conditions are encouraged to manage their health and care. The Chronic Care Model has been a catalyst to help health systems to reorient and to apply alternative approaches to care delivery, including:

- *Integrated care.* Integrated care has the potential to better articulate health and social care around individual needs and to improve care coordination (27).
- *Value-based health care*. A value-based (or outcome-based) care approach aims to measure and use the outcomes/values that are important to patients, thereby allowing the identification of individual care needs (28).
- *Person-centred care.* Person-centred care can support the shift to a partnership model in which patients are proactive in determining their own care and support needs (29).
- *Digital health technology*. Digital health technology could reshape the way chronic conditions are managed by involving patients better in the care process and promoting self-management (30).

The concepts of integrated care, value-based health care, person-centred care and digital health technology and how they relate are discussed in the sections below. They fit within the key elements of the Chronic Care Model by improving patient-provider interactions, assuring self-management support, reorganising chronic care delivery, and enhancing information systems.

Integrated care

Integrated care is a multidimensional concept without a universally accepted definition (31). It can be characterised as a proactive, person-centred and holistic approach to health and care, which is coordinated across the continuum of care (27). Older adults receive care from multiple providers at various sites such as outpatient units, primary care practices, speciality clinics, hospitals, and others, which often results in a lack of coordination (27). Integrated care includes processes of linking and coordinating services to overcome fragmentation and duplication of care (32).

Reviews on integrated care models for people with chronic conditions found beneficial effects for outcomes such as quality of life, functional health, clinical outcomes and patient satisfaction (33, 34). However, previous research on the effectiveness of integrated care for older adults remains inconclusive (35). There is a need for more knowledge on how to adapt components of integrated care to individual settings (27). Furthermore, evaluating integrated care can be challenging as it involves complex organisational changes, rather than discrete interventions. This requires the selection of appropriate methodologies for evaluation, including mixed-methods research (36).

Value-based health care

Volume-driven, fragmented and fee-for-service health care systems incentivise health care professionals to treat more patients – not providing high-quality care to the right patient (37). Instead of focusing on services, value-based health care focuses on outcomes (37). Health care providers traditionally centred their attention on clinical outcomes such as survival. However, patients perceive other factors as equally important (28). In outcome-based care, health outcomes are measured based on what is meaningful to patients and across the continuum of care (38). Moreover, it enables patients and health care professionals to discuss appropriate care and monitor outcomes over time.

Value can be defined as health outcomes achieved relative to the costs of care (28). The International Consortium for Health Outcomes Measurement (ICHOM) has emerged as an enabler of value-based health care by developing and validating condition-specific measures of health outcomes (39). This has resulted in a set of patient-reported outcome measures for older adults (40). Examples of health outcomes included in this ICHOM set are quality of life, frailty, falls, activities of daily living and loneliness.

Measurement of patient-reported outcomes may contribute to improving daily clinical practice. It has the potential to incorporate the patient perspective better into health care (39), thereby improving the quality of care (33). Therefore, value-based health care can contribute to productive interactions between informed, activated patients and prepared, proactive care teams, one of the goals of the Chronic Care Model.

Person-centred care

Person-centred care supports health care professionals to collaborate with patients to:

- learn what is important to the person;
- co-produce decisions about care and treatment;
- set and monitor a person's goals (29).

Person-centred care complements integrated value-based health care, as patients' values, needs and preferences are considered and, once discussed, guide all aspects of care, supporting patients' realistic health and life goals (29). *Values* refer to broad goals that reflect an individual's consideration of what is important and worthy (41). Their relevance can change across different situations and influence patients' needs and preferences. From a patient's perspective, a *need* can be anything to enhance health and/or comfort (42). Patient *preferences* are the result of an individual's evaluation of relevant elements of health care, including anticipated treatments and health outcomes, and how this relates to them (43).

Previous studies reported several benefits of person-centred care including increased satisfaction with care and perceived quality of care (44), as well as improved clinical outcomes (45). Yet, person-centred care remains hard to operationalise (44, 45). Understanding patients' values, needs and preferences could help health care providers to make a shift towards adopting a person-centred approach. There is a need for more research on patients' values, needs and preferences across the continuum of care, particularly concerning stroke (46).

Digital health technology

Digital health technology can be seen as an important enabler of patient-provider partnerships (30) and could, therefore, support care that is integrated, value-based and person-centred. The World Health Organization has defined digital health as "the field of knowledge and practice associated with the development and use of digital technologies to improve health" (47). Digital technologies for health include, but are not limited to, information and communication technology, mobile health technology (mHealth), artificial intelligence, big data, and robotics (47). It provides opportunities to involve patients in the care and decision-making process and to promote self-management (48). For example, studies provided evidence that mobile apps can support patients by acting as physical activity monitors to avoid sedentary behaviour (49), providing content for health education (50), and sending medication reminders (51).

Although digital health technology is being designed to address patients' needs, patients are rarely involved in the design process from an early stage (52). This could constrain the adoption and acceptance of technology in clinical practice and by end users, which includes patients, as well as their caregivers and health care professionals (53). Patients (and their caregivers) have "lived experiences" of coping with disease and bring experiential knowledge to the design (54). There is a need to incorporate the patient's and caregiver's voice better into the design of digital health technology.

In this thesis, opportunities to improve integrated care, value-based health care, person-centred care and digital health technology support are explored from the perspective of patients. We advance our understanding of how digital health technology should be designed to support patients, taking stroke as an example. Furthermore, we explore barriers and facilitators related to the adoption of digital health technology by health care organisations from a health system perspective.

DESIGN OF AN INTERVENTION FOR PERSON-CENTRED INTEGRATED CARE

The third part of this thesis presents the design of the 'ValueCare' approach. ValueCare aims to deliver value-based, person-centred integrated care supported by digital health technology for older adults to improve their health and care. A general value-based, person-centred integrated care approach supported by digital health technology is presented, which can be adapted to the local context. In this thesis, the design of a study to evaluate the ValueCare approach is described. In addition, the application of the ValueCare approach to stroke care is explored.

Stroke care

In ValueCare, seven large-scale sites in Europe (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, the Netherlands; Treviso, Italy; and Valencia, Spain) adapt and implement the ValueCare approach to their local context.

In Rotterdam, the ValueCare approach was targeted to people who have had ischemic stroke.

Stroke is (generally) a disease of ageing - approximately three-quarters of all strokes occur in people ≥65 years (55). In 2017, there were an estimated 9.53 million prevalent stroke cases in the EU, and this number is expected to rise to 12.11 million by 2047 (56). Ideally, a patient pathway begins with the recognition of and response to symptoms, followed by diagnosis and reperfusion therapy (if appropriate), and measures to prevent complications and promote recovery (57). Post-acute stroke care aims to support the restoration of a patient's functioning, including access to ongoing diagnostics, therapy, secondary prevention, rehabilitation, psychological support, and self-management strategies (58). This requires health and social care professionals to work collaboratively to exert their collective knowledge and specialist skills for the benefit of stroke survivors (59). In this context, there are many opportunities to improve integrated stroke care.

RESEARCH OBJECTIVES

The overall aim of the research presented in this thesis is to improve the quality of care for older adults by studying person-centred integrated care supported by digital health technology. First, the factors associated with health outcomes among older adults are identified, specifically falls and health-related quality of life (HRQOL). Second, the perspectives of patients and other stakeholders regarding person-centred integrated care and digital health technology are explored. Third, the design (of a study to evaluate the effects) of a person-centred integrated care intervention supported by digital health technology for older adults in multiple settings is described.

The specific study questions are:

Part I: Understanding the determinants of health outcomes that matter to older adults

- What factors are associated with falls among hospitalised and community-dwelling older adults? (Chapter 2)
- What factors are associated with health-related quality of life among community-dwelling older adults? (Chapter 3)

Part II: Stakeholder perspectives regarding person-centred integrated care supported by digital health technology

- What are the values, needs and preferences of stroke patients across the continuum of care? (Chapter 4)
- How could digital health technology support stroke patients' self-management regarding health and well-being, as well as integrated care? (Chapter 5)
- How can digital health technologies for people with chronic conditions be integrated into the Dutch health system? (Chapter 6)

Part III: Design of a person-centred integrated care intervention supported by digital health technology

- How to design and evaluate a person-centred integrated care intervention supported by digital health technology for older adults in multiple settings in Europe? (Chapter 7)

DATA SOURCES AND METHODS

The analyses in this thesis were performed using quantitative and qualitative data from three sources (**Table 2**).

Appcare

The 'Appropriate care paths for frail elderly patients: a comprehensive model' (APPCARE) study was a prospective cohort study funded by the European Commission, under Grant Agreement No. 664689. APPCARE aimed to implement and evaluate comprehensive and coordinated care for frail older adults (≥65 years). Participants filled out a baseline and 6-month follow-up questionnaire, including questions on indicators of health, lifestyle, and sociodemographic factors. The project has been conducted in three European sites (Rotterdam, the Netherlands; Treviso, Italy; and Valencia, Spain). In Rotterdam, the study sample consisted of hospitalised and community-dwelling older adults. In this thesis, baseline and follow-up data from the Rotterdam site were used for analyses.

ValueCare

The ValueCare project aims to deliver value-based, person-centred integrated health and social care for older people (≥65 years) with multimorbidity, frailty, or mild to moderate cognitive impairment in seven sites (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, the Netherlands; Treviso, Italy; and Valencia, Spain) (60). The ValueCare project is funded by Horizon 2020, under Grant

Agreement No. 875215. The evaluation of ValueCare has a pre-post-controlled design with an intervention group (using the 'ValueCare approach') and a control group ('care as usual'). Measurements are taken at baseline, after 12 months (the end of the 'ValueCare approach' intervention period), and at 18 months. Each site adapts the general ValueCare approach to its target group and local context. In Rotterdam, the target group consisted of people who have experienced an ischemic stroke. The data used in this thesis were collected in co-design sessions among stroke patients.

Amsterdam study

This study aimed to explore the barriers and facilitators affecting the integration of digital health technology in primary care in the Netherlands and to identify the stakeholders engaged in this process. A stakeholder analysis and health system assessment were conducted using several rounds of interviews and a focus group.

Table 2 Data sources and methods used in this thesis

Study from which data were used	Design	Sample	N	Research focus	Chapter
APPCARE	Cross-sectional	Hospitalised and community-dwelling older adults aged 65 years and older	890	Factors associated with falls	2
	Longitudinal	Community-dwelling older adults aged 65 years and older	661	Factors associated with health-related quality of life	3
ValueCare	Semi-structured interviews	Patients diagnosed with ischemic stroke aged 50 years and older	36	Values, needs and preferences across the care continuum	4
	Semi-structured interviews	Patients diagnosed with ischemic stroke aged 50 years and older	36	Perspectives regarding digital health technology for self-management and care	5
	Study protocol	NA	NA	Design of the ValueCare study	7
Amsterdam	Interviews and focus group	A diverse group of relevant stakeholders (e.g., chronically ill patients, general practitioners, policymakers, managers)	28	Stakeholder analysis and barriers and facilitators in integrating digital health technology in primary care	6

OUTLINE OF THIS THESIS

The first part of this thesis consists of studies exploring the determinants of health outcomes among older adults. **Chapter 2** provides insights into the factors associated with falls among hospitalised and community-dwelling older adults using a cross-sectional design. **Chapter 3** examines the factors associated with health-related quality of life among community-dwelling older adults using a longitudinal design. The results of these studies could help to identify older adults at risk for adverse health outcomes and to tailor interventions better to their needs.

The second part of this thesis is focused on exploring stakeholder perspectives, especially the patient perspective. **Chapters 4 and 5** report the results of a qualitative study to gain a deeper understanding of stroke patients' values, needs and preferences regarding care and how digital health technology could support a patient's health and care. In **Chapter 6**, the readiness of the Dutch health system to adopt digital technologies for health and care is assessed by exploring barriers and facilitators and stakeholder positions and views.

The final part of this thesis covers the design of a study to evaluate a person-centred integrated care intervention supported by digital technologies for older adults (ValueCare). In **Chapter 7**, the design of the 'ValueCare approach' is described.

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PART I

Understanding the determinants of health outcomes that matter to older adults

CHAPTER 2

Factors associated with falls among hospitalized and community-dwelling older adults: the APPCARE study

Esmée Bally, Lizhen Ye, Amy van Grieken, Siok Swan Tan, Francesco Mattace-Raso, Elena Procaccini, Tamara Alhambra-Borrás, Hein Raat

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ABSTRACT

Background: Falls are a leading cause of disability. Previous studies have identified various risk factors for falls. However, contemporary novel research is needed to explore these and other factors associated with falls among a diverse older adult population. This study aims to identify the factors associated with falls among hospitalized and community-dwelling older adults.

Methods: Cross-sectional data from the ‘Appropriate care paths for frail elderly people: a comprehensive model’ (APPCARE) study were analyzed. The study sample consisted of hospitalized and community-dwelling older adults. Falling was assessed by asking whether the participant had fallen within the last 12 months. Multivariable logistic regression models were used to evaluate associations between socio-demographic characteristics, potential fall risk factors and falls.

Results: The sample included 113 hospitalized (mean age = 84.2 years; 58% female) and 777 community-dwelling (mean age = 77.8 years; 49% female) older adults. Among hospitalized older adults, loneliness was associated with an increased risk of falls. Associations between female sex, secondary education lever or lower, multimorbidity, a higher score on limitations with activities of daily living (ADL), high risk of malnutrition and falling were found among community-dwelling participants.

Conclusion: The results of this study confirm the multi-factorial nature of falling and the complex interaction of risk factors. Future fall prevention programs could be tailored to the needs of vulnerable subpopulations at high risk for falls.

INTRODUCTION

A fall can be defined as “an unexpected event in which the participant comes to rest on the ground, floor, or lower level” (1). One in three community-dwelling older adults fall each year (2), and the incidence rate of fall-related injuries increases with age (3). After a fall, 20 to 30% of older adults have moderate to severe injuries (1). In approximately 10% of all cases falls can lead to serious injuries that require hospitalization, such as fractures, joint dislocations, and head injury (2). Falling affects not only the health of older adults, but also places a high burden on public health resources (4). In 2021, in the Netherlands, the estimated direct medical costs were 1.5 billion euros (5) which is expected to increase to 2.7 billion by 2040 as the population ages (6).

Falls can have multiple causes resulting from the complex interaction of risk factors. Previous studies have identified several predicting factors for falls in the general population, including socio-demographic (e.g., age, sex), biological (e.g., history of falls, visual impairment), environmental (e.g., home hazards, physical disability), behavioral (e.g., medication intake, sedentary behavior) and cognitive-related factors (7–10). Among community-dwelling older adults, previous studies identified older age (7-10), being female (7, 10), the presence of multiple health conditions (9), being frail (7), having mobility limitations (8–10) using multiple medications (7, 9) and having depressive symptoms (7, 8) as the predictors most strongly associated with falls.

However, differences may exist between hospitalized and community-dwelling older adults. Identifying the factors associated with falls among subpopulations is crucial in fall prevention (11). It enables the identification of older adults who are at high risk of falling, thereby allowing tailored fall prevention programs for various groups at risk. The aim of the current study is to identify the factors associated with falls among hospitalized and community-dwelling older adults. The factors included in the study are socio-demographic characteristics and potential fall risk factors (e.g., health indicators, lifestyle factors).

METHODS

Study design

A cross-sectional study was performed using data from the ‘Appropriate care paths for frail elderly people: a comprehensive model’ (APPCARE) study. APPCARE is a prospective cohort study funded by the European Commission, under Grant Agreement No. 664689. APPCARE aimed to promote healthy aging. The project has been conducted in three European sites (Rotterdam, the Netherlands; Treviso, Italy, and; Valencia, Spain). The current study used baseline data from the Rotterdam site.

Participants

The study sample consisted of hospitalized and community-dwelling older adults. Three hospitals located in the Rotterdam region contributed to the recruitment of hospitalized older adults. All patients ≥70 years and older that entered the geriatric ward were invited by their healthcare provider to participate in the study, resulting in a total of 137 invited patients. Additionally, in collaboration with the Municipality of Rotterdam, 865 community-dwelling older adults (≥65 years) were invited by letter. An information package with an information sheet, informed consent form, baseline questionnaire, and prepaid envelope was distributed by post. Data were collected between 2017 and 2018. Participants who provided informed consent and completed the baseline questionnaire were included in the study. The Medical Ethics Committee of Erasmus MC University Medical Center in Rotterdam declared that the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO), do not apply to this research (reference number: MEC-2016-559).

Data from 966 participants who provided informed consent and filled in the baseline questionnaire were available for this study. In order to conduct the full analysis, participants with missing data in the outcome variable (*n*=35), age (*n*=39), and sex (*n*=2) were excluded, resulting in 890 (92.1%) subjects included. A flow diagram of the population of analysis is presented in **Figure 1**.

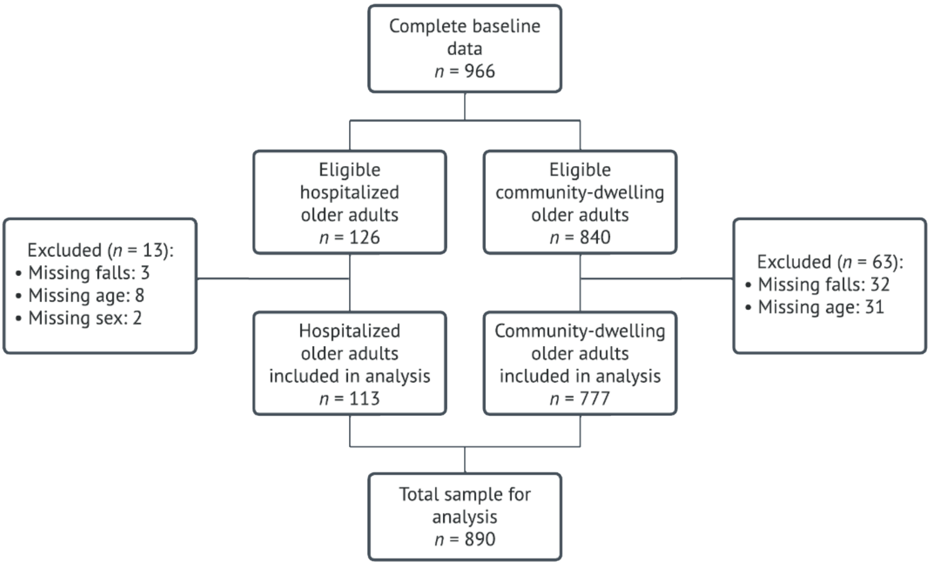

Figure 1 Population of analysis

Measures

Falling

The outcome measure used in this study is rate of falling. Falls were self-reported and assessed by asking participants "Have you had a fall in the last 12 months?" (12). Fall status was dichotomized into has fallen one or more times versus no falls.

Socio-demographic factors

Socio-demographic characteristics were assessed at baseline and included as covariates. Age (in years) was provided by participants and categorized into 65–79 years and ≥80 years for logistic regression. This cut-off was chosen based on publications by the World Health Organization, in which the oldest-old is defined as people aged 80 or older (2, 13). Living situation was categorized into living with others or living alone. Education level concerned the highest level of education the participant achieved and was split into two categories based on the International Standard Classification of Education (ISCED). ISCED level 0–5 was categorized as 'secondary or lower' and ISCED level 6–8 was categorized as 'tertiary or higher' (14).

Fall risk factors

Variables reported as risk factors in the literature (15, 16) and assessed at baseline were considered as associated factors: multimorbidity, frailty, limitations with activities of daily living (ADL), loneliness, risk of medication-related problems, risk of malnutrition, physical activity and poor vision. Multimorbidity was defined as having two or more medical conditions and/or disabilities at the same time (17). Participants were asked whether they had one or more chronic conditions diagnosed by a medical professional. A list of 13 common chronic conditions (e.g., high blood pressure, stroke, diabetes) was provided to participants to select from (18). Participants could add any health condition that was not listed. Frailty was assessed by the 15-item Tilburg Frailty Indicator (TFI) (19). The score on overall frailty ranged from 0 to 15. Participants with a total TFI-score≥5 were considered frail (19). ADL limitations were measured with the Groningen Activity Restriction Scale (GARS) (20). Response categories by activities were: 'Yes, I can do this fully independently, without any difficulty', 'Yes, I can do this fully independently, but with some difficulty', 'Yes, I can do this fully independently, but with great difficulty', and 'No, I can only do it with someone's help'. Answers were assessed on a 4-point scale with a minimum score of 18 and maximum score of 72. Higher scores represented a lower level of independence. Loneliness was measured using the 6-item De Jong-Gierveld Loneliness Scale (21). Answer options were 'no', 'more or less' and 'yes'. Scores were calculated according to the guidelines (22). Scores on overall loneliness varied between 0 or 1 'No loneliness', 2 to 4 'Moderately intense loneliness', and 5 or 6 'Intense loneliness'. In this study, the total loneliness score was dichotomized in 'not lonely' (score 0 or 1) and 'lonely' (score 2 through 6). Risk of medication-related problems was evaluated by the Medication Risk Questionnaire (MRQ) (23). The MRQ includes questions to assess polypharmacy, inappropriate prescribing, and poor adherence. The sum of eight items of the MRQ was used to calculate the risk of medication-related problems (23). Participants were classified as 'low risk' (score 0 through 3) or 'high risk' (score 4 or higher) (24). Risk of malnutrition was measured following the guidelines of the Short Nutritional Assessment Questionnaire 65+ (SNAQ65+) (25) and dichotomized in 'low risk' and 'high risk'. SNAQ65+ consists of 4 questions: mid-upper arm circumference (<25 cm), unintentional weight loss (≥4 kg last six months), appetite, and walking stairs. As this study used self-reported data, an assessment of mid-upper-arm circumference was not available. Therefore, mid-upper arm circumference was excluded from score calculation. Instead, more emphasis was placed on unintentional weight loss which was measured by one item of the TFI (26). If a participant lost 6 kg or more during the last 6months, or 3 kg or more during the last month this was categorized as high risk of malnutrition. Participants with poor appetite and problems with walking stairs and no weight loss, or no indications at all for malnutrition, were categorized as low risk. Physical activity was measured by one item of The Frailty Instrument of the Survey of Health, Aging and Retirement in Europe (SHARE-FI) (27). Participants were asked to indicate the frequency of activities requiring low to medium energy levels, such as gardening or going for a walk. Answers were dichotomized into 'once a week or less' or 'more than once a week'. Poor vision was assessed by asking participants 'Do you experience problems in your daily life due to poor vision?' If participants answered 'yes' to this question, this was categorized as poor vision.

Statistical analyses

The analyses were done separately for the two sub-samples (hospitalized and community-dwelling older adults). Analyses were conducted using SPSS version 25.0 (IBM Corp., Armonk, NY, United States). Participant characteristics were analyzed using descriptive statistics. Characteristics of fallers and non-fallers were compared by *t*-test for continuous variables and by means of chi-square tests for categorical variables. Multivariable logistic regression was used to assess associations between the associated factors and falling. Odds ratio's (OR) with 95% confidence intervals (95% CI) were calculated for each factor. Results were considered significant at $p < 0.05$. To evaluate whether the effect of associated factors on falling was modified by socio-demographic factors (age, sex, education level, household composition), an interaction term was added to the model. The interaction term socio-demographic factor*variable was tested in the multivariate logistic model, for each variable separately and with adjustment for all the other variables. Subsequently, Bonferroni correction for multivariable logistic regression was applied for analysis of the interaction items ($p = 0.05/38 = 0.001$) (28).

RESULTS

Participant characteristics

Table 1 presents the socio-demographic and fall-risk characteristics of hospitalized (*n*=113) and community-dwelling (*n*=777) older adults at baseline. The mean age of hospitalized and community-dwelling older adults was 84.2 years ± 6.8 years and 77.8 years ± 6.3 years, respectively. Among hospitalized older adults, 57.5% were women compared to 48.9% among community-dwelling older adults. A total of 72 (63.7%) hospitalized and 213 (27.4%) community-dwelling older adults reported at least one fall within the past 12 months, with an overall mean of 32%.

In the hospital group, fallers were at higher risk of medication-related problems ($p=0.013$), compared to non-fallers. Among community-dwelling participants, fallers were older ($p<0.001$), more often women ($p=0.004$), lived alone more frequently ($p<0.001$) and had more often multimorbidity ($p<0.001$), compared to non-fallers. In addition, participants who experienced a fall were at higher risk of frailty, loneliness, medication-related problems and malnutrition (*p*<0.001), compared to participants who did not fall. Furthermore, community-dwelling participants who fell were less likely to engage in physical activity more than once a week and more subject to ADL limitations and poor vision (*p*<0.001).

Factors associated with falling

The results of the multivariate logistic regression models for falling per group are presented in **Table 2**. When controlling for all factors in the model, hospitalized participants who were classified as lonely had a 3.04 (95% CI: 1.08–8.57) times higher odds of falling compared to participants who were not at risk of loneliness. There were no other significant associations between potential associated factors and falling among participants who were admitted to the hospital.

For community-dwelling participants, the multivariate regression model showed that female sex (OR = 1.57, 95% CI: 1.05–2.36) was associated with higher odds of falling. Older adults with a secondary education level or lower (OR = 0.47, 95% CI: 0.30–0.75) were at lower risk of falling compared to older adults with a tertiary education level or higher. In addition, participants with multimorbidity were at higher risk of falling (OR = 2.07, 95% CI: 1.14–3.77) compared to participants with less than two health conditions. Having a higher score on ADL limitations was also significantly associated with falling (OR = 1.03, 95% CI: 1.00– 1.06). Finally, older adults at high risk of malnutrition had a 3.05 (95% CI: 1.45–6.42) times higher odds of falling compared to participants who were at low risk of malnutrition. Interaction analyses revealed no statistically significant interactions after Bonferroni correction was applied.

Table 1 Baseline characteristics of hospitalized older adults (*n*=113) and community-dwelling older adults (*n*=777)

	Hospitalized older adults				**Community-dwelling older adults**			
	Total (*n*=113)	**Falls**		***p*-value**	**Total (*n*=777)**	**Falls**		***p*-value**
		No (*n*=41)	**Yes (*n*=72)**			**No (*n*=564)**	**Yes (*n*=213)**	
Age (years)	84.2 ±6.8	83.1 ±7.3	84.9 ±6.4	0.218[a]	77.8 ±6.3	77.0 ±5.9	79.9 ±7.0	**<0.001[a]**
Sex, female	65 (57.5%)	22 (53.7%)	43 (59.7%)	0.531[b]	380 (48.9%)	258 (45.7%)	122 (57.3%)	**0.004[b]**
Education level								
Secondary or lower	88 (83.8%)	31 (81.6%)	57 (85.1%)	0.640[b]	614 (80.2%)	447 (80.5%)	167 (79.1%)	0.666[b]
Tertiary or higher	17 (16.2%)	7 (18.4%)	10 (14.9%)		152 (19.8%)	108 (19.5%)	44 (20.9%)	
Household composition, living alone	70 (67.3%)	27 (69.2%)	43 (66.2%)	0.746[b]	314 (42.1%)	205 (37.6%)	109 (54.2%)	**<0.001[b]**
Multimorbidity, yes	96 (86.5%)	33 (84.6%)	63 (87.5%)	0.671[b]	586 (75.9%)	400 (71.2%)	186 (88.6%)	**<0.001[b]**
Frailty, yes	82 (75.9%)	27 (71.1%)	55 (78.6%)	0.383[b]	239 (32.6%)	135 (25.0%)	104 (53.9%)	**<0.001[b]**
ADL (GARS; score)	41.4 ±14.1	37.4 ±14.2	43.0 ±13.8	0.737[a]	24.9 ±9.9	23.0 ±8.2	29.9 ±12.0	**<0.001[a]**
Loneliness, yes	58 (54.7%)	17 (45.9%)	41 (59.4%)	0.184[b]	296 (39.3%)	187 (34.2%)	109 (52.7%)	**<0.001[b]**
Risk of medication-related problems, yes	58 (54.2%)	14 (37.8%)	44 (62.9%)	**0.013[b]**	268 (34.8%)	167 (29.9%)	101 (47.9%)	**<0.001[b]**
Risk of malnutrition, yes	48 (42.5%)	18 (43.9%)	30 (41.7%)	0.817[b]	53 (6.8%)	17 (3.0%)	36 (16.9%)	**<0.001[b]**
Physical activity								
Once a week or less	71 (68.3%)	22 (62.9%)	49 (71.0%)		220 (28.6%)	131 (23.4%)	89 (43.0%)	**<0.001[b]**
More than once a week	33 (31.7%)	13 (37.1%)	20 (29.0%)	0.398[b]	548 (71.4%)	430 (76.6%)	118 (57.0%)	
Poor vision, yes	30 (27.0%)	12 (29.3%)	18 (25.7%)	0.684[b]	122 (16.9%)	74 (13.9%)	48 (25.3%)	**<0.001[b]**

Table 2 Multivariable logistic regression models on associations between associated factors and falls of hospitalized older adults (*n*=113) and community-dwelling older adults (*n*=777)

	Hospitalized older adults		**Community-dwelling older adults**	
	***n*=113**[a]		***n*=777**[b]	
	OR (95% CI)	***p*-value**	**OR (95% CI)**	***p*-value**
Age				
65-79 years	Ref		Ref	
≥80 years	2.89 (0.75-11.20)	0.124	1.21 (0.79-1.85)	0.374
Sex				
Male	Ref		Ref	
Female	1.10 (0.36-3.34)	0.873	**1.57 (1.05-2.36)**	**0.029**
Education level				
Tertiary or higher	Ref		Ref	
Secondary or lower	1.51 (0.37-6.11)	0.566	**0.47 (0.30-0.75)**	**0.002**
Household composition				
Living with others	Ref		Ref	
Living alone	0.79 (0.25-2.54)	0.694	1.02 (0.66-1.56)	0.945
Multimorbidity				
0-1 health conditions	Ref		Ref	
≥2 health conditions	0.69 (0.09-5.21)	0.716	**2.07 (1.14-3.77)**	**0.017**
Frailty status				
Not frail	Ref		Ref	
Frail	1.28 (0.32-5.13)	0.730	1.42 (0.83-2.44)	0.200
ADL (GARS; score)	1.01 (0.97-1.05)	0.584	**1.03 (1.00-1.06)**	**0.025**
Loneliness				
Not lonely	Ref		Ref	
Lonely	**3.04 (1.08-8.57)**	**0.036**	1.07 (0.70-1.64)	0.762
Medication-related problems				
Low risk	Ref		Ref	
High risk	2.34 (0.82-6.72)	0.113	1.39 (0.92-2.10)	0.113
Malnutrition				
Low risk	Ref		Ref	
High risk	0.76 (0.27-2.12)	0.602	**3.05 (1.45-6.42)**	**0.003**
Physical activity				
More than once a week	Ref		Ref	
Once a week or less	1.34 (0.43-4.18)	0.612	1.51 (0.96-2.38)	0.076
Vision				
Sufficient vision	Ref		Ref	
Poor vision	0.64 (0.20-2.07)	0.452	1.06 (0.63-1.78)	0.823

OR, odds ratio; CI, confidence interval; ADL, Activities of Daily Living; GARS, Groningen Activities Restriction Scale. Significant ORs and p-values (<0.05) in bold. Multivariable model was used to analyze the association between potential associated factors and falls. All potential associated factors were included in one model.

[a] Nagelkerke *R* square = 0.18.

[b] Nagelkerke *R* square = 0.20.

DISCUSSION

This study aimed to identify the factors associated with falls among hospitalized and community-dwelling older adults. In our sample, falling was associated with female sex, education level, multimorbidity, a higher score on ADL limitations, loneliness and a high risk of malnutrition.

With respect to hospitalized older adults, participants who were indicated as lonely were more prone to falling compared to participants who were not at risk of loneliness. The direct relationship between loneliness and falls remains unclear. However, results of previous studies indicated that social isolation, living alone and low social contact were associated with falls (29–31). A possible explanation is that social relationships can result in increased access to health care services and medication compliance, reducing the risk of falling (30). Other studies suggest a link between feelings of loneliness, depression and falls (29, 32). Symptoms of major depression, such as psychomotor retardation, slow gait speed and low energy can lead to falls (32). Further research is needed to explore whether older adults are depressed due to feelings of loneliness. There were no other significant associations between potential associated factors and falling among hospitalized participants. Further research in a larger sample size is needed to examine what other factors are associated with falls in hospitalized older adults.

Among community-dwelling older adults, women were more likely than men to fall. Previous studies have reported gender differences in falls in which women are disproportionally affected (33, 34). A possible explanation is that women's bone mass decline faster than that of men, especially following menopause. This affects their physical functioning, thus increasing the risk of falling (33). Remarkably, participants who completed secondary education or lower had a relatively lower risk of falling compared to participants with a higher education level. This was not reported in the literature. In general, older adults with higher education levels have more confidence in their ability to avoid falling (35). Further studies are recommended to gain more insight in the association between education level and falling.

The association between multimorbidity and falling among community-dwelling adults is consistent with previous findings (36, 37). Sibley et al. (37) observed a linear trend between the number of chronic diseases and fall rate. More specifically, age-related health conditions such as neurodegenerative diseases were found to be major risk factors for falls (38). Aging causes loss of muscle mass and muscular strength which could lead to loss of balance and coordination resulting in falls (39).

Mobility and balance problems have been shown to be most important in the etiology of falling (39, 40). Among community-dwelling older adults, fallers had a significant higher score on ADL limitations compared to non-fallers in this group. ADL limitations could lead to slow gait speed and impact balance increasing the risk of falls (40). These findings are concurrent to the findings of other studies (8, 40, 41).

Furthermore, the present study confirms a high risk of malnutrition to be a predictor of falls in community-dwelling older adults. This is in line with findings of previous studies (42, 43). Deficiencies in nutrients can result in low body mass index which is associated with a higher risk of falls. Malnutrition in older adults is correlated with co-morbidities such as sarcopenia and frailty, increasing the risk of falling by reduced muscle strength, osteoporosis, and impaired gait speed (44). In the current study, substantial weight loss (6 kg or more during the last 6 months, or 3 kg or more during the last month) was used as the main indicator for malnutrition. If all assessment criteria are applied according to the Short Nutritional Assessment Questionnaire 65+ (SNAQ65+), the association between malnutrition and falls might even be stronger.

This study has some limitations that need to be considered when interpreting the results. First, due to the cross-sectional study design, causality cannot be inferred. Further studies with multiple follow-up measures are needed to draw conclusions on the direction of the associations. In addition, including a larger sample of hospitalized older adults can generate more information regarding the factors associated with falls among this subpopulation. Second, participants in the community-dwelling sample were recruited by sending a letter to ask if they were willing to participate. This may have resulted in selection bias in which vulnerable participants are underrepresented. However, our sample also included hospitalized older adults with a relatively high average age and poorer health outcomes. Third, dichotomous outcome measures were used for falls, which may have resulted in loss of information. However, this simplification increases the understanding for practice. A strength of this study is that potential risk factors were explored from a multidimensional perspective, including demographic characteristics, health indicators, and lifestyle factors. Moreover, a diverse study population of hospitalized and community-dwelling participants was included.

The results of this study confirm the multi-factorial nature of falling and the complex interaction of risk factors. Findings of this study imply that future fall prevention programs could be tailored to subpopulations that are vulnerable, such as malnourished or lonely older adults. Additional research is needed to determine gender differences in the underlying causes and/or circumstances of falls and across age groups. Moreover, the results of this study may be useful for screening by (informal) caregivers, health care professionals and policymakers to identify older adults at risk of falls. Future research is needed to explore longitudinal associations and to comprehensively examine the (bi-) directional associations between risk factors and falls over time.

CONCLUSIONS

The current study fills the knowledge gap in comprehensive examination of the fall risk factors in a diverse older adult population. Female sex, education level, multimorbidity, a higher score on ADL limitations, loneliness and a high risk of malnutrition were associated with falling. More research, using longitudinal designs among a diverse and representative sample, is needed to confirm these findings. Accurate identification of high-risk groups and modifiable risk factors for falls is crucial for developing effective prevention programs tailored to the needs of hospitalized and community-dwelling older adults. It is recommended to further develop effective and feasible interventions to prevent falls among older adults and to contribute to their health and wellbeing.

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CHAPTER 3

Factors associated with health-related quality of life among community-dwelling older adults: the APPCARE study

Esmée Bally, Sophie Korenhof, Lizhen Ye, Amy van Grieken, Siok Swan Tan,
Francesco Mattace-Raso, Elena Procaccini, Tamara Alhambra-Borrás, Hein Raat

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ABSTRACT

Background: Measuring health-related quality of life (HRQOL) has become an important component of public health surveillance and can be considered a valid indicator of unmet needs and intervention outcomes. This study aims to identify the factors associated with health-related quality of life among community-dwelling older adults.

Methods: Baseline and follow-up data from the 'Appropriate care paths for frail elderly patients: a comprehensive model' (APPCARE) study were analysed. Physical and mental HRQOL were measured by the 12-item Short Form Health Survey (SF-12). Linear regression models were used to evaluate associations between sociodemographic, health, and lifestyle factors and HRQOL.

Results: The sample included 661 participants (mean age = 77.4 years; 47% female). Frailty was negatively associated with physical (B = -5.56; $P < 0.001$) and mental (B = -6.65; $P < 0.001$) HRQOL. Similarly, participants with a higher score on activities of daily living limitations had lower physical (B = -0.63; $P < 0.001$) and mental (B = -0.18; $P = 0.001$) HRQOL. Female sex (B = -2.38; $P < 0.001$), multimorbidity (B = -2.59; $P = 0.001$), and a high risk of medication-related problems (B = -2.84; $P < 0.001$) were associated with reduced physical HRQOL, and loneliness (B = -3.64; $P < 0.001$) with reduced mental HRQOL. In contrast, higher age (B= 2.07; $P = 0.011$) and living alone (B = 3.43; $P < 0.001$) were associated with better mental HRQOL in the multivariate models.

Conclusion: The findings of this study imply that future interventions aimed at promoting the health and autonomy of community-dwelling older adults could be tailored to subpopulations with relatively poor self-reported HRQOL, such as frail or lonely older adults.

INTRODUCTION

In the European Union (EU), the proportion of people aged 65 and older is expected to rise substantially, from 20.6% in 2020 to 29.4% in 2050 (1). This demographic change is primarily driven by historically low birth rates combined with an increased life expectancy (2). Across the EU in 2018, men and women aged 65 years had an average life expectancy of 18.1 and 21.6 years respectively (1). However, at age 65 years, both men and women spend approximately half of their remaining lives with limitations in functioning (1). Chronic conditions such as diabetes, osteoporosis, cardiovascular disease, and dementia are increasingly common among older adults (3). These conditions may negatively impact an older person's functional independence and quality of life (4).

The WHO defines quality of life as 'an individual's 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' (5). Health-related quality of life (HRQOL) comprises those aspects of quality of life that relate to a person's perception of health (6). It is a key patient-reported outcome and usually includes various domains of health, such as general health, physical functioning, mental health, social functioning and role function (7). HRQOL can be used to assess the impact of disease on a person's life as well as within the general population (6). An example of a generic scale that has been developed to measure HRQOL is the 12-item Short Form Health Survey (SF-12) (8). The SF-12 includes eight scales yielding two summary measures: physical and mental health.

Measuring HRQOL has become an important component of public health surveillance and can be considered a valid indicator of unmet needs and intervention outcomes (6). Analysis of HRQOL data supports the identification of subgroups with relatively poor self-reported health. Interpretation and publication of these data can help to allocate resources based more efficiently and to monitor the effectiveness of community interventions (5). Previous studies have identified associations between HRQOL and sociodemographic factors, including gender and lower education (9, 10). Furthermore, chronic conditions, frailty, low levels of physical activity, and lack of social support have been associated with poor self-reported HRQOL (10-13).

Thus far studies have yielded mixed results concerning the factors associated with HRQOL. Most studies have focused on HRQOL in relation to specific diseases or subpopulations. There is a need for a comprehensive view by studying the determinants of HRQOL in the general population. New insights into the relationships between HRQOL and risk factors (e.g. sociodemographic characteristics, indicators of health, and lifestyle factors) can help to tailor interventions better to subpopulations with poor self-reported health to improve their situation and to avert more serious consequences. This study aims to identify the factors associated with HRQOL among community-dwelling older adults.

METHODS

Study design

The present study used baseline and follow-up data from the 'Appropriate care paths for frail elderly patients: a comprehensive model' (APPCARE) study - a prospective cohort study funded by the European Commission, under Grant Agreement number 664689. The APPCARE study aimed to promote healthy ageing among older adults. The project has been conducted in three European sites (Rotterdam, the Netherlands; Treviso, Italy, and; Valencia, Spain). The current study used baseline and follow-up data after six months from the Rotterdam site.

Participants

In collaboration with the Municipality of Rotterdam, 865 community-dwelling older adults (≥65 years) were invited by letter to participate in the study. An information package, including an information sheet, informed consent form, baseline questionnaire, and prepaid envelope was sent by post. After six months, a follow-up questionnaire similar to the baseline questionnaire was distributed by post to participants. Data collection took place between 2017 and 2018. Participants who provided informed consent and filled in the baseline questionnaire were included in the study. The Medical Ethics Committee of Erasmus MC University Medical Center in Rotterdam declared that the rules laid down in the Medical Research Involving Human Subjects Act, do not apply to this research (reference number: MEC-2016-559).

Data from 840 participants who provided informed consent and filled in the baseline questionnaire were available for this study. Participants who dropped out at follow-up (*n*=95) were excluded. In order to conduct the full analysis, participants with missing data in the outcome variable (*n*=64), age (*n*=20), and sex (*n*=0) were excluded, resulting in 661 (78.7%) subjects included. A flow diagram of the population of analysis is presented in **Figure 1**.

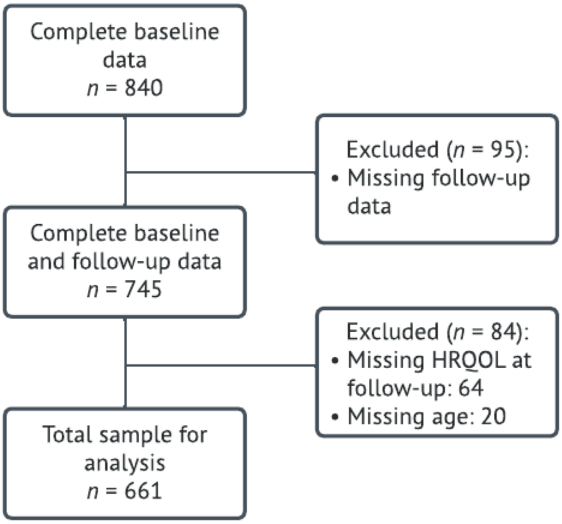

Figure 1 Population of analysis

Measures

Health-related quality of life (HRQOL)

The outcome measure used in this study is health-related quality of life (HRQOL). Physical and mental HRQOL were measured by the SF-12 (8). The SF-12 covers eight health domains: general health, mental health, vitality, social functioning, role limitation due to physical health problems, role limitation due to emotional problems, bodily pain, and physical functioning. These domains can be summarised in a Physical Component Summary (PCS) and Mental Component Summary (MCS), ranging from 0 to 100 (14). Raw summary scores were transformed into standard scores based on normalised algorithms from the United States general population (8), with a mean score of 50 and standard deviation of 10. Higher scores represent higher quality of life. A change of 3 units or more in PCS and MCS is considered clinically meaningful (15).

Sociodemographic characteristics

Sociodemographic characteristics assessed at baseline were included as covariates. Age was grouped into 65-79 years and ≥80 years. Household composition was categorised into living with others or living alone. Education level was split into two categories based on the International Standard Classification of Education (ISCED). ISCED level 0–5 was categorised as 'secondary or lower' and ISCED level 6–8 was categorised as 'tertiary or higher' (16).

Indicators of health

Indicators of health assessed at baseline included: multimorbidity, frailty, limitations with activities of daily living (ADL), loneliness, risk of medication-related problems, risk of malnutrition, and falls. Multimorbidity was defined as having two or more chronic conditions at the present time (4). A list of 13 common chronic conditions (e.g. hypertension, stroke, diabetes) was provided (17). Participants indicated whether they had one or more chronic condition(s) diagnosed by a physician. Frailty was measured by the 15-item Tilburg Frailty Indicator (TFI) (18). The score on overall frailty ranged from 0 to 15. Participants with a total TFI-score ≥ 5 were considered frail (18). ADL limitations were assessed with the Groningen Activity Restriction Scale (GARS), range 18-72 (19), with higher scores representing a lower independence level. Loneliness was evaluated by the 6-item De Jong-Gierveld Loneliness Scale (20). Overall loneliness scores varied between 0-1: 'No loneliness', 2-4: 'Moderately intense loneliness', and 5-6: 'Intense loneliness'. Overall loneliness scores were dichotomised in 'not lonely' (score 0-1) and 'lonely' (score 2-6). Risk of medication-related problems was measured by the Medication Risk Questionnaire (MRQ) (21). The MRQ assessed polypharmacy, inappropriate prescribing and poor adherence. Eight items of the MRQ were summed to calculate the risk of medication-related problems (21). The scores were dichotomised into: 'low risk' (score 0-3) or 'high risk' (score ≥4) of medication-related problems (22). Risk of malnutrition was assessed with the Short Nutritional Assessment Questionnaire 65+ (SNAQ65+) (23) and dichotomised in 'low risk' and 'high risk'. This study used two items of the SNAQ65+: appetite and walking stairs. The item 'mid-upper-arm circumference' was excluded from the score calculation as this data was not available. Instead 'unintentional weight loss' measured by one item of the TFI was used (24). If a participant lost 6 kg or more during the last six months, or 3 kg or more during the last month this was identified as high risk of malnutrition. Participants with poor appetite and problems with walking stairs and no weight loss, or no indications at all for malnutrition, were categorised as low risk. Falls were self-reported by asking participants "Have you had a fall in the last 12 months?" (25). Fall status was dichotomised into has 'fallen one or more times' versus 'no falls'.

Lifestyle factors

Physical activity, risk of alcohol harm and smoking were included as lifestyle factors. Physical activity was assessed with one item of the Frailty Instrument of the Survey of Health, Ageing and Retirement in Europe (SHARE-FI) (26) to report the frequency of low to medium energy activities, such as gardening or walking. Responses were dichotomised into 'once a week or less' or 'more than once a week'. Risk of alcohol harm was assessed by three items of the Alcohol Use Disorders Identification Test (27). Score range 0-12, with 0 indicating the lowest and 12 the highest risk. The variable was dichotomised (≥ 3 in women and ≥ 4 in men) to indicate whether a person was at risk of alcohol abuse or dependence (27). One item assessed current smoking (yes/no).

Statistical analyses

Descriptive statistics were performed to describe participant characteristics. Means and standard deviations were used to summarise the continuous variables and frequencies and percentages for categorical variables. Multiple linear regression was used to assess the association between determinants and HRQOL. Regression analyses were conducted separately for the outcome variables PCS and MCS. Unstandardized regression coefficients (B) with 95% confidence intervals (95% CI) were calculated for each variable. Results were considered significant at $P < 0.05$. To evaluate whether the association between determinants and health-related quality of life was modified by sociodemographic factors (age, sex, education level, household composition), an interaction term was added to the PCS model and MCS model. The interaction term sociodemographic variable*determinant was tested in the linear regression model, adjusted for all the other variables. Bonferroni correction was applied for evaluating the interaction terms ($P = 0.05/46 = < 0.001$) (28). Analyses were conducted using SPSS version 25.0 (IBM Corp., Armonk, NY, USA).

RESULTS

Participants characteristics

The mean age of participants was 77.4 years ±6.0 years and 47.2% were women. Most participants had a secondary education level or lower (78.4%). Furthermore, 492 participants (74.4%) reported having two or more health conditions (i.e. multimorbidity). **Table 1** presents the characteristics of the study population at baseline.

Table 1 Baseline characteristics of community-dwelling older adults (n=661)

Baseline variables	Value
Age (years)	77.4 ±6.0
Sex, female	312 (47.2%)
Education level	
Secondary or lower	518 (78.4%)
Tertiary or higher	135 (20.4%)
Household composition, living alone	254 (38.4%)
Multimorbidity, yes	492 (74.4%)
Frailty, yes	190 (28.7%)
ADL (GARS; score)	23.9 ±8.7
Loneliness, yes	238 (36.0%)
Risk of medication-related problems, yes	220 (33.3%)
Risk of malnutrition, yes	35 (5.3%)
Falls, yes	157 (23.8%)
Physical activity	
Once a week or less	173 (26.2%)
More than once a week	483 (73.1%)
Risk of alcohol harm, yes	285 (43.1%)
Smoking, yes	62 (9.4%)

SD, standard deviation; ADL, Activities of Daily Living; GARS, Groningen Activities Restriction Scale. Presented as mean ± SD or N (%). Missing items: Education level =8; Household composition =23; Multimorbidity =4; Frailty =30; ADL =5; Loneliness =14; Medication risk =5; Falls =18; Physical activity =5; Alcohol risk =10.

Factors associated with physical HRQOL

Table 2 presents the results of the univariate and multivariate linear regression models for the PCS of HRQOL. Interaction analyses revealed no statistically significant interactions for PCS (*P* > 0.001). The multivariate model for PCS showed that women had a significantly worse PCS (B = -2.38; 95% CI: -3.68, -1.07) compared to men. Furthermore, participants with multimorbidity perceived lower quality of life regarding the PCS (B = -2.59; 95% CI: -4.17, -1.00) compared to those with less than two health conditions. PCS was also significantly lower in participants indicated as frail (B = -5.56; 95% CI: -7.37, -3.75) compared to non-frail participants. Moreover, the PCS decreased as the score on ADL limitations increased (B = -0.63; 95% CI: -0.72, -0.53). Finally, participants at high risk for medication-related problems had a 2.84 (95% CI: -4.28, -1.40) reduction in PCS compared to participants with a low risk of medication-related problems.

Factors associated with mental HRQOL

Table 3 presents the results of the univariate and multivariate linear regression models for the MCS of HRQOL. There were no statistically significant interactions for MCS (*P* > 0.001). In the univariate model, participants of 80 years and older reported lower quality of life regarding the MCS compared to younger participants (B = -1.65; 95% CI: -3.24, -0.06). However, when controlling for all factors in the model, higher age was associated with an 2.07 (95% CI: 0.47, 3.68) increase in MCS. Similarly, the univariate model showed a 1.34 (95% CI: -2.90, 0.23) reduction in MCS among participants living alone, while in the multivariate model participants living alone had a significantly higher MCS (B = 3.43; 95% CI: 1.82, 5.03) compared to participants living with others. Furthermore, participants indicated as frail reported a significantly lower quality of life regarding MCS (B = -6.65; 95% CI: -8.69, -4.62) compared to non-frail participants. In addition, having a higher score on ADL limitations was significantly associated with reduced MCS (B = -0.18; 95% CI: -0.29, -0.07). Finally, participants who were classified as lonely had a significantly lower MCS (B = -3.64; 95% CI: -5.25, -2.03) compared to participants who were not at risk of loneliness.

Table 2 Linear regression models on associations between determinants of HRQOL and PCS at follow-up

	Univariate model[a]		**Multivariate model**[b]	
	B* (95% CI)	***p*-value**	**B* (95% CI)**	***p*-value**
Age				
65-79 years	Ref		Ref	
≥80 years	-6.76 (-8.57, -4.95)	**<0.001**	-0.84 (-2.27, 0.59)	0.250
Sex				
Male	Ref		Ref	
Female	-4.51 (-6.25, -2.77)	**<0.001**	-2.38 (-3.68, -1.07)	**<0.001**
Education level				
Tertiary or higher	Ref		Ref	
Secondary or lower	-3.37 (-5.54, -1.19)	**0.002**	-1.00 (-2.54, 0.53)	0.199
Household composition				
Living with others	Ref		Ref	
Living alone	-5.76 (-7.53, -4.00)	**<0.001**	-0.41 (-1.84, 1.02)	0.577
Multimorbidity				
0-1 health conditions	Ref		Ref	
≥2 health conditions	-8.68 (-10.61, -6.75)	**<0.001**	-2.59 (-4.17, -1.00)	**0.001**
Frailty status				
Not frail	Ref		Ref	
Frail	-14.68 (-16.29, -13.08)	**<0.001**	-5.56 (-7.37, -3.75)	**<0.001**
ADL (GARS; score)	-0.93 (-1.00, -0.86)	**<0.001**	-0.63 (-0.72, -0.53)	**<0.001**
Loneliness				
Not lonely	Ref		Ref	
Lonely	-5.79 (-7.59, -3.99)	**<0.001**	1.38 (-0.05, 2.81)	0.058
Medication-related problems				
Low risk	Ref		Ref	
High risk	-7.68 (-9.47, -5.89)	**<0.001**	-2.84 (-4.28, -1.40)	**<0.001**
Malnutrition				
Low risk	Ref		Ref	
High risk	-10.00 (-13.87, -6.12)	**<0.001**	0.15 (-2.76, 3.06)	0.919
Falls				
No falls	Ref		Ref	
≥1 falls	-7.65 (-9.66, -5.64)	**<0.001**	-0.88 (-2.45, 0.70)	0.274
Physical activity				
More than once a week	Ref		Ref	
Once a week or less	-8.35 (-10.25, 6.45)	**<0.001**	-1.12 (-2.68, 0.44)	0.158
Alcohol harm				
Low risk	Ref		Ref	
High risk	3.38 (1.61, 5.15)	**<0.001**	0.57 (-0.72, 1.86)	0.384
Smoking				
No	Ref		Ref	
Yes	-2.36 (-5.39, 0.67)	0.126	-0.93 (-3.05, 1.19)	0.391

CI, Confidence Interval; ADL, Activities of Daily Living; GARS, Groningen Activities Restriction Scale. Significant p-values (<0.05) in bold. *unstandardised regression coefficient.

[a] The predictor variables were entered separately in the univariate model.

[b] The predictor variables were entered simultaneously in the multivariate model.

Table 3 Linear regression models on associations between determinants of HRQOL and MCS at follow-up

	Univariate model[a]		**Multivariate model[b]**	
	B* (95% CI)	***P*-value**	**B* (95% CI)**	***P*-value**
Age				
65-79 years	Ref		Ref	
≥80 years	-1.65 (-3.24, -0.06)	**0.043**	2.07 (0.47, 3.68)	**0.011**
Sex				
Male	Ref		Ref	
Female	-1.72 (-3.22, -0.22)	**0.024**	-1.16 (-2.62, 0.31)	0.122
Education level				
Tertiary or higher	Ref		Ref	
Secondary or lower	-1.76 (-3.63, 0.11)	0.065	-0.57 (-2.29, 1.16)	0.519
Household composition				
Living with others	Ref		Ref	
Living alone	-1.34 (-2.90, 0.23)	0.094	3.43 (1.82, 5.03)	**<0.001**
Multimorbidity				
0-1 health conditions	Ref		Ref	
≥2 health conditions	-4.17 (-5.87, -2.47)	**<0.001**	-1.42 (-3.20, 0.35)	0.116
Frailty status				
Not frail	Ref		Ref	
Frail	-9.48 (-10.97, -8.00)	**<0.001**	-6.65 (-8.69, -4.62)	**<0.001**
ADL (GARS; score)	-0.44 (-0.52, -0.36)	**<0.001**	-0.18 (-0.29, -0.07)	**0.001**
Loneliness				
Not lonely	Ref		Ref	
Lonely	-6.39 (-7.88, -4.89)	**<0.001**	-3.64 (-5.25, -2.03)	**<0.001**
Medication-related problems				
Low risk	Ref		Ref	
High risk	-4.95 (-6.51, -3.40)	**<0.001**	-1.32 (-2.93, 0.30)	0.110
Malnutrition				
Low risk	Ref		Ref	
High risk	-8.63 (-11.91, -5.35)	**<0.001**	-2.37 (-5.65, 0.90)	0.155
Falls				
No falls	Ref		Ref	
≥1 falls	-4.57 (-6.31, -2.82)	**<0.001**	-1.35 (-3.12, 0.41)	0.133
Physical activity				
More than once a week	Ref		Ref	
Once a week or less	-3.72 (-5.41, -2.04)	**<0.001**	-0.43 (-2.19, 1.32)	0.627
Alcohol harm				
Low risk	Ref		Ref	
High risk	1.64 (0.12, 3.16)	**0.034**	0.48 (-0.97, 1.92)	0.517
Smoking				
No	Ref		Ref	
Yes	-1.67 (-4.24, 0.90)	0.203	-1.08 (-3.47, 1.30)	0.373

CI, Confidence Interval; ADL, Activities of Daily Living; GARS, Groningen Activities Restriction Scale. Significant p-values (<0.05) in bold. *unstandardised regression coefficient.

[a] The predictor variables were entered separately in the univariate model.

[b] The predictor variables were entered simultaneously in the multivariate model.

DISCUSSION

This study aimed to identify the factors associated with health-related quality of life (HRQOL) among community-dwelling older adults. Frailty and a higher score on ADL limitations were negatively associated with both physical and mental HRQOL. Female sex, multimorbidity, and a high risk of medication-related problems were independently associated with reduced physical HRQOL, whereas loneliness was associated with reduced mental HRQOL. In contrast, higher age and living alone were associated with better mental HRQOL in the multivariate models.

Factors associated with both physical and mental HRQOL

Frailty was associated with reduced physical and mental HRQOL at follow-up. This is in line with previous studies (12, 29-31). Frailty is characterised by increased vulnerability and may result in weight loss, fatigue, low levels of physical activity, and depressed mood (32). Frail older adults are at increased risk of poor health outcomes resulting from falls, disability, and hospitalisation, which may negatively impact HRQOL (29, 32). A higher score on ADL limitations was also significantly associated with reduced PCS and MCS. Due to the strong relationship between a person's ability to perform activities and the PCS score, this result was to be expected (33). Loss of muscle strength and mobility problems, in particular the ability to walk, have been shown to be associated with reduced physical HRQOL (33-35). In addition, it has been shown that loss of independence in general, and dependency regarding eating, bathing and toileting specifically, is associated with a decline in mental HRQOL (33, 34).

Factors associated with physical HRQOL

Consistent with previous findings, women were more likely than men to have reduced physical HRQOL (9, 10, 36). A possible explanation for differences in HRQOL by gender is rooted in the pattern of chronic conditions. More specifically, women are more prone to musculoskeletal diseases than men (37, 38). Musculoskeletal conditions may contribute to pain and disability, particularly in women, and are associated with worse physical HRQOL (9). Not only the type of condition, also the number of chronic conditions may negatively impact HRQOL (39). Consistent with previous studies, our results showed that multimorbidity was associated with poorer physical HRQOL (37, 39, 40). Furthermore, the present study confirms high risk of medication-related problems as a predictor of low physical HRQOL (41, 42). However, no association was found with mental HRQOL in contrast to a previous study (41). In a study by Zhang et al. (42), lower HRQOL was associated with polypharmacy, multimorbidity, difficulties taking medications as prescribed, and using medicines with narrow therapeutic index. Further research is recommended to gain insights into the association between medication-related risk factors and HRQOL.

Factors associated with mental HRQOL

Participants who were classified as lonely had a lower mental HRQOL compared to participants who were not at risk of loneliness. Unlike previous research, our findings did not show an association between loneliness and physical HRQOL (43, 44). A study by Tan et al. (44) showed a stronger association between emotional loneliness and mental HRQOL compared to social loneliness, which may suggests that older adults who miss an intimate or emotional relationship are at increased risk of poor mental HRQOL. Further research is needed to explore the factors contributing to poor mental HRQOL among older adults who are lonely. Furthermore, the univariate regression model showed that higher age (≥80 years) was associated with reduced mental HRQOL. In contrast, higher age was associated with increased mental HRQOL in the multivariate regression model. This result was not reported in the literature (10). Gooding et al. (45) suggest that older-old adults (≥80 years) have a better developed capacity for resilience, particularly regarding emotional regulation and problem solving, compared to younger-old adults (65-79 years) which could explain these findings. Moreover, the univariate model showed lower mental HRQOL among participants living alone. However, when adjusted for other variables, participants living alone had a significantly higher mental HRQOL. This finding challenges a common belief that living alone negatively impacts HRQOL (46). According to Burnette et al. (47), those who live alone have high levels of social interaction and participation. More specifically, living along can have positive effects on younger older adults and those living in urban areas. Future studies need to explore if this finding holds true among various age groups and across settings.

Methodological considerations

A strength of our study is the comprehensive assessment of determinants, including sociodemographic characteristics, indicators of health, and lifestyle factors. In addition, we were able to maintain a relatively high response rate during follow-up. However, this study also has some limitations. First, participants were recruited by sending a letter to ask if they were willing to participate. This may have resulted in selection bias in which vulnerable participants are underrepresented. Second, some of the variables were collapsed into dichotomous categories which may have resulted in loss of information. Future studies are recommended to explore important factors, including frailty, loneliness and malnutrition in more detail, particularly regarding their social dimension. These factors may have a considerable effect on the association between age and HRQOL, and living alone and HRQOL. Finally, due to the limited observation time of six months between baseline and follow-up, a causal relationship cannot be inferred. Further research, including multiple follow-up measures, is required to confirm the direction of the associations. Finally, the possibility of generalisation to other cultural contexts remains unclear. Future studies need to determine whether cultural factors might change the associations observed within our population.

The results of this study confirm that HRQOL is influenced by multiple factors, including sociodemographic characteristics, indicators of health and lifestyle factors (10). Longitudinal research is needed to comprehensively examine the (bi-) directional associations between determinants and HRQOL over time. Future studies could assess socioeconomic status more extensively by including, for example, neighbourhood socioeconomic characteristics, socioeconomic factors earlier in life, and social support. The findings of this study imply that future interventions aimed at promoting the health and autonomy of community-dwelling older adults could be tailored to subpopulations with relatively poor self-reported HRQOL, such as frail or lonely older adults. Additional research is needed to extend our knowledge of the factors related to HRQOL in older (pre)frail adults. This information can be useful for clinicians working with older people to identify those at risk of reduced quality of life and to target interventions accordingly.

CONCLUSIONS

Our findings expand evidence from previous cross-sectional studies indicating an association between higher age, female sex, living alone, multimorbidity, frailty, a higher score on ADL limitations, loneliness, a high risk of medication-related problems and HRQOL. The results of this study show the importance of sociodemographic characteristics in relation to HRQOL, encouraging better linking of health and social care services. Further longitudinal research is needed to confirm our findings and to understand the role of frailty in the relationship between determinants and HRQOL.

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PART II

Stakeholder perspectives regarding person-centred integrated care supported by digital health technology

CHAPTER 4

A qualitative study of the values, needs and preferences of patients regarding stroke care: the ValueCare study

Esmée Bally, Demi Cheng, Amy van Grieken, Dianne van Dam-Nolen,
Stefania Macchione, Mireia Ferri Sanz, Áine Carroll, Bob Roozenbeek,
Diederik Dippel, Hein Raat

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ABSTRACT

Background: An in-depth understanding of patient perspectives contributes to high quality, value-based health care. The aim of this study was to explore the values, needs, and preferences of stroke patients across the continuum of care.

Methods: We performed a qualitative study, as part of the larger ValueCare study, involving 36 patients who have had ischemic stroke within the past 18 months at the time of recruitment. Data were collected between December 2020 and April 2021 via one-to-one telephone interviews. All interviews were audio-taped and transcribed verbatim. The interview data were analyzed using a thematic approach.

Results: The analysis resulted in five themes: (1) patients' values about health care, (2) information and education, (3) psychological support, (4) follow-up care, and (5) continuity and coordination of care. Patients valued a compassionate professional who is responsive to their needs. Furthermore, patients indicated a need for tailored health information, psychosocial services, proactive follow-up care and improved coordination of care.

Conclusion: Stroke patients emphasised the need for tailored information, psychological support, proactive follow-up, and improved coordination of care. It is advocated for professionals to use a value-based care approach in order to satisfy the individual needs of patients with regard to information, communication, and follow-up care.

INTRODUCTION

Each year approximately 1.12 million European citizens have a stroke (1), of which 85% are ischemic strokes (2). Due to population ageing and improved survival rates, the number of people living with stroke is projected to rise from 9.53 million in 2017 to 12.11 million in 2047 – an increase of 27% (2, 3). Despite advancement in medical care, stroke remains a leading cause of disability (4). Patients can experience long-term difficulties in terms of physical impairments, social reintegration and emotional functioning (5–7). Post-acute stroke care aims to address these social and functional determinants of recovery including access to ongoing diagnostics, therapy, rehabilitation, psychological support, and self-management strategies (8).

Stroke care consists of three phases: (i) acute care, (ii) rehabilitation, and a (iii) chronic phase of long-term support (9). Usually, a patient journey begins with the timely recognition of and response to symptoms, followed by rapid diagnosis and reperfusion (if appropriate), and measures to prevent complications (10). In most high-income countries, care at a stroke unit is the central feature of modern stroke service (11). This includes early rehabilitation activities to advance discharge home from the hospital. Early supported discharge teams have the potential to link hospital care and community-based care to support ongoing rehabilitation (12). The Action Plan for Stroke in Europe recommends providing a documented plan for community rehabilitation and self-management support for all stroke patients (8).

The involvement of various disciplines, institutions and organizations in stroke care, such as hospitals, rehabilitation centers, nursing homes, general practices, and home care providers, could complicate the care process of this patient group. Stroke care providers in the Netherlands are reimbursed using a fee-for-service system; each care provider receives separate reimbursement (13). Fee-for-service systems lack incentives to improve patient transitions and coordination of care. Stroke services are, therefore, best positioned in regional partnerships that encourage integrated care among all care providers (14). This includes processes of linking and coordinating services to overcome fragmentation. Value-based health care can support this process by reorganising care delivery around a patient's medical condition. 'Value' in value-based health care can be defined as health outcomes achieved relative to the costs of care (15). By bundling the costs of all services delivered to a patient across the continuum of care, bundled payments create a financial incentive for providers to quality and efficiency of care (16).

In a value-based care system, outcomes are measured across the continuum of care and based on what is meaningful to patients (17). Subsequently, identified care needs are discussed with patients and their caregivers. This personalised (i.e. person-centred) care approach supports active collaboration between patients, families, and providers to create and manage a comprehensive care plan. It requires engaging patients in decision-making and recognising they are unique individuals with their own values, needs and preferences (18). *Values* can be defined as broad goals that reflect an individual's consideration of what is important and worthy and that are relevant across different situations (19). They express what is desirable and influence patients' needs and preferences. 'Health care needs' refer to practices that a patient can benefit from, such as health education, disease prevention, or treatment (20). From a patient perspective, a *need* can be anything to enhance health and/or comfort. Patient *preferences* are the result of an individual's evaluation of relevant elements of health care, including anticipated treatments and health outcomes, and how this relates to them (21). More specifically, a *preference* is an indication of the attractiveness of an option that aims to fulfil a person's *need*, and is based on one's *values* (see **Figure 1**; based on Van Haitsma et al. (22)).

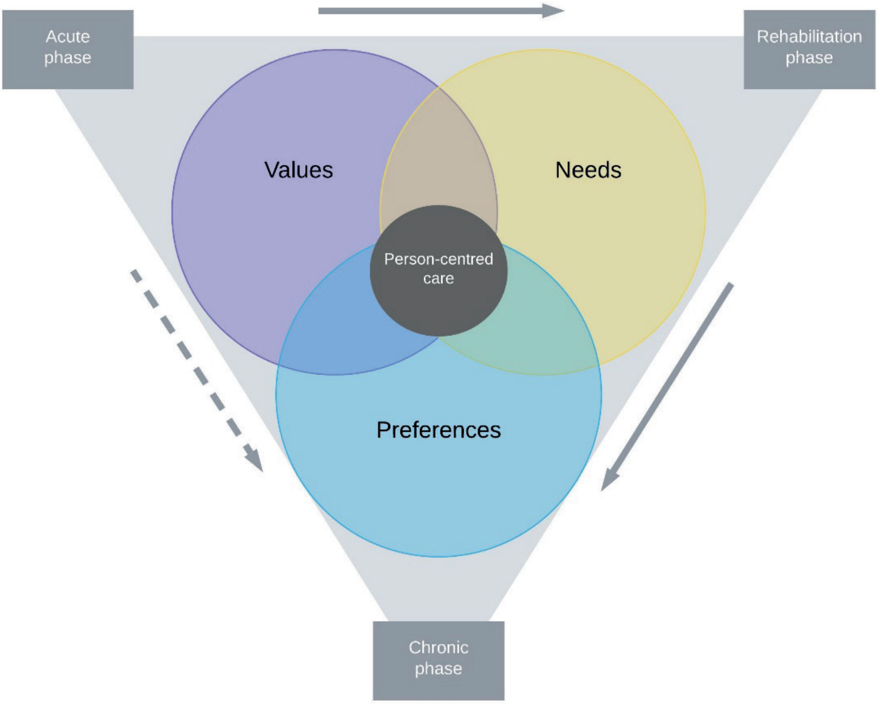

Figure 1 Relationship between patient values, needs and preferences across the continuum of care, based on Van Haitsma et al (22)

Understanding patients' values, their needs and preferences across the continuum of care is essential to make a shift towards person-centred value-based health care. Existing literature on patient values is scarce, particularly with regard to stroke (23, 24). Previous studies about stroke patients' needs and preferences have focused on specific aspects of the patient journey, such as the hospital to home care transition, or follow-up care (25–28). However, value for the patient is produced by combined efforts of health professionals across the continuum of care. Therefore, there is a need for more knowledge about patients' needs and preferences in all phases of stroke care including acute care, care transitions, rehabilitation, long-term support and reintegration to normal living. Moreover, preferences and needs are determined based on one's values. Our research contributes to fulfilling the knowledge gap regarding stroke patient's values. The aim of this study was to explore the values, needs, and preferences of stroke patients across the continuum of care.

METHODS

Study design

We conducted a qualitative semi-structured interview study using inductive thematic analysis (29). Qualitative research is considered appropriate to acquire an in-depth understanding of patient's values, needs and preferences (30). Semi-structured interviews were used to ensure a flexible structure of follow-up questions in exploring patients' thoughts and experiences (31). Furthermore, the inductive approach allowed research findings to emerge from the raw data without imposing pre-existing assumptions on the setting under inquiry. This study was conducted in Rotterdam, The Netherlands, as part of the larger ValueCare study (32). The Information and Communication Technology (ICT) enabled value-based methodology for integrated care (ValueCare) project aims to develop and implement efficient outcome-based, integrated health and social care for older people with multimorbidity, and/or frailty, and/or mild to moderate cognitive impairment in seven sites (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, The Netherlands; Treviso, Italy; and Valencia, Spain). The Medical Ethics Committee of Erasmus MC University Medical Center in Rotterdam, The Netherlands, declared that the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO), do not apply to this research proposal (reference number: MEC-2021-0866).

Participants

Patients were recruited from a single-site large university hospital in Rotterdam, The Netherlands. Electronic patient files were screened to select eligible patients based on the following inclusion criteria: (1) diagnosed with ischemic stroke (first ever or recurrent) within the past 18 months at the time of recruitment; (2) community-dwelling (not in long-term care) at the time of recruitment, and (3) able to provide written consent to participate in this study. Patients who did not speak Dutch were excluded. Purposive sampling was used to include patients with a variety of background characteristics in terms of sex, age, time since stroke and severity of stroke. Eligible patients received an invitation letter by post with information about the study and an informed consent form. Patients who returned the signed informed consent form to the researchers were contacted to plan the interview. All interviews have been conducted by telephone.

Data collection

Patients were interviewed between December 2020 and April 2021 by the first author (EB) and a research student assistant. A topic guide was developed as part of the ValueCare project and adapted to the local context. Interview questions were derived through discussions within the research team (See Appendix for sample interview guide). Before the start of the interview, the interviewer explained that she was a researcher, independent of the clinical team. Informed consent was obtained from all participants. The interview started with asking patients to provide a description of the health care (e.g. treatment, rehabilitation, after care) they received and to reflect on the strong and weak points of received health care. Subsequently, patients were asked to indicate what mattered to them regarding their treatment and how services can be improved. Several follow-up questions were asked to deepen the conversation about patients' preferences for health care improvements (See Appendix). As part of the interview, patients were asked to fill in a short questionnaire about their characteristics (e.g. living arrangements, perceived health). Interviews lasted between 12 minutes and 38 minutes (24 minutes on average), were audiotaped and transcribed verbatim.

Data analysis

Thematic inductive analysis was conducted (29), using the software program NVivo, version 12. The process of coding was based on the six phases of thematic analysis described by Braun and Clarke (33): familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final analyses. Two researchers (EB, DC) independently read the transcripts. Separately from each other, the researchers applied inductive coding with a focus on experiential claims, particularly with regard to values, needs and preferences. Subsequently, the two researchers discussed initial codes and patterns in the data. Relevant coded data extracts were clustered into potential themes and sub themes. Themes were identified when they appeared consistently in a number of transcripts. Identified themes and sub themes were reviewed and discussed by the research team to ensure they are coherent. If necessary, recoding was performed. The analysis resulted in 5 final themes. A selection of quotes was translated into English using forward and backward translations.

RESULTS

Sample characteristics

The final sample was formed by 36 participants (15 women and 21 men) of which two-third was aged 70 years or older. Most of the participants had a secondary education level or lower (64%). Among the 36 participants, 26 (72%) had their stroke 12 to 18 months ago. Participant characteristics are further detailed in **Table 1**.

Table 1 Characteristics of patients (*n* = 36)

Variable	***n* (%)**
Gender	
Female	15 (42%)
Male	21 (58%)
Age	
50-59	2 (6%)
60-69	10 (28%)
70-79	16 (44%)
80-89	7 (19%)
90-99	1 (3%)
Education level[a]	
Primary or lower	1 (3%)
Secondary or equivalent	22 (61%)
Tertiary or higher	10 (28%)
Missing	3 (8%)
Living alone	
Yes	11 (34%)
No	25 (66%)
Time since stroke	
6-12 months	10 (28%)
12-18 months	24 (72%)
First ever stroke	
Yes	30 (83%)
No	6 (17%)
Perceived health	
Good	16 (44%)
Fair	15 (42%)
Poor	2 (6%)
Missing	3 (8%)

[a] Highest level of education achieved based on the International Standard Classification of Education (ISCED). ISCED level 0–1 was categorized as 'primary or lower'; ISCED level 2–5 was categorized as 'secondary or equivalent', and; ISCED level 6–8 was categorized as 'tertiary or higher' (34).

The themes that emerged from the interviews are described below: (1) patients' values about health care, (2) information and education, (3) psychological support, (4) follow-up care, and (5) continuity and coordination of care. An overview of the values, needs and preferences of patients based on identified themes and sub themes is provided in **Textbox 1**.

Textbox 1 Values, needs and preferences of stroke patients

Values

- Being treated as a unique individual
- Autonomy
- Good communicative skills of the professional
- Compassionate professional
- Responsive professional

Needs

- Information regarding the causes, consequences and treatment of stroke
- Psychological support
- Proactive follow-up by health care professional
- Continuity of care

Preferences

- Tailored information based on individual needs, preferably on paper
- Counselling by social worker or peer support
- Timely and coordinated follow-up
- A familiar face – seeing the same health care professional over time
- Flexible services and professionals

Theme 1: Patients' values about health care

Values

This theme includes the aspects that patients valued in health care practices. Five sub themes have been identified: (i) patient uniqueness, (ii) patient autonomy, (iii) communicative skills of the professional, (iv) compassionate professional, and (v) responsive professional.

Some patients expressed the wish to be seen and treated as a unique individual rather than a patient with a health condition.

- *"It is very pleasant for a patient to be approached and treated as a human being. And not that they [the professionals] are discussing things with someone else about me, while I am in bed and able to talk to them." P01*

Furthermore, patients expected to be involved in their treatment and told that they wanted to be well-informed by the professional. Some patients brought forward that this allows them to feel they are respected and trusted partners in their care.

- *"If I lie there and cannot move, tell me what you [the professional] are doing. I was not well-informed about what was going on. It is important to engage patients in what you are doing, let them think along." P36*

A simple explanation of their condition and clear information regarding their treatment was also valued by patients. This requires good communicative skills of the professional, described by patients as using plain language, being emphatic and a good listener.

- *"I prefer to speak to a nurse. A nurse is usually more calm and can explain better in simple language than a physician." P02*

Another key value related to the attitude of the professional was compassion. It was described by patients in many forms, such as a chat, a smile, an act of kindness, or by listening to a patient's story.

- *"A listening ear. And not fast, fast, fast. That you have been heard only half and you have to tell your story all over again." P34*

Moreover, patients appreciated to have personal, face-to-face contact with the professional. An understanding professional who is easily approachable and listens sincerely was important to patients.

- *"It is important that I can tell my story to that person [the professional]. If you feel like we can talk to each other about things, then you can go into depth." P07*

Examples mentioned by patients show that small things can make a big difference in how care is experienced.

- *"Those small gestures I experienced as very pleasant. Getting a toothbrush is not essential, you can do of course without, but the gesture it symbolized the concern one had. The attention for patients." P26*

Patients expected the professional to be committed and responsive to their expressed needs regarding treatment and care.

- *"The doctor you visit should listen to your problem and take action. That is important to me, being heard." P30*

Theme 2: Information and education

Need for information about stroke

Patients mentioned the importance of receiving information from their health care professional. More specifically, they expressed the need for information regarding causes of stroke, symptoms and consequences of stroke, treatment decisions, prognosis, and follow-up care.

- *"You keep asking yourself: how did this happen? My feeling is that I have never had a problem that could cause stroke. I am interested in the causes. I like to discuss this with someone." P07*

Preferences for tailored information

Patients wanted information that is specifically tailored to their diagnosis and needs, preferably first hand from their professional and written on paper. Information was used to know what to expect and prepare for during all stages of recovery.

- *"If a person has had a stroke, the consequences need to be well-explained and what you can expect over time… that you won't recover the full 100%." P02*

Theme 3: Psychological support

Need for psychological support

After discharge, psychological support was indicated by some patients as needed but often lacking for patients and their families. Attention for the psychosocial impact of stroke during follow-up consultations with health care professionals was important to patients. Patients reported to be more emotional than they used to be. Feelings of anxiety and a lack of confidence were mentioned.

- *"In the beginning I had terrible fear, because you just walk on the street and can collapse. You no longer trust your body. I live alone, and yes, I fear that something like this would happen again." P15*

Preference for counselling or peer support

Some patients also experienced feelings of anger and frustration. Having someone with whom to discuss difficulties was suggested by patients to cope with emotional changes after stroke. Examples mentioned were counselling by a social worker or peer support.

- *"Physically, I think I am doing okay. […] But my head is full of weird things. I am easily angry, sad, emotional. And I would have liked to talked to someone about that." P20*

Theme 4: Follow-up care

Need for proactive follow-up by health care professional

We defined follow-up care as care after a stay in the hospital or rehabilitation clinic. A few patients received follow-up care from a community stroke nurse; they appreciated it and considered it helpful. Some patients were dissatisfied with a lack of proactive follow-up from their GP, the hospital, or allied health care professionals. Most of them expressed they received limited follow-up care or not well dosed.

- *"I actually had to arrange everything myself, for example, home care and physiotherapy. I mean all of that did happen in the end, but the follow-up care from the hospital, I just think that is very bad." P25*

In some cases, patients experienced the relationship with their GP to be difficult. They expect their GP to be informed about their situation and felt disappointed by the lack of follow-up.

Preference for a timely and coordinated follow-up

In general, patients expressed the wish to have more frequent and coordinated follow-up consultations by their health care professional to check how they are doing.

- *"Of course she [GP] received all information from the hospital. Even if it was a bit delayed, she could still have called." P29*

Theme 5: Continuity and coordination of care

Need for continuity of care

All patients indicated the need for continuity of care – an ongoing relationship with the same health care professional. Patients experienced failures in coordination particularly at points of transition which required shifts of responsibilities and information flow.

Preference for a familiar face

All patients indicated the need for continuity of care – an ongoing relationship with the same health care professional. Patients experienced failures in coordination particularly at points of transition which required shifts of responsibilities and information flow.

Preference for flexible services

Preference is given to services and professionals that are flexible and able to adapt to the needs of patients over time.

- *"When you get home you need the most help. And over time, after a few weeks, that will be less. And they [home care organization] turn it right around. They give minimal help, and they say if you need help, let us know but that can take up to eight weeks." P32*

DISCUSSION

This study aimed to explore the values, needs, and preferences of stroke patients across the continuum of care. The interviews yielded a deeper understanding of the long-term impacts of stroke on patients and provide input to enhance person-centred stroke care. Five themes emerged from the analysis: (1) patients' values about health care, (2) information and education, (3) psychological support, (4) follow-up care, and (5) continuity and coordination of care.

The aspects that patients valued in health care practices were mainly related to the skills and attitudes of professionals, such as good communicative skills and being compassionate. Compassion can be described as the ability of the professional to understand a person's suffering and the willingness to promote the wellbeing of that person (35). Consistent with previous studies, patients valued a concerned professional who is easily approachable and communicates clearly (23, 24, 35). This is particularly important regarding providing information to patients. In a qualitative study by Martin-Sanz et al. (36) among stroke patients, listening, asking questions to patients, and not being in a hurry was associated with being a good health care professional. Yet, traditional fee-for-service payment models, in which different providers are paid separately for their services, provide little or no reward for delivering optimal stroke care and enhanced coordination of care (16).

Patients expressed the need for clear written information tailored to their diagnosis and needs. Tailoring information can enhance person-centred communication which is associated with increased patient participation (37). Furthermore, patients preferred a simple explanation of their condition. This requires adequate communication skills of professionals to be able to recognize patients with low health literacy (38). Previous studies have reported that information can be difficult to assess for stroke patients if language is too medical (6, 28). It is recommended to use short sentences, to define technical terms and to use visuals, which represent older people in a positive way (39).

One of the strengths of this study is that patients were asked to elaborate on their experiences with care from hospital to home. Stroke patients emphasized the need for psychological support after discharge. Frustration, anger management issues, emotional lability, and anxiety were commonly experienced. This stresses the need for early and easy accessible psychological services including peer support, as well as support for informal caregivers because of the impact of emotional distress on the close environment (5). Improved coordination between health care providers across the care continuum, such as neurologists, GPs, social workers, and psychologists, can facilitate the identification of unmet psychological needs (6).

With respect to follow-up care, patients had mixed experiences. Follow-up visits by a community stroke nurse were experienced positively by patients. However, patients also reported to be dissatisfied with a lack of proactive follow-up from their GP or hospital. They expected to have more frequent and coordinated follow-up visits once they were home. Similar to our findings, studies on the experiences of stroke survivors show patients often feel abandoned post-discharge (6, 28, 40). In a qualitative study by Lindblom et al. (27) stroke patients describe a lack of active involvement and dialogue around their transition from hospital to home. Consequently, patients may feel that the responsibility for their own care is forced upon them without support or preparation. This links to a need among patients for continuity of care which was defined as a continuous relationship with a health care provider.

Continuity of care includes pre-discharge and post-discharge activities, such as discharge planning, provision of adequate information and education, and timely communication between health care providers (11). According to patients, this process requires improvement, as they experienced a lack of communication among health care providers, which adversely affects the continuity and coordination of care. Consistent with the literature, a trusted relationship between the patient and health care professional is crucial in order for patients to feel secure, especially during the period shortly after discharge (36, 41). The findings of this study emphasized the need for long-term support in the chronic phase of care to address the social and functional determinants of recovery.

A limitation of this study was that patients were approached by letter to ask them if they were willing to participate in the study. This may have led to selection bias, oversampling those patients with critical comments and an underrepresentation of vulnerable patients. However, our sample also included patients with poor perceived health, therefore this appears not to be a major problem. In addition, the results of this study might be impacted by the COVID-19 pandemic as this affected face-to-face patient-provider communication which was emphasized by patients as an important aspect in their care experience. Furthermore, the study was performed within the specific context of the Netherlands, therefore insights might not be transferable to other settings. To increase the generalizability of our findings, we have reached variation in our sample in terms of patient characteristics (e.g. sex, age, severity of stroke). Moreover, this study includes a high number of patient perspectives resulting in a rich data set and adjudication of the analysis was done through consensus coding. A strength of this study is that our qualitative approach, using a sound methodology, allowed broad insight into values, needs, and preferences of patients regarding the full trajectory of stroke care instead of focusing on certain aspects of care. This manuscript integrates concepts from multiple disciplines which cannot be translated one-on-one to interviews. Instead patients were asked what mattered to them regarding treatment and care (values), how services can be improved (needs), and more specifically how needs could be met (preferences). Our sample included relatively few participants with low literacy. To engage patients with low literacy better, visual and artistic methods can be used, for example, asking participants to respond to pre-selected images related to the topic of interest (42). Future research is recommended to explore how the values, needs and preferences of patients can inform practice guidelines and ultimately improve care delivery.

Current (post-)stroke care practices are variable and do frequently not address patients' individual needs. Results of this study imply that value-based care for stroke patients can be improved by taking a more personalised approach. Recognizing patients' values is a key element to move towards personalised (i.e. person-centred) care (18). Further research is needed to validate and enrich our findings on patient values. Our results also indicate a need for tailored information provision and improved communication skills of professionals. Shared decision-making tools can promote a patient's knowledge and satisfaction by enhancing patient participation (43). In addition, mobile health applications can be used to facilitate tailored information provision for patients (44). Moreover, health technologies that facilitate data sharing and support health care delivery have the potential to improve communication between health care providers (45). In combination with a community stroke nurse, who supports patients individually and coordinates access to required stroke services, this can enhance the continuity of care (46). Future research is recommended to explore the role of the community stroke nurse in improving the continuity and coordination of stroke care.

CONCLUSIONS

The aspects that stroke patients valued in health care practices were mainly related to the skills and attitudes of professionals. Stroke patients emphasized the need for tailored information and education, psychological support, follow-up visits, and improved continuity and coordination of care. It is advocated for professionals in stroke care to adopt a more personalised care approach, in order to satisfy the individual needs of patients with regard to information, communication and follow-up care. The findings of this study provide insight in values, needs and preferences of stroke patients to adopt person-centred value-based care.

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APPENDIX: SAMPLE INTERVIEW TOPIC GUIDE

Introduction

- Introduction with background of the study, aims and structure of the interview.
- Check for provision of informed consent and permission for audio-taping.

Experiences and needs

- What is/was going well, considering all health and social care you currently receive/have received in relation to your stroke treatment?
- What is/was not going so well, considering all health and social care you currently receive/have received in relation to your stroke treatment?
- How can stroke services across the continuum of care (hospital, rehabilitation and at home in the community) be improved?

Values and preferences

- According to you, what is important and/or valuable for stroke patients regarding treatment and care?

Closing

- Additional topics raised by the patient.
- Thank you statement and closing.

CHAPTER 5

Patients' perspectives regarding digital health technology to support self-management and improve integrated stroke care: qualitative interview study

Esmée Bally, Demi Cheng, Amy van Grieken, Mireia Ferri Sanz, Oscar Zanutto, Áine Carroll, Andrew Darley, Bob Roozenbeek, Diederik Dippel, Hein Raat

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ABSTRACT

Background: Digital technologies such as mobile apps and robotics have the potential to involve stroke patients better in the care process and to promote self-management. However, barriers exist that constrain the adoption and acceptance of technology in clinical practice. Examples of barriers are privacy concerns, challenges regarding usability, and the perception that there is no need for health-related technology. To address these barriers, co-design can be used to enable patients to reflect on their experiences of a service and to tailor digital technologies to the needs and preferences of end users regarding content and usability. This study aims to explore the perspectives of stroke patients toward how digital health technology could support self-management regarding health and well-being, as well as integrated stroke care.

Methods: A qualitative study was conducted to understand patient perspectives. Data were collected in co-design sessions during the ValueCare study. Patients from a Dutch hospital who experienced an ischemic stroke (n=36) within the past 18 months were invited to participate. Data collection took place between December 2020 and April 2021 via one-to-one telephone interviews. A short self-report questionnaire was used to collect data on sociodemographics, disease-specific information, and technology use. All interviews were audio-taped and transcribed verbatim. The interview data were analyzed using a thematic approach.

Results: Patients held mixed attitudes toward digital health technologies. Some patients viewed digital technology as a convenient product or service, while others expressed no desire or need to use technology for self-management or care. Digital features suggested by stroke patients included (1) information about the causes of stroke, medication, prognosis, and follow-up care; (2) an online library with information regarding stroke-related health and care issues; (3) a personal health record by which patients can retrieve and manage their own health information; and (4) online rehabilitation support to empower patients to exercise at home. Regarding the user interface of future digital health technology, patients emphasized the need for easy-to-use and simple designs.

Conclusions: Stroke patients mentioned credible health information, an online library with stroke-related health and care information, a personal health record, and online rehabilitation support as the main features to include in future digital health technologies. It is recommended that developers and designers of digital health for stroke care listen to the “voice of the stroke patients” regarding both functionality and the characteristics of the interface.

INTRODUCTION

Stroke is a leading cause of death and long-term disability (1). In 2017, there were an estimated 9.53 million prevalent stroke cases in the European Union, and this number is expected to rise to 12.11 million by 2047 (2). Stroke patients often experience long-lasting physical and psychological consequences after stroke that can result in disruption of cognitive and emotional functioning and social relationships (3-5). Postacute stroke care aims to support restoration of a patient's functioning, including access to ongoing diagnostics, therapy, rehabilitation, psychological support, and self-management strategies (6).

Rehabilitation, including physical therapy, speech and language therapy, and occupational therapy, can improve mobility, communication skills, and activities of daily living in stroke patients (7, 8). The Action Plan for Stroke Europe recommends a documented plan for community rehabilitation and self-management support for all stroke patients including periodic reviews to adjust rehabilitation and other needs over time (6). However, due to budget constraints, rehabilitation in inpatient facilities is often restricted to a few weeks, and resources are limited in long-term outpatient rehabilitation (9).

In response to these challenges, digital health technology could support existing clinical practice, as it provides opportunities to involve patients in the care and decision-making process and to promote self-management among patients (10, 11). The World Health Organization has defined digital health as "the field of knowledge and practice associated with the development and use of digital technologies to improve health" (12). It includes a wide range of digital technologies for health such as information and communication technology, mobile wireless technology, artificial intelligence, big data, and robotics (12).

One example is telerehabilitation for stroke care that can be delivered via robotics, virtual reality, commercial gaming devices, and communication tools such as videoconferencing and telephoning (11). It can be used to make rehabilitation training accessible for patients, especially for those living in remote areas (9, 13). A recent Cochrane review found moderate-level evidence that telerehabilitation is more effective or similarly effective as in-person rehabilitation (14).

In addition, previous studies indicate that mobile apps can support patients by, for example, acting as physical activity monitors to avoid sedentary behavior (15), providing content for stroke education (16), and sending medication reminders through text messaging (17). The majority of commercial apps designed specifically for stroke patients or their caregivers focus on activities to help improve language and communication difficulties (18). Furthermore, digital health technologies could support successful integrated care by facilitating good communication of information with the patient and between stroke care providers (19). The involvement of various disciplines, institutions, and organizations in stroke care, such as hospitals, rehabilitation centers, and home care providers, requires processes of linking and coordinating services to overcome fragmentation.

Previous pilot studies on digital health interventions for stroke patients suggest that technology could be a meaningful tool for postacute stroke care (20-22). However, there might be barriers constraining the adoption and acceptance of technology in clinical practice and by end users; these barriers include privacy concerns, challenges regarding the usability, and the perception that there is no need for health-related technology (10, 23). In this regard, co-design enables patients, their caregivers, and health care staff to reflect on their experiences with a service and to identify improvement priorities (24). Furthermore, co-design ensures digital technologies are tailored to the needs and preferences of end users regarding content and usability (25).

As part of the ValueCare study (26), a co-design approach was undertaken to develop value-based integrated care supported by digital technologies. This study used data from co-design sessions with stroke patients. The aim of this study was to explore perspectives of stroke patients toward how digital health technology could support self-management regarding health and well-being, as well as integrated stroke care.

METHODS

Study design

A qualitative study design was undertaken (27). We conducted a semistructured interview study to gain an in-depth understanding of patient perspectives (28). Semistructured interviews were used to ensure a flexible structure of follow-up questions in exploring patients' thoughts and experiences (29). This study was conducted in Rotterdam, The Netherlands, as part of the larger ValueCare study (26). The ValueCare project aims to develop and implement efficient, outcome-based, integrated health and social care for older people with multimorbidity, frailty, or mild to moderate cognitive impairment in 7 sites (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, The Netherlands; Treviso, Italy; and Valencia, Spain). Each site is expected to adapt the general value-based methodology to their target group and local context. In order to have an in-depth, multifaceted exploration of stroke patients' perspectives, this study solely focused on the data collected at the Rotterdam site.

Due to the COVID-19 pandemic, all interviews were conducted by telephone. Included questions were reviewed and discussed by the ValueCare consortium to fulfill the project requirements. Subsequently, interview questions were adapted to the local pilot site context. An interview guide of 5 questions (see Appendix) was used for the interviews, which were iterative in nature. The interview started by asking patients to describe the onset of stroke and how they experienced received care. Subsequent questions explored their values and needs regarding postacute stroke care and how stroke care can be improved, particularly with help from digital technologies. This study focused on 1 open-ended question: How can digital solutions support you to manage your health and care? We asked participants to share their associations regarding digital solutions used in health care and what would be useful for them. Several follow-up questions regarding the characteristics of the technology and foreseen barriers to use of the technology were asked to deepen the conversation (see Appendix).

Recruitment

Patients were purposively sampled from a single-site, large, academic hospital in Rotterdam, The Netherlands. Purposive sampling was used to include patients with a variety of background characteristics in terms of sex, age, time since stroke, and severity of stroke (30). Patients' eligibility for the study was assessed by a physician-researcher of the Department of Neurology by screening electronic patient files. The inclusion criteria were as follows: (1) diagnosed with ischemic stroke (first ever or recurrent) within the past 18 months at the time of recruitment, (2) community-dwelling (not in long-term care) at the time of recruitment, and (3) able to provide written consent to participate in this study. We aimed to avoid excluding patients with cognitive or communication deficits, for example, by allowing support from the (informal) caregiver when communication was slow. Therefore, patients were excluded only if they did not speak Dutch or were unable to communicate sufficiently to participate. Exclusion was determined at the time of the interview.

In collaboration with the Department of Neurology, 310 patients were invited to join the study. An information package with an invitation letter, information sheet, informed consent form, and prepaid envelope was distributed by post to eligible patients. Patients were invited to share their care experiences and to provide suggestions on how to improve stroke care in general and with the support of digital technologies specifically. Interested patients who returned the signed informed consent form to the researchers were contacted to plan the interview. Recruitment continued until a diverse sample with maximum variation was achieved. We aimed for balanced participation of men and women with at least one-half of the participants aged 70 years and older and inclusion of patients with a poor health status, recurrent stroke, or severe stroke. This resulted in a sample of 42 interviews. From the interviews available (*n*=42), 6 interviews were excluded due to poor audio quality. Finally, 36 interviews were included in the analysis taking into consideration the depth and duration (>10 minutes) of the interview.

Data collection

Patients were interviewed between December 2020 and April 2021 by the first author (ELSB) and a research assistant. As part of the interview, patients were asked to complete a short questionnaire about their characteristics, including sex assigned at birth (male/female), age, living situation, time since stroke, first ever or recurrent stroke, perceived health, and technology use. Interviews lasted between 12 minutes and 38 minutes (24 minutes on average), were audio-recorded, and were transcribed verbatim resulting in 284 pages of transcribed material, of which 60 pages were about digital technologies.

Data analysis

Thematic analysis was conducted (27) using the software program NVivo, version 12. The process was based on the 6 phases of thematic analysis described by Braun and Clarke (27): familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final analyses. Thematic analysis allowed research findings to emerge from the raw data without imposing pre-existing assumptions on the setting under inquiry (27). Two researchers (ELSB, DC) independently read the transcripts. Separately from each other, the researchers applied inductive coding with a focus on experiential claims, needs, and preferences regarding their health, social care, and digital health technology. Subsequently, the 2 researchers discussed initial codes and patterns in the data. Relevant coded data extracts were clustered into potential themes and subthemes. Themes were identified when they appeared consistently in a number of transcripts. Identified themes and subthemes were reviewed and discussed by the research team to ensure they were coherent. If necessary, recoding was performed. The analysis resulted in 3 final themes. A selection of quotes was translated into English using forward and backward translations.

Ethical considerations

The Medical Ethics Committee of Erasmus MC University Medical Center (Erasmus MC) in Rotterdam, The Netherlands, declared that the rules laid down in the Medical Research Involving Human Subjects Act (also known by its Dutch abbreviation WMO) do not apply to this research proposal (reference number: MEC-2021-0866). All participants provided written informed consent for participation in the study. To protect the privacy of participants, study data were de-identified (ie, pseudoanonymization). The contact details and research data of participants were coded and stored separately. Participants who completed the interview received a gift voucher of €15 (US $15.93) for their time and effort to participate in the study.

RESULTS

Sample characteristics

The final sample consisted of 36 participants (15 women and 21 men) with two-thirds of participants aged 70 years or older. Time since stroke onset was 1 year or more for 72% (26/36) of participants. Among the 36 participants, 30 (83%) had their first ever stroke. Most of the participants used the internet every day (26/36, 72%), owned a smartphone or tablet (31/36, 86%), and used apps (29/36, 81%). Participant characteristics are further described in **Table 1**.

Table 1 Sample characteristics (*n*=36)

Patient	Sex	Age (years)	Time since stroke (months)	First ever stroke	Perceived health	Use of internet	Smartphone or tablet	Use of apps
P01	Male	60	12-18	Yes	Good	Every day	Smartphone	Every day
P02	Male	64	12-18	Yes	Fair	Every day	Smartphone	Multiple times a week
P03	Male	70	12-18	Yes	Good	Every day	Smartphone	Multiple times a week
P04	Male	76	12-18	Yes	Fair	Multiple times a week	Smartphone	Multiple times a week
P05	Male	83	12-18	Yes	Good	Every day	No	Never
P06	Female	71	12-18	Yes	Fair	Every day	Both	Every day
P07	Male	81	6-12	No	Good	Every day	Smartphone	Once to twice a week
P08	Male	71	6-12	Yes	—[a]	—	—	—
P09	Male	69	6-12	Yes	Good	Every day	Both	Every day
P10	Female	70	12-18	Yes	Fair	Every day	Both	Never
P11	Male	54	12-18	Yes	Good	Every day	Both	Every day
P12	Female	86	12-18	Yes	Good	Every day	Both	Every day
P13	Female	75	12-18	No	Fair	Multiple times a week	Both	Every day
P14	Male	54	6-12	Yes	Fair	Every day	Both	Every day
P15	Female	64	12-18	Yes	Fair	Every day	Both	Multiple times a week
P16	Female	70	12-18	Yes	Fair	Every day	Both	Every day
P17	Female	73	6-12	Yes	Good	Every day	Both	Every day
P18	Female	68	12-18	Yes	Good	Every day	Smartphone	Every day
P19	Female	90	12-18	Yes	—	—	—	—
P20	Female	72	12-18	Yes	Fair	Every day	Both	Every day
P21	Male	75	12-18	Yes	Fair	Multiple times a week	Tablet	Never
P22	Female	60	12-18	No	Good	Every day	Tablet	Every day
P23	Male	89	12-18	Yes	Fair	Every day	No	Once to twice a month
P24	Male	70	12-18	Yes	Good	Multiple times a week	Both	Every day
P25	Female	85	12-18	Yes	Fair	Every day	Smartphone	Once to twice a month
P26	Male	85	6-12	No	Fair	Every day	Both	Every day
P27	Female	69	12-18	Yes	Poor	Every day	Both	Every day
P28	Male	79	6-12	Yes	Fair	Multiple times a week	Both	Every day
P29	Male	73	6-12	No	Good	Every day	Both	Every day
P30	Male	82	12-18	Yes	—	—	—	—
P31	Male	75	12-18	Yes	Good	Every day	Both	Every day

Table 1 Continued

Patient	Sex	Age (years)	Time since stroke (months)	First ever stroke	Perceived health	Use of internet	Smartphone or tablet	Use of apps
P32	Female	78	12-18	No	Poor	Multiple times a week	Both	Once to twice a week
P33	Male	73	6-12	Yes	Good	Every day	Both	Every day
P34	Female	68	6-12	Yes	Fair	Once to twice a week	Smartphone	Every day
P35	Male	60	12-18	Yes	Good	Every day	Smartphone	Every day
P36	Male	66	12-18	Yes	Good	Every day	Tablet	Never

[a]Not answered.

The following themes that emerged from the interviews are described in subsequent sections: (1) attitudes toward using digital health for care, (2) suggested features of digital health technologies, and (3) suggested user interface design features of digital health technologies (see **Figure 1**). Barriers to the use of digital technologies have been integrated in themes 1 and 3. An overview of the identified barriers is provided in **Textbox 1**.

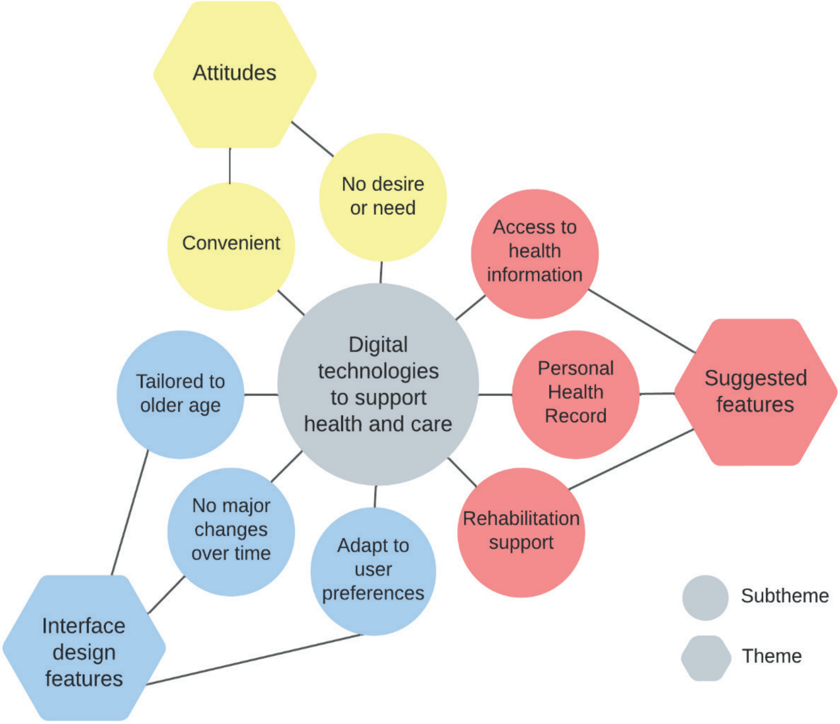

Figure 1 Themes and subthemes identified during data analysis

Textbox 1 Barriers to the use of digital technologies

Barrier
1. No need for health-related technology
• Satisfied with received care • Preference for physical contact with health care professional
2. Too complicated
• Missing the skills to use technology • Challenging to get familiarized with new technologies
3. App updates
• Not able to cope with changes in a familiar interface design
4. Inflexible
• Feeling pressured and/or annoyed by push notifications • Not wanting to depend on your phone – a phone can get lost

Theme 1: Attitudes toward using digital health for care

Analysis revealed mixed attitudes among patients toward using digital health to support their self-management and improve the care they receive. Most participants viewed digital health technology as a product or service, such as an online portal to manage their care, which was believed to be convenient and valued for the ability to access relevant health information.

- *"Yes, that [patient portal] is certainly useful. I think it is quite convenient to be reminded of your doctor's appointment the day before. I have my agenda on my iPhone to be able to receive notifications in case I forget an appointment." P07*

Other patients mentioned they experienced no desire or need to use digital health to self-manage their health and care. These participants preferred to have in-person physical contact with their health care professional rather than receiving care using technology.

- *"I would rather have physical contact to explain what I am thinking or feeling. No, I am not in favor of technology. At least, it depends what it concerns, but with regard to my health, I prefer to have someone physically attending." P05*

- *"You have to be able to look each other in the eyes. This allows you to see whether your complaints are taken seriously and if the physician is listening. [...] it has to be personal by talking to each other in person and not via video call." P02*

Theme 2: Suggested features of digital health technologies

This theme consists of the features patients suggested to include in future digital solutions to support their self-management and to improve the care they receive. We identified 4 elements: (1) the need for information about the causes of stroke, medication, prognosis, and follow-up care; (2) an online library with information regarding stroke related health and care issues; (3) a personal health record by which patients can retrieve and manage their own health information; and (4) online rehabilitation support to empower patients to exercise at home.

Some patients suggested including educational features about their condition. More specifically, they expressed the need for information about the causes of stroke, medication, prognosis, and follow-up care.

- *"I have had this prescription from my physician. I received the medication, it had the name on it, but what does it do exactly taking such a pill?" P36*

- *"I thought: What the hell happened to me? And then they [health care professionals] are going to tell you all about it. I thought sure but I just did not know. So, in little chunks, I asked [the nurse] something every time." P16*

Patients also emphasized it was difficult to navigate the internet in their search for relevant information. An easy-to-find online library, preferably hosted by the hospital, with credible information was suggested for stroke patients.

- *"Some sort of digital information channel which is centrally regulated by the hospital and the rehabilitation center. It should include clear information that serves the needs of stroke patients." P22*

A few patients suggested access to a personal health record to manage information about their health and care. Patients identified the potential benefits of personal health records by being able to access up-to-date information about their condition, such as medical files and prescribed medications.

- *"I would like to see something in which you can view your medical files, but also your appointments, reminders, and a short report of the consultation you have had." P01*

Patients also discussed how digital solutions could potentially support rehabilitation at home. More specifically, patients wanted tips to increase their physical activity or support to perform exercises as part of their rehabilitation program.

- *"I would like to have tips about exercises I can do from home. I have tried this exercising program on TV, but that is not feasible for me as my balance is not so good." P27*

In addition, participants discussed a lack of understanding regarding the exercises they are intended to perform in their home setting. A number of participants suggested that the use of visual aids (i.e., pictures or videos) to explain rehabilitation exercises would help them understand and to engage with their training at home.

- *"Usually, I recognize the exercises but sometimes I forget how to perform the exercise. For example, do I have to stand on one leg or both? [...] I like this app that shows pictures of the exercises, it also provides written text and audio explaining how to perform the exercises." P32*

Theme 3: Suggested user interface design features of digital health technologies

Patients offered suggestions for the user interface of future digital solutions. Some patients expressed the need to tailor digital health technologies to older age in order to ensure technologies are acceptable to potential users.

- *"Adapt it [the technology] to our age group. Younger people grow up with these technologies in a playful way, but I had to learn using these technologies at later age. It should not be too complicated." P05*

Participants proposed that technologies need to be designed in a way that are easy to use without consciously thinking about how to use them. This appeared to be an important factor in incorporating technology in their daily life.

- *"There are no standards mobile apps have to comply to. For example, having always a button at the top right to log out. It depends on the developers, make it intuitive." P01*

Furthermore, participants viewed typing written text in a mobile app as difficult. Consequently, some patients preferred to use a device with a larger screen such as a tablet device or computer. Some participants suggested that it would be helpful if users could log into applications on various devices.

- *"I have an iPhone, a small one, which means I am always pressing next to the letters with my fingers. So, to type on my phone is inconvenient. I prefer to use the tablet or computer." P28*

Another suggestion was to allow for flexibility and to ask users about their interface preferences. For example, some patients experienced push notifications of mobile apps as annoying.

- *"I think you have to do it [being physically active] yourself. In the morning, when I go shopping, I walk my round. It is not something that has to be done, it happens automatically. Notifications won't help much, I think. It is all on command, on time… no." P33*

Furthermore, introducing new design features in relation to technology was perceived by patients as hard to cope with. However, most patients accepted these challenges or asked a family member for assistance.

- *"Some apps you get used to and those you like. Other apps require an update. Once the update has been completed, you do not recognize them anymore. Then I think: Oh no, I will wait for the next update because this is not working for me." P01*

DISCUSSION

Principle findings

This qualitative study provides insights from stroke patients into how digital health technology could support self-management regarding health and well-being, as well as integrated stroke care. Three themes emerged from the analysis: (1) attitudes toward using digital health for care, (2) suggested features of digital health technologies, and (3) suggested user interface design features of digital health technologies. Unlike previous studies focusing on exploring the experiences with digital technologies (10, 31) or testing a prototype technology (32-34), our study adds to the literature by exploring how digital health technology should be designed in order to support patients. Stroke patients mentioned credible health information, an online library with stroke-related health and care information, a personal health record, and online rehabilitation support at home as the main features to include in future digital health technologies. Moreover, the results demonstrate that patients prefer digital technologies that are easy to use.

Comparison with prior work

Consistent with previous studies, stroke patients used digital technologies, such as the computer or smartphone, to manage everyday life (e.g., reminders, calendar) and to seek information (10, 31). However, the findings showed mixed attitudes of patients toward using digital health to support their self-management and to improve the care they receive. Some patients viewed digital health as a product or service that can be convenient and valuable to access relevant health information. It could be that the COVID-19 pandemic has positively altered patients' perceptions of digital health, as during the pandemic, technology became essential to social interactions in general and patient provider communication specifically. Other patients considered digital health as not needed and shared the concern that technology would replace physical contact with their health care professional. Previous studies indicated that experiencing the benefits of digital health technology influences its acceptance and use (35, 36). This requires that patients have knowledge on the potential benefits of digital health technology to provide assistance and support (37). The findings of the analysis emphasized the need to communicate concrete benefits of digital health to the patient and, at the same time, reduce technology-related concerns such as challenges regarding usability (38). The varying views also highlighted that a "one size fits all" approach is not appropriate for this patient population.

Suggested features of digital health technologies by patients included (1) the need for information about the causes of stroke, medication, prognosis, and follow-up care;

(2) an online library with information regarding stroke-related health and care issues; (3) a personal health record by which patients can retrieve and manage their own health information; and (4) online rehabilitation support to empower patients to exercise at home. The findings emphasized the importance of tailoring information to patients' needs and concerns, as described in earlier studies (39, 40). Therefore, features of digital health technologies should facilitate a personalised approach to meet individual needs. Patient portals have the potential to enhance patient engagement in managing their health by allowing access to, for example, discharge summaries, medications, lab results, and secure patient-provider communication (41). Furthermore, patients brought forward that digital health could potentially support rehabilitation at home by using visual aids to explain and perform exercises. The use of digital health technology is proposed as a useful tool to effectively deliver rehabilitation care, including the use of brain games, virtual reality, and telerehabilitation (14, 42).

Suggestions for the user interface design features of digital health technologies illustrated the need to consider older patients' preferences in all aspects of design. Patients indicated technology should be aligned with their ability to use technology, which is consistent with other studies (37, 43). More specifically, patients emphasized the need for design elements that favor simplicity, are easy to use and intuitive. Previous studies testing the usability of digital interventions for stroke patients showed that a simple design is highly valued by patients (32, 34). In addition, some patients noted that they often felt forced to engage in new technologies by push notifications, which was perceived as inflexible. It was suggested to ask users about their interface preferences before they start using the technology. Furthermore, new design features introduced by the developers of technology were perceived by patients as hard to cope with. The large diversity in patients' familiarity with using digital technologies has been reported in previous studies (37, 44). Understanding user characteristics of stroke patients by focusing on age-related and disease-specific ability changes, including sensory, physical, and cognitive abilities, is essential to develop user interfaces that are acceptable and engaging (45). Providing technical support to older patients tailored to their needs can enhance their digital skills and address barriers regarding usability.

Strengths and limitations

This study has some limitations. First, 310 patients were sent an invitation letter for the study, and only 42 participants agreed to participate. Reasons why patients did not want to participate remain mostly unclear. Some patients indicated they were too tired to participate or did not feel a need to talk about their experiences. Although the applied method may have resulted in selection bias toward relatively healthy participants, our sample also included patients with poor self-perceived health. Second, there were no pilot interviews performed, as included questions had to be in line with project requirements. However, the semistructured nature of the interview allowed for flexibility in asking follow-up questions. In addition, we closed the interview with the following question: "Have we failed to ask any question that is important to you regarding this topic?" We recommend performing pilot interviews in future research. Finally, the study was conducted within the specific context of the Netherlands; therefore, the findings may not be transferable to other settings. The Netherlands has one of the highest smartphone use rates in Europe. In 2019, 76% of people aged 65 years to 74 years and 40% of people aged 75 years and older used social media, such as WhatsApp or Facebook (46). To increase the generalizability of our findings, we reached variation in our sample in terms of patient characteristics (e.g., sex, age, severity of stroke). We recommend replication of our findings in other countries.

A strength of this study was our exploratory approach using a rigorous qualitative methodology. This allowed patients to think freely about their needs and preferences regarding digital health without commenting on an existing prototype. However, particularly for nonfrequent users of digital technologies, it was hard to bring in their own suggestions. To address this, the interviewer asked participants to share their associations regarding digital solutions used in health care and what would be useful for them. Furthermore, our study places emphasis on the requirement to include patients early in the design process of digital interventions. This involvement is considered crucial to ensure that the intervention is meaningful to the population(s) it will serve (47).

Future directions

The findings of this study imply that future digital health technologies could support postacute stroke patients in managing their health and care by taking a personalised approach and adapting technologies to their abilities. In this study, input was gathered from stroke patients prior to the development of the technology product or service within the ValueCare project. Future research is needed to explore the suggested features of digital health technologies in more detail. It is recommended to use an iterative co-design approach involving relevant end users, including stroke patients, their informal caregivers, and health and social care professionals. Co-design ensures digital solutions are tailored to stroke patients' needs and preferences regarding content and usability, as it allows for continuous feedback and interaction between designers and end users (24). In addition, this study also identified potential barriers to using digital health technologies that can be considered during design to optimize its uptake, usability, and usefulness. Future studies with a larger variety of data could focus on subgroup analyses to explore patterns in the data in more depth. The next step within the project is to translate the concept features and user requirements that resulted from this study into improved care supported by digital health technologies for stroke patients.

CONCLUSIONS

Variability exists in stroke patients' perspectives toward how digital health technology could support self-management regarding health and well-being, as well as integrated stroke care. Credible health information, an online library with stroke-related health and care information, a personal health record, and online rehabilitation support at home were mentioned by patients as the main features to include in future digital solutions for stroke care. In designing digital health technologies for stroke patients, the need for simplicity should be emphasized. In addition, the findings emphasized the importance of tailoring information to patients' needs and concerns. Our study supports that designers of digital solutions should have a holistic view and complete understandings of older stroke patients by understanding their user requirements using a co-design approach. The findings of this study provide insight in the needs and preferences of stroke patients for using digital health technologies to manage their health and care, which serve as touch points that can be explored further in co-design sessions.

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APPENDIX: SAMPLE INTERVIEW TOPIC GUIDE

Introduction

- Introduction with background of the study, aims and structure of the interview.
- Check for provision of informed consent and permission for audio-taping.

Experiences and needs

- What is/was going well, considering all health and social care you currently receive/have received in relation to your stroke treatment?
- What is/was not going so well, considering all health and social care you currently receive/have received in relation to your stroke treatment?
- How can stroke services across the continuum of care (hospital, rehabilitation and at home in the community) be improved?

Values and preferences

- According to you, what is important and/or valuable for stroke patients regarding treatment and care?

Digital health technology

- How can digital solutions support you to manage your health and improve the post-acute stroke care you receive?
    - What can (future) digital health technologies do to support you?
    - What kind of characteristics should digital health technologies have for you to use it?
    - Do you foresee any barriers in using digital health technologies?
    - How can we overcome barriers?

Closing

- Additional topics raised by the patient.
- Thank you statement and closing.

CHAPTER 6

Toward integration of mHealth in primary care in the Netherlands: a qualitative analysis of stakeholder perspectives

Esmée Bally, Tomris Cesuroglu

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ABSTRACT

Background: There is a growing need to structurally change the way chronic illness care is organized as health systems struggle to meet the demand for chronic care. mHealth technologies can alter traditional approaches to health care provision by stimulating self-management of chronically ill patients. The aim of this study was to understand the complex environment related to the introduction of mHealth solutions into primary care for chronic disease management while considering health system functioning and stakeholder views.

Methods: A transdisciplinary approach was used informed by the Interactive Learning and Action (ILA) methodology. Exploratory interviews (*n* = 5) were held with representatives of stakeholder groups to identify and position key stakeholders. Subsequently, professionals and chronically ill patients were consulted separately to elaborate on the barriers and facilitators in integration, using semi-structured interviews (*n* = 17) and a focus group (*n* = 6). Follow-up interviews (*n* = 5) were conducted to discuss initial findings of the stakeholder analysis.

Results: Most stakeholders, in particular primary care practitioners and patients, seem to have a supporting or mixed attitude toward integration of mHealth. On the other hand, several powerful stakeholders, including primary care information system developers and medical specialists are likely to show resistance or a lack of initiative toward mHealth integration. Main barriers to mHealth integration were a lack of interoperability with existing information systems; difficulties in financing mHealth implementation; and limited readiness in general practices to change. Potential enablers of integration included co-design of mHealth solutions and incentives for pioneers.

Conclusions: Stakeholders acknowledge the benefits of integrating mHealth in primary care. However, important barriers perceived by end-users prevent them to fully adopt and use mHealth. This study shows that the complexity of introducing mHealth into primary care calls for strategies encouraging collaboration between multiple stakeholders to enhance successful implementation.

INTRODUCTION

Management of chronic diseases has become a major priority for healthcare systems around the world (1, 2). The rising prevalence of chronic diseases combined with severe shortages of medical staff pressures the ability of systems to meet the demand for chronic care services (2, 3). Given these circumstances, many Western countries implemented policies to make the shift from an acute model of care toward an integrated and proactive approach to chronic disease management (4). One such a comprehensive approach is the Chronic Care Model (CCM).

Since 2008, the CCM has a guiding role in chronic disease management in the Netherlands (5, 6). This evidence-based framework is recognized for its ability to improve care processes and clinical outcomes (1, 7). The model is structured around a number of elements that encourage productive interactions between integrated healthcare teams and patients (1). An important element to achieve this constructive patient-professional relationship is the support for patient self-management. Self-management enables an individual to cope with his or her disease. This includes the ability to manage symptoms, make lifestyle changes and adhere to treatment regimen (8).

The effect of self-management on the quality of chronic care has been studied extensively in recent years. Research has shown that patients who actively engage in their own care experience improved self-efficacy and better quality of life (9–11). Mobile health (mHealth) can be effective to stimulate self-management (12). In contrast to eHealth (electronic Health), which refers to the general use of information and communication technologies for health, mHealth encompasses a spectrum of mobile technologies aimed at facilitating the collection and communication of health data to improve healthcare service delivery processes (12, 13). This includes technologies such as mobile phones, personal digital assistants (PDA), smartphones, video-game consoles, and handheld computers (12, 13). These devices can be used to send text messages, share photos and video, enable conversations, access the World Wide Web, and support software application (12–14). Typically, mHealth interventions use tools for self-monitoring (e.g., graphs), reminders to perform self-care behaviors (e.g., to take medication), motivational messages, and educational material (14). It increases patient ownership by allowing users to have insight in their health data. Additionally, mHealth fosters collaboration by facilitating communication between patients and healthcare providers (13, 15).

Despite its potential, difficulties in implementation prevent mHealth solutions to be fully embedded in real-world settings (15). A recent study on the readiness of patients with congenital heart disease to adopt mHealth in their care shows the majority to be willing to use mHealth (16). However, only a small portion used mHealth in their care.

To date, there have been various pilots on mHealth in chronic care, but scale-up has not taken place (16–18). In order to successfully introduce mHealth in chronic care, critical stakeholders need to be engaged (15, 16). Particularly, involving end-users, such as patients and practice nurses engaged in chronic care, is crucial to achieve wide-spread integration. Furthermore, the overall health system needs to be well-understood with a systematic approach in order to understand its dynamics that lead to barriers and facilitators for mHealth integration (19, 20).

This study aims to understand the complex environment related to the introduction of mHealth solutions into primary care in the Netherlands in order to explore strategies for integration while considering health system functioning and stakeholder views. In seeking strategies to support integration, barriers, and facilitators in the integration of mHealth were examined systematically (20). Exploring stakeholder positions and views, including end-user perspectives will contribute to better-informed and more effective integration strategies.

METHODS

Study design

The exploratory research was initiated by a medical technology company and conducted in partnership with a university institute specialized in participatory methodologies and health systems. The medical technology company contributed to the research by representing the mHealth developers' perspective. A transdisciplinary approach, informed by the Interactive Learning and Action (ILA) methodology (21), was selected to unravel the barriers and facilitators that influence mHealth integration and to explore the stakeholders engaged in this process. ILA is a well-established methodology characterized by a multi-stakeholder dialogue process aiming to enhance knowledge integration (22). This particular strength of ILA aligned with the focus of this research to engage multiple stakeholders, including health policymakers, health insurers, primary care professionals, and chronically ill patients.

The process of ILA is structured according to five phases: exploration, consultation, integration, prioritization, and implementation (22). Activities are guided by the learning-action spiral of recurring activities of planning, action, observation, reflection, re-planning, etc. (**Figure 1**). Ideally, studies using the ILA methodology complete several learning cycles in which participants reflect on research outcomes and provide suggestions for adjustments in project activities (23). However, in the context of this exploratory study the focus has been on exploration and consultation.

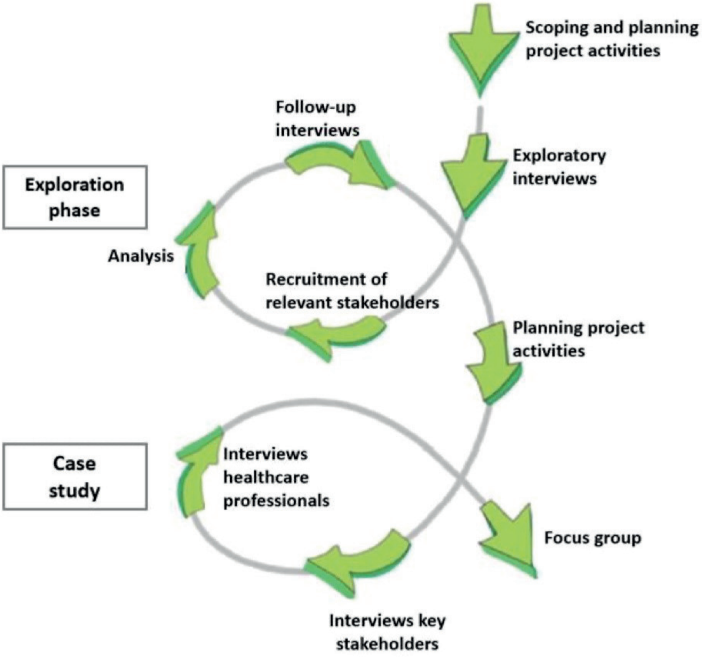

Figure 1 Learning cycles in the research process

In this study, key characteristics of the first three phases of ILA were applied to the Dutch primary care context and provided a sound basis to understand health system functioning and considering stakeholder views related to future mHealth integration. The last two phases of the ILA approach were not within the scope of this research and therefore not applied. Interviews and a focus group were used to support participation, dialogue and reflection among the stakeholders. Interviews were considered a suitable method to stimulate reflection and to gain in-depth knowledge of several stakeholders. A focus group was held to encourage dialogue and to include experiential knowledge (24, 25). **Textbox 1** provides an overview of activities conducted in this study.

Textbox 1 Activities structured per project phase

Activities

Phase 1: Preparation and exploration (May – August 2017)

- Scoping meetings with partner to determine research objectives
- Study design was reviewed and approved by the Internal Committee Biomedical Experiments of Philips Research, The Netherlands
- Exploratory interviews (n=5) with representatives of the Ministry of Health, the national GP association, a health insurance company and patient organizations to identify stakeholders engaged in future integration
- Recruitment of participants for interviews and the focus group

Phase 2: Data collection (November 2017 – April 2018)

- In-depth interviews (n=6) with professional stakeholders from government and insurance companies to explore views on the barriers and facilitators in the integration of mHealth in primary care
- Primary care professionals (e.g. GPs, practice nurses, and managers) were consulted (n=12) regarding their work situation and their perspectives on the barriers and facilitators regarding the adoption of mHealth solutions
- The needs and perspectives of chronically ill patients were explored using a focus group (n=6)

Phase 3: Analysis and integration (January – September 2018)

- Perspectives of different stakeholders were analyzed and compared
- Perspectives of primary care professionals obtained through interviews were presented and discussed in the patient focus group
- Results of the stakeholder analysis were discussed with participants during exploratory interviews to validate findings (n=5)

The first phase comprised exploratory interviews to identify stakeholders involved in the integration of mHealth in primary care (**Textbox 1**). Findings of the exploratory interviews informed the recruitment of key stakeholders. In the third phase, a learning cycle was established by a follow-up of post-interviews with participants at exploratory interviews to present and discuss the findings of the stakeholder analysis (**Figure 1**, exploration phase).

The second phase included in-depth interviews with key stakeholders to examine the barriers and facilitators in the integration of mHealth in primary care (**Textbox 1**). Additionally, semi-structured interviews were held with primary care professionals. A second learning cycle started by sharing the perspectives of this particular end-user group in the focus group with chronically ill patients (**Figure 1**, case study). As a heterogeneous dialogue meeting of chronically ill patients and primary care professionals was not possible, integration of perspectives, and thus mutual learning was encouraged through this method.

Analytical approach

To assess the estimated power and interest of stakeholders, three levels were used based on Covey's circle of concern/circle of influence (26):

1) control (i.e., the stakeholder has the ability to control the adoption of innovations, can prevent further integration or help making it happen);
2) influence (i.e., the stakeholder has the ability to influence developments with regard to the adoption of innovations; less control but important to realize or prevent integration);
3) interest/concern (i.e., the stakeholder is interested in the adoption of innovations or concerned but has no significant ability to impact integration) (26, 27).

For assessment of the health system, a modified version of Murray and Frenk's model for assessing the performance of health systems was used [**Figure 2**; (19, 20)]. Functions of a health system, namely stewardship, financing, service provision and resource generation as defined by Murray and Frenk, provided the broad framework for approaching the health system in a comprehensive way. Furthermore, potential areas to explore within these functions were identified at the design stage of the study with the help of an earlier research which explored integration of an innovation into primary care services (20).

Setting

Data collection took place between May 2017 and September 2018 in the Netherlands. Face-to-face or, when preferred, telephone interviews with key stakeholders were held within the national scope of the study. Nine general practices agreed to participate in the research. Due to a lack of time of GPs, practice nurses and managers, semi-structured telephone interviews proved a feasible method to include this stakeholder group. General practices were located both in urban and rural areas and consisted of solo and group practicing GPs. The patient focus group was held in a rural area, however, through Skype one chronically ill patient from an urban area was able to join the focus group.

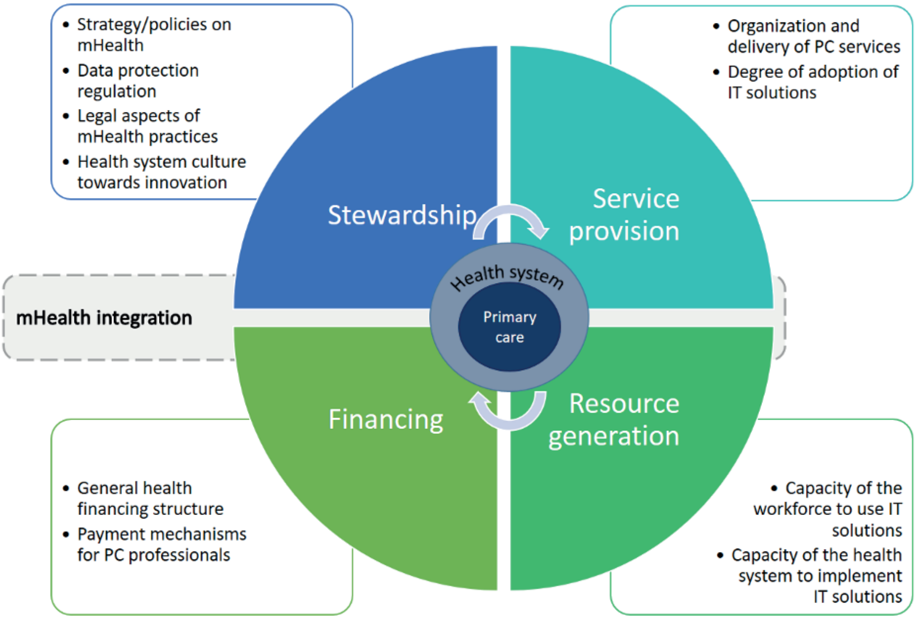

Figure 2 Analytical approach to assessment of the health system for the integration of mHealth (18, 19)

Participants

Participants of the interviews were recruited based on purposive sampling to achieve maximum variation. Convenience sampling was used to recruit patients for the focus group.

Representatives of stakeholder groups

Exploratory face-to-face interviews (*n*=5) were held with a representative of the national patient organization, the heart foundation, the national GP association, the Ministry of Health and a health insurance company. The chosen participants were of high representative value as each of them reflected the view of the community they represent. Following inclusion criteria were applied: (1) representatives worked at organizations or institutions representing key stakeholder groups, including chronically ill patients, GPs, health policymakers and health insurers; (2) representatives held a management or policymaking position in mHealth, health innovation or an equivalent; and (3) representatives had sufficient knowledge of the Dutch health system. Representatives with <6 months experience in the mHealth or health innovation setting were excluded. The mHealth developers' perspective was included by a scoping interview conducted with a representative of the medical technology company which initiated the research.

Professionals in health policy and financing

In-depth face-to-face or telephone interviews (*n*=6) were conducted with heath innovation managers at three different health insurance companies and policymakers at relevant government institutions, including the Directorate for Medicine and Medical Technology and the Program for Healthcare Innovation. Professionals were included based on their expertise to encourage or scale-up health innovations.

Primary care professionals (GPs, practice nurses, and managers)

Eighty general practices (40 urban and 40 rural practices) were invited to participate based on random selection using "Zorgkaart Nederland" (map of Dutch general practices). Of these, nine expressed interest in participating. In total, 12 primary care professionals agreed to a short (25 min) semi-structured telephone interview (*n*=12). Exclusion criteria for selection were: (1) practice nurses not providing care to chronically ill patients and (2) professionals having <6 months experience within the general practice. Participant characteristics are listed in **Table 1**.

Table 1 Characteristics of primary care professionals

Variable	***n***
Gender	
Female	3
Male	9
Age (Median= 40)	
25-45	8
45-65	4
Profession	
GP	7
Practice nurse	4
Practice manager	1
Years of experience	
<5	6
5-15	2
>15	4
Location (*n*=9)	
Urban (>2000 inhabitants)	5
Rural (<2000 inhabitants)	4
Practice type (*n*=9)	
Solo	1
Duo	2
Group (>3 GPs)	6

Chronically ill patients

Participants of the focus group (*n*=6) were recruited through the researcher's personal network by sending out an information leaflet. Those interested to participate were provided with additional information about the research and sampling procedure. People were eligible to participate if they suffered from a chronic disease and were Dutch speaking. For example, patients suffered from asthma, diabetes mellitus (type 1 and type 2), and arrhythmia. The participants' ages ranged from 17 to 83 (median 45) and had the diagnosis for 4–25 years.

Data collection

All participants were made aware of the nature and objectives of the research and gave written informed consent prior to the interview. Interviews lasted between 25 and 60 min. Probing techniques were used to explore perceptions and experiences. Interviews and the focus group were audio-taped and transcribed verbatim. Only the researcher had access to audio-recordings and transcripts which were treated with the strictest confidentiality and safely stored. Participants were registered anonymously by changing the name into a code.

At the start of the interview or focus group, the respondent(s) and interviewer reached consensus on what mHealth solution was referred to in response to interview questions. An example was provided by the interviewer of a smartwatch used by the patient to continuously self-monitor health data, such as heart rate monitoring and physical activity levels. The smartwatch can provide feedback to users on goal progress, send medication notifications and enable communication with Healthcare providers.

Exploratory interviews were conducted face-to-face. These interviews were held: (1) to identify the stakeholders engaged in future integration of mHealth, (2) to assess the level of support for mHealth integration, and (3) to map a stakeholder's position. Interviews were semi-structured and followed a topic guide based on the WHO stakeholder analysis guidelines (28). Participants reflected on issues as power, influence, motivation, resources, and interests in describing the role and position of key stakeholders. Additional documents, such as regulations, policies, and research reports mentioned as highly relevant by the participants were also included as data sources.

In-depth semi-structured interviews with professionals in health policy and financing were carried out face-to-face in the workplace (*n*=2) or over the telephone (*n*=4). Respondents were asked about the barriers and facilitators in the integration of mHealth in primary care. In addition, professionals were encouraged to think of strategies to ensure the scale-up of mHealth in primary care.

Primary care professionals participating in semi-structured telephone interviews were given the same core questions on exploring barriers and facilitators and formulating strategies to mHealth adoption. However, they focused on the barriers and facilitators they (expect to) encounter or experienced when implementing mHealth solutions in their practice. Additionally, primary care professionals were asked to provide sociodemographic information and to describe their workplace, such as practice type and patient population served.

A focus group was held to support participation and to establish a dialogue between patients to exchange experiences in managing their chronic illness. Initially, a heterogeneous focus group of patients and practice nurses was planned. However, it was not feasible for health professionals to join the focus group. In line with the literature, reasons provided were a lack of time, no (financial) incentive, not able to participate due to the many requests to join research studies (22, 29). Therefore, their perspectives obtained in the interviews were shared in the focus group and discussed among patients. During the focus group, the implications of a future integration of mHealth in primary care on patient self-management were discussed. In addition, participants jointly formulated the needs to make integration successful and identified barriers to the process of integration.

Data analysis

A number of methods were applied to improve the rigor and credibility of the research. First, the thematic analysis was conducted iteratively to reflect on transcripts and to verify (initial) findings in further interviews. Second, a member check of synthesized data took place by adding a validation step in which participants of exploratory interviews reflected on the results of the stakeholder analysis. Third, the researcher asked regularly for feedback after interviews and the focus group on the research process and whether participants were satisfied with (intermediary) outcomes. Moreover, triangulation was established by using various research methods—document analysis, interviews, and a focus group. Both written and oral data sources were used, and the study included a large and diverse sample of participants. Transcripts of audio-recordings were analyzed using the data analysis software program MAXQDA version 12.

Stakeholder analysis

Identified stakeholders were grouped under six headings: government, research community, private business, civil society, health consumers/patients, and healthcare providers. As the stakeholder component was based on preliminary explorative research inductive codes were of prime importance to generate categories of information. Nonetheless, the stakeholder analysis was informed by all data gathered. During interviews, informants estimated the relative influence of each stakeholder on integration (power) and to what extent a stakeholder is affected by integration or held accountable in the process of integration (interest) (27, 30). In a second step, the power-interest grid was used to assess stakeholders' levels of influence and position toward mHealth integration at the time of the fieldwork (2017) (30). During the exploratory interviews, informants identified 42 stakeholders across the health system (**Figure 3**). They can be categorized in three main groups:

1) individual patients/consumers and their representative organizations.
2) health care professionals interacting with patients (e.g., GPs, practice nurses, medical specialists), and their professional organizations/associations.
3) institutions and organizations not directly in contact with patients/consumers, but able to affect their health (e.g., governmental institutions, health insurers, mHealth providers).

The first two groups comprise the end-users of mHealth solutions. They are directly affected by the potential adoption of new mHealth initiatives. The third group has the ability to influence the integration of mHealth in the health system. They considered their role mainly as a facilitator; providing knowledge and (financial) resources contributing to the functioning of the health system.

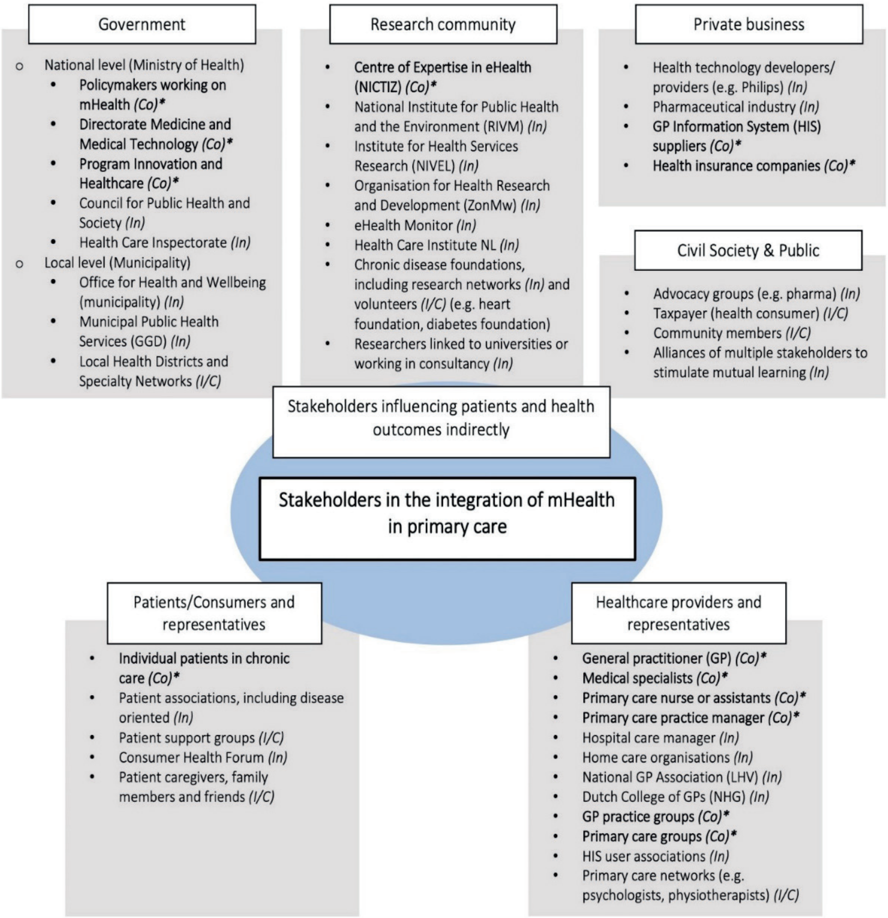

Figure 3 Stakeholder identification map

*Estimated power of stakeholder in terms of control *(Co)* (also, influence *(In)* and interest/concern *(I/CI)*. Stakeholders regarded as having control *(Co)* over the adoption process are key stakeholders written in bold letters.

Of all 42 stakeholders identified, 13 were considered to have “control” over the adoption process, 22 to have “influence” and seven to have an interest or to be concerned about the situation (**Figure 3**). All 13 stakeholders in the “control group” were identified as key stakeholders based on their position to steer (or obstruct) successful integration. **Textbox 2** illustrates the diversity in perspectives on who to involve in the integration process. Their characteristics are listed in **Table 2**.

Textbox 2 Selected quotes of key stakeholders' perspectives

Quote 1:

> *"It is important to include the Dutch expert organization on eHealth as they set the standards for health information exchange. These specifications are necessary for developers of mHealth to build high quality solutions."*

Representative GP association

Quote 2:

> *"You need to have the GP information system developers around the table. Some of these providers have quite a market share and financial assets. Changes to the system, such as allowing patients to access their own health data, needs to be discussed first and agreed to with the provider."*

Representative patient association

Quote 3:

> *"We [health insurer] believe the GP should be the ambassador of mHealth solutions for primary care. As the main provider of primary care,the GP is in a position to implement and offer mHealth solutions to patients."*

Innovation manager health insurer 1

Health system analysis

To identify and analyze barriers and facilitators in the integration of mHealth a directed content analysis, including deductive and inductive coding was used. Coding was based on a modified version of Murray and Frenk's framework for assessing the performance of health systems (19, 20). First, the deductive coding method allowed to see where in the four functions of the health system barriers and facilitators exist [**Figure 2**; (19)]. Subsequently, an inductive approach was used to explore relevant concepts that did not fit the framework and needed to be assessed in broader perspective. This contributed to an in-depth understanding of barriers and facilitators.

Table 2 Characteristics of key stakeholders

Abbreviation	Stakeholder	Characteristics				
		Involvement in the integration of mHealth	**Interest**	**Influence/ power**	**Position**	**Impact integration on actor**
P	Individual patient in chronic care	Potential user of mHealth solutions	High	Low	Mostly supportive	High
MS	Medical specialist	Secondary care to chronically ill patients; due to a loss of income not likely to refer patients back to primary care	Low	Medium-high	Likely to be opposed	Low
GP	GP	Potential user and/or promotor of mHealth	Medium	Medium	Mixed	Medium
N	Practice nurse	Potential user of mHealth	High	Low	Mostly supportive	High
M	Practice manager	Providing support to GP on management tasks; potential promotor of mHealth	Medium	Low-medium	Likely to be supportive	Medium
GPGr	GP practice groups	Collaboration of GPs in group practices; potential users/and or promoters of mHealth	Medium	Medium	Mixed	Medium
PCG	Primary care group	Representing interests GPs; establishing contracts with insurers on behalf of GPs; potential promotor of mHealth	Medium	Medium-high	Likely to be supportive	High
PM	Policymaker (MoH)	Developing and shaping policies on mHealth	Medium-high	Low-medium	Supportive	Medium
PIH	Program Innovation & Healthcare	eHealth policy formulation and support; facilitator of stakeholder collaboration	High	Medium	Supportive	Medium
DMT	Directorate Medical Technology	Assessing and approving health technologies on accessibility, quality and safety	Medium	Medium	Supportive	Medium
NIC	Centre of Expertise in eHealth (NICTIZ)	Policy support, particularly by setting health data exchange standards	Medium	Medium	Likely to be supportive	High
HIS	GP information system developer	Development and control of information systems in primary care; monopoly market position	Low-medium	High	Likely to be opposed	High
I	Health insurer	Pays for healthcare; searching for solutions to keep healthcare affordable	High	High	Supportive	Medium-high

RESULTS

This section presents the identified stakeholders and provides an analysis of the barriers and facilitators in the integration of mHealth. In discussing mHealth solutions participants referred to examples they learned of but were not necessarily working with professionally or using in daily life. Examples participants considered relevant are mobile phone applications to promote healthy behavior, a smartwatch for self-monitoring, and medication reminders through SMS. In contrast, eHealth applications were frequently used among the end-user groups, such as an online tool to plan a GP appointment or request (repeat) prescriptions.

Stakeholder analysis

The analysis of exploratory interviews indicated that most stakeholders were supportive of the integration of mHealth in primary care, although differences exist in their level of influence (**Table 2**). The power-interest grid was used to compare the positions of individual stakeholders and the relations among them (**Figure 4**).

Supportive stakeholders with high and medium-high influence

As illustrated in **Table 2**, key supportive stakeholders with high and medium-high influence are primary care groups and health insurers. Primary care groups are legal entities owned by GPs in a particular region (31). They differ in size from 4 to 150 GPs. Approximately 80% of Dutch GPs was part of a care group in 2014 (32). Core functions of care groups are to coordinate chronic illness care and to negotiate a fixed fee per patient with a health insurer. To receive such a bundled payment requires a contract between a care group and health insurer (32). These contracts may include budget reservations for health innovation. One interviewee illustrated the process of negotiation.

- *"It is open to discussion to use health technology, [say it is] A, B or C. This is determined in the contract between the health insurer and healthcare provider. Health insurers usually push the discussion toward health technologies they find useful to purchase." (Policymaker Directorate Medicine and Medical Technology)*

Care groups were identified as potential promotors of mHealth integration. They are interested in implementing health technologies, such as mHealth, for three reasons: (i) to reduce the workload of health professionals; (ii) to increase the quality of care; and (iii) to meet the expectations of the patient population they serve. However, care groups, but also individual GPs might experience difficulties in receiving funding for mHealth solutions. Ideas for innovation are assessed based on criteria of improved quality of care, reduced healthcare costs, and increased satisfaction among patients. Unless health technologies fulfill these criteria, health insurers are hesitant to provide funding for implementation.

- *"Only when the effectiveness of a mHealth solution is demonstrated by evidence we might step in. We won't provide funding if we think it is a risky investment." (Innovation manager health insurer 1)*

Although their influence is substantial, health insurers describe their role as "facilitating". This facilitating role is portrayed two-fold. First, health insurers encourage primary care providers to think about innovative ways to deliver affordable, high-quality care within existing budgets. In addition, health insurers may help realizing new ideas by revising the contract or referring to external sources of funding, such as funds at regional governments.

- *"We ask GPs to share their thoughts on how to enhance patient-centered care at an affordable price. Once there is a good idea, we discuss what changes to the contract are necessary for GPs to realize their plans." (Innovation manager health insurer 2)*

Second, a facilitating role is observed toward the clients of health insurers—the insured health consumer. A health insurer's main interest is to create best value for money and keep premiums low. mHealth has the potential to provide health services at decreased costs (33, 34). Particularly with regard to disease prevention, health insurers will actively promote the supply of effective mHealth solutions. This is either done by providing guidance to clients on how to purchase available mHealth services, or through collaboration with mHealth enablers. This collaboration may lead to health applications specifically designed for clients to prevent or manage chronic diseases.

Supportive stakeholders with medium/medium-low influence

Supportive stakeholders with medium influence were mainly working in government agencies under the Ministry of Health, including the Program of Innovation and Healthcare, the Directorate Medicine and Medical Technology and the Centre of Expertise in eHealth (NICTIZ). Departments of the Ministry of Health prepare and implement policies and programs to support the uptake of innovation in Health care.

Policy support by providing research evidence on eHealth and health innovation is a key role of NICTIZ. Here, the term eHealth refers to the use of Internet and related information technologies to communicate health-related information and deliver interventions. They are an important stakeholder in the integration of mHealth in primary care as they set the standards for health information data exchange and are responsible for the eHealth application already used in primary care, such as online tools for making a GP appointment (**Textbox 2**, quote 1).

Whether, more focused on conducting research or formulating policy, these governmental stakeholders have in common that they want to facilitate knowledge exchange between various stakeholder groups. A policymaker at the Ministry of Health illustrates this role.

- *"We [Ministry of Health] do not envision a top-down approach in integrating mHealth in chronic care. Rather we bring stakeholders together, including representatives from health insurers, patient and physician organizations, industry and research to discuss ideas for implementation." (Policymaker Ministry of Health).*

Supportive stakeholders with low influence

Supportive stakeholders who agree that mHealth should have a profound role in chronic care delivery but have less influence on the integration of mHealth in primary care, include chronically ill patients and practice nurses. They are the main potential users of mHealth technologies. Among all end-users, chronically ill patients expressed the highest interest in mHealth adoption. This group noted some perceived benefits of mHealth, such as quick and easy communication with healthcare providers, and increased patient autonomy.

- *"mHealth can make daily life easier, because it enables quick communication with my doctor in a convenient way. I can have an answer to my questions within minutes." (Patient 1, age 49)*

- *"Having an overview of my blood sugar level on my phone would allow me to have better insight in my health. It can help to understand blood sugar fluctuations, so I can focus on improvements." (Patient 2, age 17)*

Despite perceived benefits, representatives of patient organizations emphasize the diversity in perspectives with regard to mHealth among patients. Particularly adolescents and young adults support the use of mHealth solutions in primary care, while the older patient population is more skeptic. This contrast was explained by the extent to which patients are familiar with mHealth technologies and able to use them in managing their health. Nonetheless, patients encourage the availability of relevant and easy-to-use mHealth solutions.

Another important end-user in this respect is the practice nurse. As the main provider of chronic care, they have a high interest in the adoption of mHealth. Practice nurses are responsible for the regular check-ups of chronic care patients and supervise in chronic disease management. Faced with a substantial (administrative) workload, practice nurses perceive mHealth as a supportive tool which can potentially save time.

- *"It [mHealth] saves time. My patients will be able to contact me directly, instead of talking to a practice assistant first." (Practice nurse, urban group practice).*

Barriers and facilitators

Findings on the barriers and facilitators in mHealth integration are structured along the four health system functions: stewardship, financing, service provision and resource generation. Additionally, the thematic analysis revealed several themes that do not fit one of the four functions and are therefore analyzed in wider perspective of the health system.

Stewardship

Stewardship aims to set, implement and monitor the rules for all actors (healthcare providers, payers, and consumers) within the health system. In this domain, respondents indicated barriers related to an inadequate set of core standards, and difficulties in informing end-users on mHealth. Using reflexive learning approaches including multiple stakeholders and gathering evidence were seen as facilitating factors.

An inadequate set of core standards

Respondents identified a lack of specific regulation on mHealth to ensure health information obtained by mHealth applications complies to privacy and data security standards. End-users suggested to define a set of clear principles applied to all use of patient data and to all data controllers to guarantee the protection of mHealth data. The need for universal standards was also observed in enabling health information exchange.

- *"Making sure mHealth data is not used for commercial purposes is something we [the government] can actively promote by setting the rules." (Policymaker Directorate Medicine and Medical Technology)*

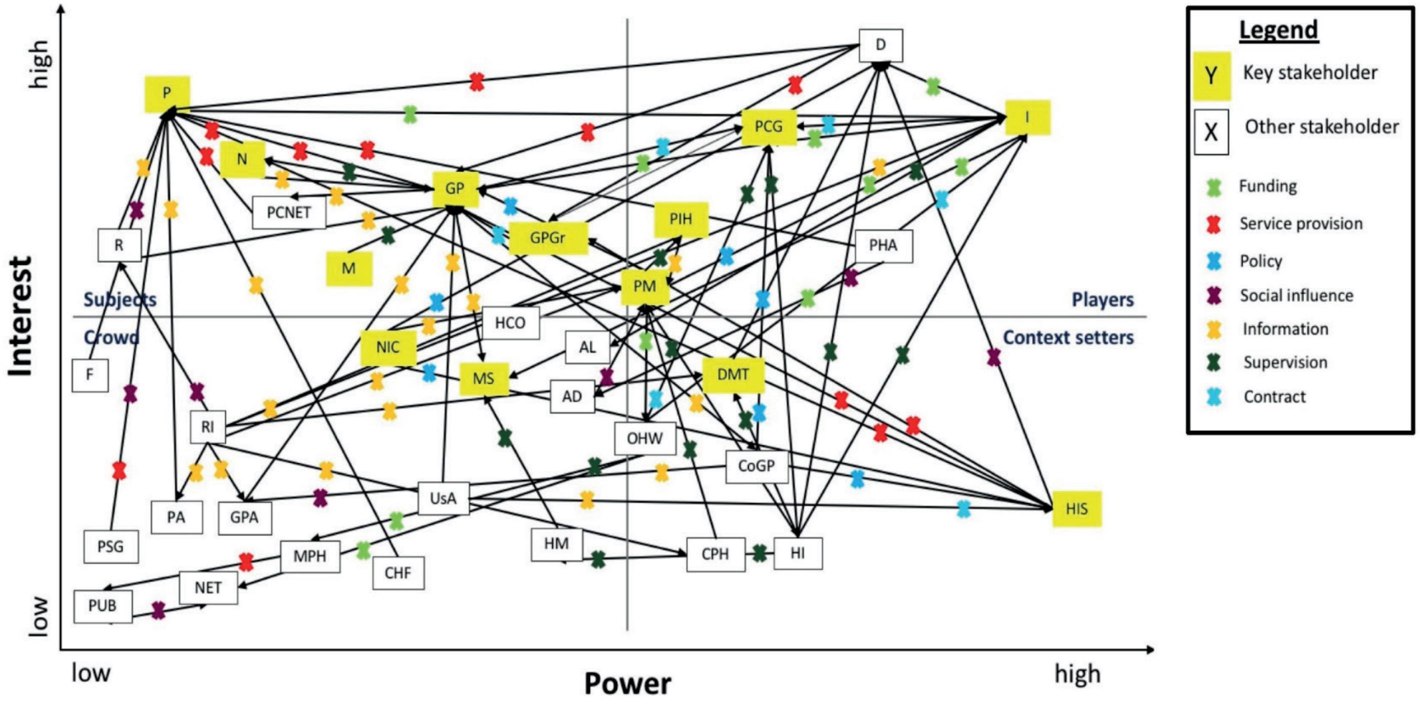

Figure 4 Power-interest grid of stakeholders engaged in the integration of mHealth
AD, advocacy groups; AL, alliances; CHF, consumer health forum; CoGP, college of GPs; CPH, council of public health; D, mHealth developer/provider; DMT, directorate medicine and medical technology; F, family and caregivers; GP, general practitioner; GPA, national GP association; GPGr, GP practice groups; HCO, home care organization; HM, healthcare manager; HI, healthcare inspectorate; HIS, GP information system suppliers; I, health insurer; M, primary care manager; MPH, municipal health services; MS, medical specialist; N, primary care nurse; NET, local networks; NIC, expert organization eHealth (NICTIZ); OHW, office health and well-being (municipality); P, patient; PA, patient association; PCG, primary care group; PCNET, primary care networks; PHA, pharmaceutical industry; PIH, program innovation & health care (MoH); PM, policymaker; PSG, patient support group; PUB, public; R, researcher; RI, research institute; USA, GP information system user association.

Currently, patients are not able to view, download, and transmit their own health information from an electronic health record (EHR) to a personally controlled health record. However, recently the law "electronically processing of patient data" was implemented, stating that patients should have access to their own health information by 2020 (35). Allowing patients access to their own health information is a first step enabling mHealth implementation. However, despite new regulation, barriers exist in the interoperable exchange of health data. Healthcare providers cannot directly transfer patient data received from sensors or applications to an EHR. This prevents (self-measured) mHealth data to be saved in health records. There is a need to produce a set of core standards and specifications that enable EHRs to communicate seamlessly.

<u>*Difficulties to inform on mHealth*</u>

In addition to barriers related to the legal framework, respondents identified obstacles in informing end-users. A key role of the Ministry of Health is to inform and make health consumers and professionals aware of the possibilities of mHealth. The validation of mHealth applications is necessary to prevent false claims made by mHealth developers on the effectiveness of certain mHealth products or services. However, established research methods aiming to measure effectiveness lag behind.

- *"It is not easy to validate and measure the effectiveness of over 200 000 health applications. Traditional methods of clinical trials are not appropriate anymore. Clinical trials usually take long. By the time evidence is produced the technology is outdated." (Policymaker Program on Healthcare Innovation)*

Collaboration with mHealth developers is necessary to communicate standards on the quality criteria to be followed during app development. Moreover, appropriate assessment methodologies are needed to measure validity and reliability of mHealth apps in order to provide recommendations to consumers.

<u>*Encourage reflexive learning*</u>

A recurrent theme within the dimension stewardship was the lack of collaboration between stakeholders. Respondents identified the enhancement of interaction between stakeholders as a key facilitator inmHealth adoption at greater scale. More specifically, the Ministry of Health was appointed to have an important role in this process of bringing stakeholders together.

In steering collaboration, it was suggested to encourage stakeholders to learn about each other's perspectives and experiences on how mHealth can be of added value in chronic care delivery. Reflexive learning approachesmay support this vision of realizing collaboration in mHealth adoption. A policymaker at the Program for Health Innovation reflected on this.

- *"Not all parties are willing to share their insights to come to collaboration. They mainly think from their own perspective. The scale-up of mHealth can only be achieved when stakeholders step out of their comfort zone and develop a shared vision to integrate solutions" (Policymaker Program on Healthcare Innovation).*

Gathering evidence

There is a need for scientific evidence on the effectiveness of mHealth solutions. Evidence-based information would allow stakeholders to make informed decisions in considering the use or reimbursement of mHealth solutions. A possible explanation for the lack of evidence is the large, non-regulated (international) market for digital health technologies, making it hard to assess what technologies can be successfully adopted. Due to a lack of time and resources, GPs are hesitant to adopt mHealth services without proven effectiveness.

- *"We [GPs] won't immediately implement the newest technologies. The technology should prove itself and earn our trust." (GP, rural group practice)*

A GP described how evidence may be gathered.

- *"Ideally scientific research shows the effectiveness of a mHealth solution. If this is not possible, respected physicians need to testify on its added value." (GP, urban duo practice).*

Financing

Health system financing comprises a range of processes, including revenue collection, fund pooling, and purchasing. Within this dimension, specific focus lies on payment structures in primary care. Currently, there are no specific funds available for mHealth adoption by GPs in the Netherlands.

However, based on the guidelines for financing eHealth solutions, GPs have several opportunities to mobilize funds within the existing payment system [**Textbox 3**; (36)]. Within these payment structures, the main barriers were a lack of time and resources to ensure financing for mHealth, and difficulties in applying for (extra) funding. Presenting a good revenue model for the implementation of mHealth solutions was perceived as a facilitator.

A lack of time and resources to establish financial flows for mHealth

GPs mentioned that existing budgets were not satisfying to realize mHealth service provision. They felt compelled to apply for additional funding which was identified as a time-consuming and resource intensive process, particularly for stand-alone practices. While in group practices a manager takes on administrative and financial tasks, solo-practicing GPs must constantly monitor their financial resources.

Textbox 3 Guidelines for financing eHealth solutions (36)

Mobilization of funds for health innovation within existing primary care payment system:

- the capitation fee can be used to build an online health environment to facilitate communication between patients and primary care professionals;
- remote consults can be reimbursed as regular, face-to-face consults;
- revenues collected to finance chronic care can be spend on solutions for the remote delivery of chronic care or self-management programs;
- health insurers and health care providers may have additional negotiations about reimbursing or rewarding the use of digital health solutions in delivering primary care services.

Difficulties in applying for funding

GPs indicated the health insurer as the first contact point to turn to for financial support to implement mHealth. Applying for funds was reported by the majority of GPs as a time-consuming and inconvenient process. Another barrier to the application process was the request of health insurers to have access to patient data. GPs felt disturbed to allow access to patient data and were hesitant to do so.

- *"I tried to apply once. [..] However, I withdrew my application as I was pretty annoyed by the unwieldly and bureaucratic system, leaving me with a high administrative burden." (GP, rural solo practice).*

Thinking about a revenue model

Health insurers noted a better chance of receiving funding, if a GP presented a long-term revenue model. To be able to do so, it is important to remove barriers from the application process, making it easier and less time-consuming to apply for funding.

Moreover, GPs indicated a lack of knowledge to develop a smart financing model. Better cooperation between GPs and health insurers is needed to make existing budgets fit for implementing new innovations.

Service provision

By service provision is meant personal health services directly consumed by the health system user which can be preventive or disease management services in which mHealth might assist. Despite perceived benefits, negative perceptions of end-users toward mHealth may obstruct adoption. Concerns were expressed on a changing physician-patient relationship, and risk of misinterpreting health data. Facilitators were associated with providing high quality and relevant mHealth solutions.

Risk of losing personal contact

The risk of losing physical contact was perceived as a barrier to using mHealth solutions. GPs indicated that face-to-face consults help to pick up signs relevant to the course of treatment, but without this interaction remain under the surface. Moreover, particularly older patients preferred personal contact with their GP.

- *"I would rather go to the GP than communicate remotely. I like to be there and to have a chat." (Patient 3, age 83)*

- *"Why would you want to communicate remotely, if you can talk with each other directly by paying a visit? An inconvenient way to communicate with your doctor, I believe." (Patient 4, age 58)*

However, this view was not shared among all end-users. Using mHealth services was also associated with perceived benefits, such as a reduced workload and saving time. A GP using mHealth services commented.

- *"I prefer online interaction as it is quicker. I settle a lot online, which means I have less patients who visit me in person. While a GP consult normally is 10 minutes, in my practice I can spend 20 minutes on a face-to-face consult. It is more relaxed and satisfying than it used to." (GP, urban group practice)*

Generally, a common notion exists that mHealth is an additional tool which is not able to replace physical contact. When necessary or preferred a face-to-face consult should be possible.

Risk of misinterpreting health data

Another barrier identified by primary care professionals was the concern to misinterpret mHealth data. The risk of misinterpretations was mainly observed in assessing self-measured data. GPs and nurses said to have difficulties to make sense of the data patients collect. More specifically, the quality of self-measured data was sometimes doubted as patients need to carry out self-measurements at the right time and under the right circumstances, following procedures correctly to ensure data validity.

As a result of poor data quality, healthcare providers might be inclined to see a patient in person to conduct the test themselves. Therefore, it was suggested to devote time of practice nurses on informing and educating patients on the use of mHealth services as it has the potential to save time in future consults.

Good working mHealth solutions

A facilitator in the service provision domain was to create high-quality mHealth solutions tailored to the needs of end-users. It was suggested that mHealth developers focus on the usability and user-experience of end-users. By usability was meant applications that are easy to use and potentially timesaving, while user-experience included the alignment with daily life situations and having an added value to the care process. Subsequently, it was suggested among end-users to harmonize the use of validated apps. This implies the possibility to align high-quality applications in one portal, that can be easily accessed by end-users.

Resource generation

Health systems include a diverse range of inputs to provide health services, such as human resources, equipment and knowledge. Barriers within the function resource generation were associated with the knowledge, skills and attitudes of stakeholders. Education was mentioned as a facilitator to overcome barriers.

A lack of knowledge

GPs mentioned they are poorly informed about the possibilities of mHealth. Moreover, if they were informed, GPs stated they have insufficient knowledge on how to adopt and use health technologies in their practice. A graduate of the GP specialty training program explained.

- *"My study taught very little about entrepreneurship. Only a few GPs like the entrepreneurial aspect of their job, but most of them don't. They want to focus on providing health services." (Graduate in Medicine, GP specialization)*

Knowledge on the possibilities of mHealth, but also operational support in how to implement mHealth services is necessary to realize adoption.

A lack of digital skills

Another obstacle for end-users is a lack of digital skills to work with mHealth solutions. Particularly, older generations may experience difficulties in using mHealth technologies as they need to switch to a new way of working. A lack of digital skills results in extra time needed to enter or process data. It was suggested to develop mHealth technologies which are user-friendly and very easy to use to keep the need for digital skills at a minimum.

Negative attitudes of stakeholders

Attitudes of stakeholders refer to constructs defined by values stakeholders hold. The attitude of GP information system developers was identified as a barrier to the adoption of mHealth.

- *"GP information system controllers hold the key to providing access to their system by other providers. If access is not granted to certain mHealth technologies, we cannot easily transfer the collected mHealth data to our GP information system." (Practice nurse, urban group practice)*

The lack of motivation among GP information system developers to optimize the systems they produce obstructs quick information exchange between the GP information system and the mHealth technology. Consequently, health care professionals spent extra time entering (self-measured) patient data in the EHR. Therefore, partnerships were suggested between mHealth technology developers and GP information system owners to ensure alignment of services. The government has a crucial role to stimulate this collaboration or might even intervene in the market to encourage mHealth adoption.

The attitude of GPs was also frequently discussed among respondents as a barrier in the integration of mHealth in primary care. First, GPs are afraid of resistance toward the implementation of new technologies by their patient population. Furthermore, GPs doubt their patient population to be capable of working with technological solutions. Particularly, GPs working in rural areas or serving a patient population with a low social economic status (SES) mention this problem. Second, GPs are hesitant in taking initiative. They find it hard to embrace and accept a new way of working. The little drive for entrepreneurship in combination with a lack of time and resources led to an attitude of "wait and see" instead of taking initiative to innovate.

Education

Proving education on how to use and implement technologies was mentioned as a facilitator in tackling barriers related to knowledge, skills and attitudes. Currently, curricula devote little time to the entrepreneurial aspects of being a GP. Reserving time in the curriculum of prospective primary care professionals to teach on topics as management and health technology adoption will increase their knowledge of the possibilities to innovate in general practices.

Overarching health system factors

The analysis revealed themes that did not fit any of the four health system functions. Instead, they were analyzed at a higher, overarching level. One barrier identified in this area related to system design: a production-stimulating system leading to a wrong financial impulse among physicians. A facilitating factor enhancing the adoption at health system level was the inclusion of stakeholders and relates to the responsiveness of the health system.

A production-stimulation system

The production-stimulating impulse in the health system causes healthcare professionals to provide more service. This is encouraged by a fee-for-service payment system. While detaining chronic care patients in primary care is saving healthcare costs, medical specialists are not likely to refer patients back.

- *"The financial impulse is wrong. Medical specialists have no reason to send chronic care patients back to primary care, because they earn money for treating quite healthy people. It is cheaper and better for the continuity of care to help these patients in primary care." (Innovation manager health insurer 2)*

Medical specialists find it hard to accept a loss of income when referring (chronically ill) patients back to primary care. However, money can be better spent in primary care. Therefore, gradually reducing the budget for medical specialists who refer patients back and providing more budgets to GPs taking care of these patients is necessary to make this transition.

Inclusion of stakeholders

At health system level, a facilitator was to ensure stakeholder inclusion in mHealth integration. Inclusion was observed in two areas. First, including end-user perspectives from the start of product development will ensure mHealth services meet the needs of end-users. This co-design of mHealth technologies contributes to high-quality and relevant solutions that are more likely to be used and adopted by end-users. Second, respondents suggested to create a business case. This implies collaborations of multiple stakeholders engaged in mHealth integration to establish a thorough adoption strategy. A beneficial business case represents common interests, by including advantages for all stakeholders, such as increased affordability of care, high quality of care, and consumer satisfaction.

DISCUSSION

This research extends our understanding of how to integrate mHealth solutions into primary care. On the one hand, end-users of mHealth, i.e., primary care practitioners and patients, seem to have a supporting or mixed attitude toward integration of mHealth. On the other hand, several powerful stakeholders, including primary care information system developers and medical specialists are likely to show resistance or a lack of initiative toward mHealth integration. Key barriers to integration perceived by stakeholders included: a lack of interoperability with existing information systems, difficulties in obtaining funding for implementation, and limited readiness of general practices to change. In contrast, key strategies to facilitate integration were collaboration between stakeholders, and incentives for pioneers. The findings indicate that mHealth integration is challenged at different levels, including higher health system level barriers, organizational level barriers and technical features as barriers.

At system level, the lack of universal standards obstructs the interoperability between mHealth devices and existing primary care information systems. The role of standardization has been a long-recognized topic in eHealth and mHealth (37, 38) and has been reported earlier in policy documents (39, 40). However, our findings indicate that this is still a significant barrier in integration of mHealth. Previous studies have shown that addressing interoperability by establishing a regulatory framework can be favorable to the success of mHealth implementation (15, 41, 42). Regulation is needed to create an infrastructure to facilitate information exchange and ensure all information systems adhere to interoperability standards. This requires regular involvement and communications between the Ministry of Health, the Centre of Expertise in eHealth (NICTIZ), GP information system developers, and mHealth developers to set data standards and specifications. NICTIZ has a key role to ensure systems fulfill requirements prior to entering the market.

Another barrier that needs to be addressed at system level is the perceived difficulty in establishing budgets and ensuring financial flows for mHealth implementation. GPs indicated a lack of time and resources to transform existing budgets to fit mHealth costs. Meanwhile, insurers argued that uncertainty about return on investment led them to withdraw from providing funding for mHealth. This tense relationship has been reported by other studies and can be explained by the different interests and values these stakeholders hold (43–45). Whereas, GPs are concerned with providing acceptable, high-quality health services on a long-term basis, insurers' main concern is affordable Health care with return on investment in the short run.

Demonstrating evidence on return on investment is critical for insurers to reimburse mHealth services (46, 47). There is a need to define robust metrics for measuring the efficacy and (cost-) effectiveness of mHealth services (40, 46). Rather than conducting traditional clinical trials, such studies could use practical evaluation methodologies including clinical, patient-reported and economic outcomes (46, 48–50). An example is the use of a micro-randomized trial design to assess the causal moderated effect of intervention components by using standardized effect sizes (48). This design allows comparison of the effectiveness of different intervention components. A proposed solution would be to combine evidence on effective intervention components and a pragmatic approach when designing or adapting mHealth solutions to allow conditional reimbursement approval (20, 46, 47, 49). This financing model serves to encourage practice-based interventions, while decreasing the risks for health insurers.

At organizational level, barriers were found in the practice "readiness" for implementation. Overall, primary care professionals were positive about mHealth adoption. However, some GPs indicated a lack of "sense of urgency" and motivation to implement mHealth solutions. One explanation is that GPs feel comfortable the way they operate their practice and are satisfied with the IT solutions they use. Pilot studies implementing mHealth technologies in primary care processes in Denmark and Sweden found healthcare clinics with a pre-existing culture of desire to provide care in a more modern way and attitudinal ethos of quality improvement to be more receptive to the introduction of mHealth services (50, 51). These characteristics, together with strong internal and external stakeholder collaboration, are essential to create an "implementation climate" for successful adoption (50, 51). Another explanation is uncertainty about whether mHealth solutions can meet expectations of saving time and maintaining high-quality care, and thus have an added value in delivering health services. Building end-user trust in mHealth solutions, preferably by providing evidence-based information on app credibility, is an important enabler to increase promotion of mHealth solutions by GPs (45, 52, 53). This includes information on perceived usefulness, ease of use, risks associated with accessing and communicating personal health data and a measure of trust in the developers of the mHealth technologies (54, 55).

With respect to technical features, end-users, including GPs, practice nurses, and chronically ill patients experienced a lack of time and technical skills to adopt mHealth solutions. To promote use and acceptance, respondents indicated that mHealth solutions need to be very easy to use, reflect meaningful functionality, and align with the context of an end-user's daily life and workflow. In line with findings from the literature, mHealth technologies perceived to be easily embedded in existing structures and timesaving have a better chance of being adopted (15, 44, 45, 54). GPs and practice nurses emphasized their limited amount of time; therefore, adding extra mHealth-related tasks to their workload would be undesirable.

By exploring health system constraints and opportunities, and stakeholder views two main strategies emerged to steer mHealth integration. A first strategy is stimulating co-design of mHealth technologies. It has been demonstrated that end-user involvement in the development of mHealth solutions is crucial to support acceptance and adoption of new technologies (42, 47, 56). This requires a thorough examination of end-user needs and capabilities to use ICT equipment. Continuous feedback loops in the development process help to assess the level of support for adoption and lead to tailored solutions (41, 51).

A second strategy is for the government or health insurer to provide incentives for pioneers to make mHealth adoption more attractive. Several studies found strong stakeholder collaboration in which financial support is assured to initiate and energize the mHealth adoption process (47, 52, 57). A crucial facilitator is therefore to create collaborative platforms including key stakeholders, such as end-users, health insurers and industry players to make a sound business case shaping the adoption process. The ILA methodology used in this study is a good example of an iterative approach to involve and analyze stakeholders in the integration process. The learning cycles presented in this study form the basis for follow-up research to continue studying and supporting the integration process.

Regional care groups may act as a pioneer as they have, compared to small practices, the organizational means for implementation. These care groups can use (conditional) funding to slowly introduce mHealth solutions in local general practices. An option would be to appoint a key person in the organization (e.g., the practice nurse specialized in chronic care) who familiarizes with the mobile technology at hand and is trained to use it. Previous studies show that healthcare professionals are more likely to accept adaptations in their workflow from someone they trust and is seen as important to the job (51, 55). This person can introduce the wider team to the app and gradually inform and educate patients in using mHealth services. By weekly evaluating the adoption process in existing team meetings, barriers can be quickly picked up and improvements made to optimize the process (20, 51). In this way, general practices implementing mHealth solutions should be viewed as “learning cases” and can stimulate others for change.

One of the strengths of this study lies in the use of a transdisciplinary approach. This facilitated the inclusion of different types of knowledge from a variety of stakeholders. Considering health system functioning and stakeholder views allowed for a comprehensive understanding of the mechanisms involved in mHealth integration. Moreover, the stakeholder analysis complemented this study by providing information on stakeholder interests and power which contributed to the development of a strategic view on future mHealth integration (28, 58). Through member checking by discussing results in post-interviews, a validation step was added. However, this was only done among participants of exploratory interviews. Another strength of this study is a whole-of-system approach to capture important cross-system relationships instead of solely focusing on several aspects of adoption.

This research has several limitations. A major limitation was the limited time available to establish learning cycles. During this research, only one learning cycle was completed by discussing the results of the stakeholder analysis in follow-up interviews. A second learning cycle, discussing mHealth integration among different stakeholder groups proved difficult. Another limitation is that the software developers and suppliers of mHealth solutions were not or weakly represented. Furthermore, due to a lack of time, GPs and practice nurses could not be included in the focus group. Previous research shows that lack of time and interest is a main reason for physicians not to participate in participatory research. Yet, their participation is considered crucial for implementation (22, 29). To minimize bias, their views were shared in the focus group to encourage reflection and learning. Another limitation was the small size of the focus group in which chronically ill patients from mainly rural areas participated. More extensive research is needed to have a representative and detailed view of patient perspectives.

It is recommended to examine how proposed strategies can be applied in practice. The cross-sectional nature of this study does not allow to see patterns of adoption change over time. Hence, in future studies, it would be interesting to gather longitudinal data to establish causal relations on what impact various determinants have on adoption over time. In addition, extending this research to other European countries representing a variety in health systems would complement the research as this study only focused on the Dutch context. Finally, further research is recommended to examine the effectiveness of the ILA methodology in facilitating mHealth adoption in health systems.

CONCLUSIONS

This study shows that interests and values of stakeholders may contradict each other and have substantial influence on the potential integration of mHealth in primary care. Nevertheless, most stakeholders support the adoption of mHealth in primary care. Addressing barriers with regard to the legal, financial, socio-cultural and technical aspects associated with mHealth adoption is needed to steer integration. This complex array of factors obstructing the scale-up of mHealth calls for future integration strategies that encourage collaboration between multiple stakeholders. Although this study focuses on the Dutch case, and is therefore not generalizable, findings are transferable to contexts similar to the Netherlands, including features of strong primary care with GPs as gatekeepers and an advanced technological environment in Health care.

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PART III

Design of a person-centred integrated care intervention supported by digital health technology

CHAPTER 7

‘Value-based methodology for person-centred, integrated care supported by Information and Communication Technologies’ (ValueCare) for older people in Europe: study protocol for a pre-post-controlled trial

Esmée Bally, Amy van Grieken, Lizhen Ye, Maite Ferrando, Mirian Fernández Salido, Rachael Dix, Oscar Zanutto, Maurizio Gallucci, Vanja Vasiljev, Áine Carroll, Andrew Darley, Alejandro Gil-Salmerón, Sofia Ortet, Tasos Rentoumis, Nikos Kavoulis, Oscar Mayora Ibarra, Nancy Karanasiou, George Koutalieris, Jan Hazelzet, Bob Roozenbeek, Diederik Dippel, Hein Raat, and on behalf of the ValueCare consortium

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ABSTRACT

Background: Older people receive care from multiple providers which often results in a lack of coordination. The Information and Communication Technology (ICT) enabled value-based methodology for integrated care (ValueCare) project aims to develop and implement efficient outcome-based, integrated health and social care for older people with multimorbidity, and/or frailty, and/or mild to moderate cognitive impairment in seven sites (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, the Netherlands; Treviso, Italy; and Valencia, Spain). We will evaluate the implementation and the outcomes of the ValueCare approach. This paper presents the study protocol of the ValueCare project; a protocol for a pre-post-controlled study in seven large scale sites in Europe over the period between 2021 and 2023.

Methods: A pre-post-controlled study design including three time points (baseline, post-intervention after 12 months, and follow-up after 18 months) and two groups (intervention and control group) will be utilised. In each site, (net) 240 older people (120 in the intervention group and 120 in the control group), 50–70 informal caregivers (e.g. relatives, friends), and 30–40 health and social care practitioners will be invited to participate and provide informed consent. Self-reported outcomes will be measured in multiple domains; for older people: health, wellbeing, quality of life, lifestyle behaviour, and health and social care use; for informal caregivers and health and social care practitioners: wellbeing, perceived burden and (job) satisfaction. In addition, implementation outcomes will be measured in terms of acceptability, appropriateness, feasibility, fidelity, and costs. To evaluate differences in outcomes between the intervention and control group (multilevel) logistic and linear regression analyses will be used. Qualitative analysis will be performed on the focus group data.

Conclusions: This study will provide new insights into the feasibility and effectiveness of a value-based methodology for integrated care supported by ICT for older people, their informal caregivers, and health and social care practitioners in seven different European settings.

Trial registration: ISRCTN registry number is 25089 186. Date of trial registration is 16/11/2021.

INTRODUCTION

The increase in life expectancy observed globally is one of the greatest public health successes of the 20th Century. In 2019, the global population aged ≥65 years was estimated to be 703 million and this number is expected to double by 2050 (1). Ageing is correlated with a higher risk of multimorbidity, frailty, and cognitive impairment (2-4). Firstly, having two or more medical conditions and/or disabilities at the same time (i.e. multimorbidity) is increasingly common among older adults, as mortality rates have declined and the population has aged (4, 5). Secondly, community-dwelling older adults are prone to developing frailty whereby multiple physiological systems gradually lose their intrinsic capacity (6, 7), which increases the risk of falls, disability, and long-term care (8, 9). Finally, age-related diseases accelerate the decline in performance on cognitive abilities such as remembering, reasoning, and planning which can lead to the development of cognitive impairments (10).

Multimorbidity, frailty, and cognitive impairment can have significant implications for an older person's functional independence and quality of life (10-12). Furthermore, these conditions are correlated with an increased risk of unplanned health and care utilisation, especially costly hospital admissions, being thus challenging for the health and care systems related costs (11, 13, 14). The objective, therefore, is to help maintaining older people's intrinsic capacity and independence for as long as possible and to prevent hospitalisation. Integration of care will enable a proactive, predictive, and personalised delivery of health and social care and support services for this ageing population.

"Integration" of service delivery includes processes of linking and coordinating services to overcome fragmentation (15). Older people receive care from multiple providers at various sites — outpatient units, primary care practices, specialty clinics, hospitals, and others – which often results in a lack of coordination. Integrated care aims to better articulate health and social care around the individual's needs and therefore improve their health outcomes and experiences (16, 17). Moreover, a recent meta-analysis has shown that integrated care is likely to reduce costs and to improve outcomes (18) such as reducing the risk of hospital admissions and increasing the patients' care satisfaction (19-21). In this regard, integrated care partnerships are increasingly acknowledged as an organising framework and mechanism to deliver value-based health care with the purpose of maximizing value for patients, health and care practitioners, managers, and policymakers (22).

Value can be defined as health outcomes achieved, relative to the costs of delivering these outcomes (23). In a value-based system, outcomes are measured across the continuum of care and according to what is meaningful to its end users, such as functional status and quality of life (24, 25). Standardisation of outcome measures is essential for improving care and supporting people living with a condition in making informed decisions with their care team members and service funders. This requires a combined effort by care team members in the continuum of care to collect data and to use data accordingly (26). Furthermore, it requires Information and Communication Technologies (ICT) platforms that facilitate data sharing and support healthcare delivery (22, 26).

Whilst there is evidence showing the value of integrated care programs for older people (21, 27), previous research on ICT-enhanced integrated care interventions showed mixed results for this population. In this regard, Kim et al. (2021) found significant effects of ICT-enhanced integrated care management for frail older adults on overall quality of life and functional outcomes (28). In contrast, studies by Mateo-Abdad et al. (2020) and Piera-Jiménez et al. (2020) reported that ICT-enhanced integrated care programs have only small clinical effects (29, 30). There is a need for more knowledge on adapting ICT-enhanced integrated care interventions for older people to individual settings, the effectiveness of interventions in key target groups, and its cost-effectiveness (31, 32). The purpose of this article is to describe the framework of the evaluation of the value-based methodology for integrated care supported by ICT developed by the ValueCare consortium members.

Project ValueCare

ValueCare aims to deliver technology-enabled, outcome-based integrated health and social care for older people facing multimorbidity, and/or frailty, and/or mild to moderate cognitive impairment to improve their quality of life, thus supporting the sustainability of European health and social care systems. The ValueCare project is funded under the Horizon 2020 Topic call Digital Transformation in Health and Care, under Grant Agreement No. 875215. ValueCare is developing a robust, secure, and scalable digital solution which is co-designed with end users (older people, their informal caregivers, and health and social care practitioners). To this end, ValueCare aims to satisfy the 'Quadruple Aim' of improved care experience, better outcomes for citizens, optimization in the use of resources, and job satisfaction and wellbeing of care team members (33). In this project, seven large-scale sites in Europe (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, the Netherlands; Treviso, Italy; and Valencia, Spain) will contribute to the implementation of the ValueCare approach in which each site is expected to adapt the general value-based methodology to their local context.

Objectives

The aim of the study is to evaluate the ValueCare approach, using a pre-post-controlled design, measuring the benefits for each one of the target groups (older people using health and social care services, their informal caregivers, and health and social care practitioners), and thus to be able to properly evaluate implementation outcomes.The specific objectives are:

1. To compare the benefits of the ValueCare approach versus usual care for older people with regard to indicators of health, wellbeing, quality of life, lifestyle behaviour, and health and social care use.
2. To evaluate the benefits of the ValueCare approach for older people's caregivers (e.g. relatives, friends), and health and social care practitioners in terms of wellbeing, perceived burden and (job) satisfaction.
3. To evaluate the acceptability, appropriateness, feasibility, fidelity, and costs of the ValueCare approach.

Hypotheses

Our hypothesis is that older people in the intervention group (i.e. individuals benefiting from ValueCare) have more favourable results with regard to indicators of health, wellbeing, quality of life, lifestyle behaviour, and reduced health and social care usage compared with older people participating in the control group (i.e. individuals receiving 'usual care'). With respect to informal caregivers and health and social care practitioners, we expect a lower caregiver burden, and improved wellbeing and (job) satisfaction among participants in the intervention group. Furthermore, we hypothesise the costs of care for the intervention group will be lower, compared to the control group.

METHODS

Study design

The evaluation of ValueCare has a pre-post-controlled design with an intervention group (using the 'ValueCare approach') and a control group ('care as usual'). Measurements are taken at baseline (*T*0), after 12 months (*T*1; the end of the 'ValueCare approach' intervention period), and at 18 months (*T*2) (32, 34, 35). In each of the seven European countries, intervention and control sites (GP practices, community centres for health and wellbeing, and hospitals) are chosen. **Table 1** shows the timeline of enrolment, interventions and assessments for this study. Baseline data collection is scheduled to commence by the end of 2021.

Table 1 Timeline of enrolment, interventions and assessments

	STUDY PERIOD					
	Pre-intervention	**Baseline**	**Intervention**	**Post-intervention**	**Follow-up**	**End**
TIMEPOINT	**Month -1**	**T_0**	**Month 1–12**	**T_1 (Month 12)**	**Month 13–18**	**T_2 (Month 18)**
ENROLMENT:						
Training of professionals	X					
Eligibility of screening	X					
Invitation to participate	X					
Informed consent	X					
INTERVENTIONS:						
Care as usual			●—●		●—●	
ValueCare			●—●		●—●	
ASSESSMENTS:						
Participant demographics		X		X		X
PROMIS-10		X		X		X
Tilburg Frailty Indicator		X		X		X
ICHOM older person set (multiple items)		X		X		X
UCLA 3-Item Loneliness Scale		X		X		X
Modified Barthel Index		X		X		X
Visual Analogue Scale for Fear of Falling		X		X		X
One item of the SHARE-Frailty		X		X		X
One item of the IPAQ		X		X		X
SNAQ65+		X		X		X
MRQ-10		X		X		X
Modified SMRC Health Care Utilization		X		X		X
iMTA iVICQ		X		X		X
Zarit Burden Interview 4-item		X		X		X
Adult Social Care Outcomes Toolkit		X		X		X
Culture of Care Barometer tool		X		X		X
Minnesota Satisfaction Questionnaire		X		X		X
Copenhagen Burnout Inventory		X		X		X
iMTA Productivity Cost Questionnaire		X		X		X
EQ-5D-5L		X		X		X
Acceptability of Intervention Measure				X		X
Intervention Appropriateness Measure				X		X
Feasibility of Intervention Measure				X		X
Focus group interviews	X		X			

Participants

The ValueCare target group consists of older people living with: (1) medical conditions and/or disabilities, (2) frailty and/or, (3) mild to moderate cognitive impairment; also their informal caregivers (e.g. relatives, friends), and health and social care practitioners will be involved in the study. Each site in the seven participating countries performs the study in accordance with the contextual and organisational factors and capacity (see **Table 2**).

We aim to include 1680 *older people* (i.e. patients, clients) in total: 120 participants in the intervention group and 120 participants in the control group in each site. Study participants will be included if they: (i) are aged ≥65 years, (ii) have a confirmed diagnosis of the targeted chronic condition at the time of enrolment, (iii) are community-dwelling (not living in long-term care facilities) or are temporarily in a hospital or institution and are expected to be referred to their home, and (iv) are able to give informed consent.

With regard to the older people enrolled in the study, the researcher will ask the participant whether they have an informal caregiver, and will ask who is/are the most relevant formal caregivers. These informal and formal caregivers will be approached (with the permission of the participant) and invited to participate in the study. In each of the seven sites, we aim to enrol 50–70 *informal caregivers* (e.g. relatives, friends) and 30–40 *health and social care practitioners* who work with older people having the targeted condition.

Table 2 Target group per site

Site	Target group of older people
Athens (Greece)	Type II Diabetes Mellitus and hypertension as comorbidity, living independently in the community
Coimbra (Portugal)	Patients/clients with no or mild cognitive impairment, and two or more chronic conditions, and a lack of social or familiar support
Cork/Kerry (Ireland)	Older people (≥ 75 years old) with mild to moderate frailty
Rijeka (Croatia)	Patients who had a myocardial infarction, with inclusion after the clinical phase of rehabilitation
Rotterdam (the Netherlands)	Patients who had an ischemic stroke
Treviso (Italy)	Mild cognitive impairment and/or frailty, in combination with hypertension, or diabetes or cardiovascular diseases
Valencia (Spain)	Mild to moderate frailty

Recruitment

Study enrolment is planned to be conducted between the end of 2021 and summer 2022. Participants will be recruited with the support of health and social care providers. Physicians, nurses and other care professionals are invited to discuss the project with eligible patients who visit the hospital or care centre. In addition, health and social care providers can invite patients to participate in the study by sending a letter to introduce them to the project. Posters and brochures will also be made available throughout care facilities to support recruitment. All participants who provide informed consent and participate in the data collection at baseline are enrolled in the study.

Intervention: the 'ValueCare approach'

Co-design component in ValueCare

Prior to the start of the intervention, in ValueCare, older people, their informal caregivers, health and social care practitioners, as well as other stakeholders (e.g. policymakers, managers, ICT experts) are progressively involved in a co-design iterative process to assess the ValueCare concept and technical solution. In this regard, co-design enables patients, their caregivers and healthcare staff to reflect on their experiences of a service and to identify improvement priorities (36, 37). Furthermore, co-design ensures the technical solution is tailored to the needs and preferences of end users regarding content and usability (38). Each site will engage at least 40 older people, 40 informal caregivers, 20-30 health and social care practitioners, and 5–10 other stakeholders in semistructured interviews, focus group discussions, or workshops. Qualitative analysis methods will be used to gather stakeholders' perspectives on care experience, service provision, priorities for improvement and how digital solutions can contribute to such improvements. The co-design sessions are organised in two rounds between April 2020 and the end of 2021.

The 'ValueCare approach'

Based on the E-health Enhanced Model for Chronic Care Management the 'ValueCare approach' will be developed and validated (39). In order to do so, knowledge from the literature, as well as the findings from the co-design activities will be used as input. The 'ValueCare approach' consists of six key components: (1) health system support, (2) self-management support, (3) delivery system design, (4) clinical decision support, (5) care information systems, and (6) digital education.

The 'ValueCare approach': care pathways

Each site will apply the design of an integrated care pathway based on the 'ValueCare approach' for the target population. Care pathways map out the care journey an individual can expect given a certain (chronic) condition (40). Each site designs a ValueCare pathway in its specific context based on co-design activities, the ValueCare approach and the current care pathways.

The 'ValueCare approach': outcome-based care delivery

In this project, an 'outcome-based' (or 'value-based') approach will be applied aiming to achieve better health outcomes and patient experiences. In the 'ValueCare approach', care professionals will measure and use the 'outcomes'/'values' that are important for patients (clients) (41). In all sites, in the intervention group, the '*value-based care approach*' will be applied to assess, discuss with patients (clients), and monitor 'outcomes' that are relevant to the patient (client). This is a specific application of 'outcome-based care delivery' developed by the International Consortium for Health Outcomes Measurements (ICHOM) (42). It entails that a selfreported questionnaire will be administered to assess 'outcomes' that are relevant to the patient (client); examples are physical, mental, and overall well-being of the patients (clients). The aim of this assessment is to identify the individual care needs of the participating patients (clients) in the intervention group, and to discuss and monitor the findings with the patient (client) and their caregivers. Based on the assessment's outcomes and detected needs, with each patient (client) a personalized care plan will be decided upon. This care plan is co-produced by the patient, (when applicable) their informal caregiver and their health or social care practitioner. The shared care plan will be periodically reviewed and can be adjusted according to the patients' (clients') health, wellbeing and preferences.

ValueCare technical solution

The 'ValueCare approach' will include technical solutions to support patients (clients), their informal caregivers, and their health or social care practitioners. The ValueCare technical solutions will enhance the assessment and the monitoring of the personalised care plan by a mobile health application for older people. Participants will have access to a potential range of functionalities linked to their individual care plan using a motivational and goal-setting approach, such as lifestyle coaching, disease management (e.g. medication monitoring) and care provider-participant communication. Additionally, a "Virtual Assistant" will support the accomplishment of the personal goals set by the participant and their care provider in a shared decision process. Therefore, this virtual assistant will act as a conversational agent that can interact with the participant through a chat bot following person-centredness principles and using artificial intelligence. Furthermore, wearable sensors, including fitness trackers can be added as part of the ValueCare technical solution to enhance activity monitoring of the participant. Moreover, if the participant provides consent, informal caregivers, and health and social care practitioners can have access to a web-based application, which monitors the progress of the patient (client). Participating health and social care practitioners, as well as the older people and their informal caregivers, will be invited to use the digital solutions in accordance with their roles. Additionally, capacity building activities will be provided using a 'train the trainers' methodology for the adoption and implementation of the ValueCare sites.

Data collection

Data will be collected through self-reported questionnaires filled in by older people, informal caregivers and health and social care practitioners. Assistance to fill in the questionnaire will be provided by the research team if necessary. Additionally, with permission of the participant, data will be collected from clinical sources, and from the ValueCare technical solution. The general data collection instruments used are based on the Standard Set for Older Person developed by ICHOM (24, 42). This standard set includes outcomes that matter to older people and therefore fits the purpose of ValueCare to deliver value-based care. Sites can apply particular ICHOM Standard Sets according to the specific (chronic) condition(s) of their target population. The instruments used for the outcome measures are described in the outcome measures section. Instruments for which no validated translations are available will be translated (forward and backward translations). Before starting the study, the questionnaire will be tested and validated in all sites to assure its user-friendliness in terms of appropriateness, comprehensibility and usability. Basic psychometric indicators (e.g. internal consistency) will be calculated when applicable.

Evaluation of health, wellbeing, quality of life, lifestyle behaviour, and health care use outcomes in older people

Table 3 describes the outcome measures used in the evaluation for older people. In addition, collected wearable data can provide information on for example number of steps taken or sitting time that can be used to enhance the self-reported data. The main outcome is the health-related quality of life (HR-QoL) score measured by the PROMIS Scale v1.2 – Global Health (PROMIS-10) representing physical health, pain, fatigue, mental health, social health, and overall health (43). The PROMIS-10 is a domain-specific quality of life instrument that has been validated by modern psychometric methods and computerized adaptive testing to ensure greater precision and less burden (44). Additional outcome measures include health and wellbeing outcomes, outcomes related to lifestyle behaviour, and care use. Methods and instruments have been selected because they are patient-centred, well-validated, and comprehensive measures that can be self-administered. This allows comparing our results with other studies.

Table 3 Effectiveness outcomes in older people

Outcome	Outcome measure(s)	Methods and instruments
Health, wellbeing and quality of life	Physical HR-QoL	PROMIS-10 (43)
	Mental HR-QoL	
	Frailty	Tilburg Frailty Indicator (45)
	Comorbidities	ICHOM Older Person Set (42)
	Loneliness	UCLA 3-item Loneliness Scale (46)
	Activities of daily living	Modified 10-item Barthel Index (47)
	Falls	Visual Analogue Scale for Fear of Falling (48)
Lifestyle behaviour	BMI	ICHOM Older Person Set (42)
	Smoking status	ICHOM Older Person Set (42)
	Alcohol consumption	ICHOM Older Person Set (42)
	Physical activity	One item of the SHARE-Frailty (49)
		One item of the International Physical Activity Questionnaire (IPAQ) (50)
	Nutrition and undernutrition	SNAQ65+
	Medication intake	Medication Risk Questionnaire (MRQ-10) (52)
Care use	Care utilization	Modified SMRC Health Care Utilization Questionnaire (53)

Evaluation of wellbeing, perceived burden, and (job) satisfaction outcomes in informal caregivers, and health and social care practitioners

Table 4 summarises the effectiveness outcome measures used for informal caregivers and health and social care practitioners. Regarding indicators of wellbeing, perceived burden, and (job) satisfaction, we hypothesise more favourable results at follow-up compared to baseline measurement. Selected methods and instruments aim to provide a complete and comprehensive overview of perceived wellbeing, burden and satisfaction of participants engaged in the implementation of the ValueCare approach.

Table 4 Effectiveness outcomes in informal caregivers and health and social care practitioners

Outcome	Outcome measure(s)	Methods and instruments	Target group(s)
Wellbeing	Physical HR-QoL	PROMIS-10 (43)	All
	Mental HR-QoL		
Perceived burden	Carer burden	iMTA Valuation of Informal Care Questionnaire (iVICQ) (54)	Informal caregivers
		Zarit Burden Interview 4-item (42, 55)	
	Autonomy and control	Adult Social Care Toolkit (42, 56)	
Job satisfaction	Working conditions	Culture of Care Barometer tool (57)	Health and social care practitioners
	Satisfaction	Minnesota Satisfaction Questionnaire – Short Form (58)	
	Work-related burn-out	Copenhagen Burnout Inventory (59)	

Evaluation of implementation outcomes in terms of acceptability, appropriateness, feasibility, fidelity, and costs

Table 5 provides the implementation outcomes and related measures for evaluating the performance of the ValueCare approach implementation across the seven sites. The implementation outcome evaluation is based on the taxonomy of implementation outcomes defined by Proctor et al. (2011) (60). Included implementation outcomes are acceptability, appropriateness, feasibility, fidelity, and costs (60). A mixed methods approach is used to collect implementation outcomes. This includes the 12-month self-reported follow-up questionnaires (*T*1), focus group interviews and data routinely collected by the ValueCare application. Focus groups will be held with older people, informal caregivers, and health and social care practitioners 12 months after implementation, and at the end of the intervention. At least 2 focus groups will be held in each site with *n* = 8–12 participants per focus group. Participants will be asked to share their experiences, for example, regarding shared-decision making, satisfaction with care, perceived fit and barriers and facilitators to implement the ValueCare approach.

The costs of implementing the ValueCare approach in each setting will be estimated and reported using standard procedures (64, 65). The direct costs of using all types of health and social care services will be measured by a modified version of the SMRC Health Care Utilization questionnaire (53). Services specific to the ValueCare implementation including training, outreach services, and time spent by care team members on elements of the program will be captured and quantified. Real cost prices will be used when unit resource prices are not available. The iMTA Valuation of Informal Care Questionnaire (iVICQ) is used to report an informal caregiver's time spent on activities to care for a patient. Societal costs will be calculated by productivity losses for informal caregivers who perform paid labour during the study period using the friction cost method (66). The incremental cost-effectiveness ratio (ICER) will be expressed as costs per quality-adjusted life years (QALYs) gained, based on EQ-5D-5L scores.

Table 5 Implementation outcomes

Outcome	Outcome measure(s)	Methods and instruments	Target group(s)
Acceptability: willingness to receive the service offered	Enrolment rate (%)	Comparison of reported enrolment rates and targets set for the study	Older people
	Attrition/retention rate (%)	Descriptive statistics and reasons for nonconsent	Older people
	Engagement	*T*1 follow-up questionnaire. Examples of items: engagement of patient in care plan, app functions used, cooperation between patient and care team members	All
	Perceived acceptability	4-item Acceptability of Intervention Measure (AIM) scale (61)	All
		Focus group interviews with a sample of patients, informal caregivers, and care team members	All
Appropriateness: perceived fit, relevance and compatibility of the service	Perceived fit	4-item Intervention Appropriateness Measure (IAM) scale (61)	All
		Focus group interviews with a sample of patients, informal caregivers, and care team members	All
Feasibility: extent to which a service is successfully used	Training of end users	Evaluation of training materials	All
	Perceived delivery of the intervention	4-item Feasibility of Intervention Measure (FIM) scale (61)]	All
	Perceptions of barriers and facilitators	Focus group interviews with a sample of patients, informal caregivers, and care team members	All
Fidelity: extent to which the service was implemented as prescribed in the original protocol	Engagement rate (% at least one month app use)	Descriptive statistics	All
		Several items in the *T*1 follow-up questionnaire	All
		Focus group interviews with a sample of patients, informal caregivers, and care team members	All
	Dose delivered (completeness)	File analysis and *T*1 follow-up questionnaire: presence of care plan, app functions used, number of (digital) interactions between patients and care team	All
	Perceived quality of the delivery	Focus group interviews with a sample of patients, informal caregivers, and care team members	All
Costs: from a societal perspective	Productivity losses	iMTA Productivity Cost Questionnaire (iPCQ) (62)	Older people, informal caregivers
	Health care use	SMRC Health Care Utilization questionnaire (53)	Older people
	Quality of life	EQ-5D-5L (63)	Older people

Power calculation

In each of the seven sites, 120 participants will be included in the intervention group and 120 participants in the control group. Assuming a 20% participant loss to follow-up between T0 and T1 (e.g. due to disability, rehousing, mortality, study withdrawal), we expect to get complete data from 672 participants in the intervention group and 672 participants in the control group of all sites at follow-up; in total n = 1344 study participants. We assume equal standard deviations in the intervention group and the control group, alpha of 0.05 and power of 0.80. Thus, given seven participating study sites each with an intervention group and control group, we applied a correction factor to account for the cluster design, assuming an average cluster size of 96 older citizens (1344/14) and an intra-class correlation coefficient of 0.02. For this expected overall sample size and assumptions, regarding the continuous outcome measures, a difference of 0.23 SD between the intervention and the control group can be detected at follow-up. This means that both at the European level and within each individual site, small differences regarding the outcomes in the intervention group compared to the control group can be shown (67).

Data management and analyses

A data management plan is being developed as part of the ValueCare project and will be updated throughout the project. The document describes the data life cycle, from definition to reuse after the project. It follows a privacy-by-design approach and includes procedures for ensuring a high-quality data standard, in compliance with the FAIR principles. As the project will collect health-related data, special attention is attributed to the role of each partner in terms of controllers and processors, and to the organisational and technical measures to be put in place to ensure General Data Protection Regulation (GDPR) compliance. In addition, the risks associated to data processing will be defined in the Data Protection Impact Assessment (art. 35 GDPR) to be evaluated together with the Controllers' Data Protection Officers. Erasmus University Medical Center is responsible for the data management, analysis and reporting.

Descriptive statistics will be used to describe participant characteristics in each site and in the total study population. Differences between *T*0, *T*1 and *T*2 measurements are evaluated using multilevel linear regression analyses for continuous outcome variables and multilevel logistic regression analyses for dichotomous outcome variables. We will perform subgroup analyses through formal interaction tests including those variables that are likely to influence the effect of the intervention itself, such as age, sex, living situation, education level and the baseline status of the outcome variable. Statistical analyses are repeated for each site separately. We consider a P value of 0.05 or lower to be statistically significant.

To assess changes in implementation outcome measures from baseline (*T*0) to follow-up (*T*1, *T*2) *t* tests for continuous measures and chi square for categorical variables will be used. Qualitative analysis will be performed on the focus group data. Focus groups will be digitally recorded and transcribed. The data will be managed using N-Vivo 10 software. The data will be analysed using thematic content analysis.

Using the baseline measurement as control group, a preliminary cost-effectiveness analysis will be performed from a societal and healthcare perspective. The healthcare costs per individual participant will be calculated by multiplying resource use (e.g. doctor appointments, hospital admissions) with corresponding unit prices. The results from the iPCQ are used to determine productivity losses for individual participants (lost productivity at paid work due to absenteeism and lost productivity at unpaid work). Information from the EQ-5D-5L will be used to calculate utility values.

DISCUSSION

This study aims to evaluate the ValueCare approach in comparison with 'usual care' practices in terms of benefits for the target groups (older people, their informal caregivers, and health and social care practitioners), and to evaluate implementation outcomes. Benefits of the intervention will be measured in multiple domains; for older people: health-related quality of life (HR-QoL), frailty, comorbidities, loneliness, activities of daily living, falls, BMI, smoking status, alcohol consumption, physical activity, nutrition and undernutrition, medication intake, and care utilization; for informal caregivers: health-related quality of life, caregivers' burden, and autonomy and control; for health and social practitioners: health-related quality of life, working conditions, job satisfaction, and work-related burnout. Implementation outcomes will be measured in terms of acceptability, appropriateness, feasibility, fidelity, and costs. A pre-post-controlled design is used to explore the effects of the ValueCare approach in seven European sites in Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, the Netherlands; Treviso, Italy, and Valencia, Spain.

We expect to encounter some challenges in the study. Firstly, previous research has indicated that recruiting and retaining older people with chronic conditions in research studies can be difficult due to for example reduced vision and hearing, the severity of health problems, or fatigue (68). For that reason, the recruitment strategy seeks to encourage the participation of this population by providing a fair opportunity for them to participate and to ensure we reach our target sample size. Furthermore, capacity building activities including training sessions and regular communication with health and social care practitioners will be put in place by local study teams to reduce recruitment challenges and increase the adherence to the study. Furthermore, it is possible that some elements of the technical solution may not be used by older people, family members or professionals due to the lack of interest or an unfriendly interface design (69). To encounter these challenges, the research team developed the intervention implementing a key co-design process of the ValueCare approach and technology solution. Moreover, training activities are expected to facilitate the implementation of the intervention and the use of the new technology, increasing the adherence to the ValueCare intervention and use of the technical solutions by the target groups (37).

Moreover, this study has several strengths which are important to stress. First of all, the ValueCare project addresses challenges of fragmentation in providing integrated care for a growing number of older people with multimorbidity, frailty, and mild to moderate cognitive impairment. Second, the study combines the evaluation of effectiveness outcome measures and the process. This comprehensive approach to evaluation will help to understand the complexity of the interactions between many contextual factors, and therefore contributes to reducing the research-to-practice gap (70). Third, this study explores the effects of the ValueCare approach among diverse older adult populations in seven different European settings which generates contextual information on its generalisability and feasibility. By utilising a uniformed questionnaire and measurements, including the ICHOM Standard Set for Older Person, a cohesive evaluation will be applied. Fourth, the ValueCare technical solution will be co-designed with end users to ensure the solution serves their needs and preferences (71). The use of ICT can increase patient empowerment by allowing users to have insight in their health data (72).

In summary, the results of this study will provide evidence on the benefits of an innovative and value-based integrated care approach that could potentially support the 'Quadruple Aim' regarding care for older people with multimorbidity, frailty, and mild to moderate cognitive impairment. By developing a model of care following the principles of value-based health care and integrating health and social care, supported by appropriate technical solutions within current practices across seven European countries, this study can contribute to new ways of providing person-centred and value-based integrated care supported by ICT solutions to older people.

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CHAPTER 8

General Discussion

The overall aim of the research presented in this thesis was to improve the quality of care for older adults by studying person-centred integrated care supported by digital health technology.

The six study questions were:

Part I: Understanding the determinants of health outcomes that matter to older adults

- What factors are associated with falls among hospitalised and community-dwelling older adults? (Chapter 2)
- What factors are associated with health-related quality of life among community-dwelling older adults? (Chapter 3)

Part II: Stakeholder perspectives regarding person-centred integrated care supported by digital health technology

- What are the values, needs and preferences of stroke patients across the continuum of care? (Chapter 4)
- How could digital health technology support stroke patients' self-management regarding health and well-being, as well as integrated care? (Chapter 5)
- How can digital health technologies for people with chronic conditions be integrated into the Dutch health system? (Chapter 6)

Part III: Design of a person-centred integrated care intervention supported by digital health technology

- How to design and evaluate a person-centred integrated care intervention supported by digital health technology for older adults in multiple settings in Europe? (Chapter 7)

MAIN FINDINGS AND INTERPRETATION

Part I: Understanding the determinants of health outcomes that matter to older adults

Part I consisted of a cross-sectional study about the factors associated with falls **(Chapter 2)** and a longitudinal study about the factors associated with health-related quality of life (HRQOL) **(Chapter 3)**. The analyses were performed using questionnaire data from the 'Appropriate care paths for frail elderly patients: a comprehensive model' (APPCARE) project. More specifically, data at baseline **(Chapter 2)** and data at baseline and follow-up after 6 months **(Chapter 3)** were used from the Rotterdam site (The Netherlands) to conduct the studies.

Factors associated with falls

Multivariable logistic regression models were used to assess associations between sociodemographic characteristics, potential fall risk factors, and falls. The sample included 113 older adults who had been hospitalised and 777 community-dwelling older adults. Regression analyses for the two subsamples were done separately. Female sex, education level, multimorbidity, a higher score on ADL limitations, loneliness and malnutrition were associated with falling **(Chapter 2)**.

The findings showed that among older adults who had been hospitalised, participants classified as lonely were relatively more prone to falling compared to participants who were not classified as lonely. The nature of the relationship between loneliness and falls remains unclear (1). One explanation could be that a lack of social relationships can result in a less healthy lifestyle or reduced medication adherence, which might increase the risk of falling (1). Other studies suggest a link between feelings of loneliness, depression and falls (2, 3). Symptoms of major depression, such as psychomotor retardation, slow gait speed and low energy can lead to falls (2). Further research in a larger sample is needed to examine the association between loneliness and falls.

In the subgroup of community-dwelling older adults, women were more likely to fall than men. A possible explanation is that women's bone mass may decline faster than that of men, which can affect their physical functioning, thus increasing the risks associated with falling (4, 5). Furthermore, in our study, participants who completed secondary education or less had a relatively lower risk of falling compared to participants with a higher education level. This was not reported in the literature (6). Further studies are recommended to gain more insight into the association between education level and falling. In addition, multimorbidity was associated with falling which is consistent with previous studies (7, 8). More specifically, age-related health conditions such as neurodegenerative diseases have been reported as a major risk factor for falls (9). Moreover, participants who reported a fall had a significantly higher score on activities of daily living (ADL) limitations compared to those who did not report a fall. Previous studies have suggested that ADL limitations could lead to slow gait speed and impact balance negatively increasing the risk of falls (10, 11). Finally, the present study confirms malnutrition to be a predictor of falls in community-dwelling older adults (12, 13). Malnutrition in older adults is correlated with co-morbidities such as sarcopenia and frailty, which can increase the risk of falling (14).

Factors associated with health-related quality of life (HRQOL)

Linear regression models were used to assess associations between sociodemographic characteristics, health indicators, lifestyle factors and HRQOL in a sample of 661 community-dwelling older adults. Regression analyses were conducted separately for the outcome variables PCS (physical HRQOL) and MCS (mental HRQOL). Higher age, female sex, living alone, multimorbidity, frailty, a higher score on ADL limitations, loneliness and a high risk of medication-related problems were associated with HRQOL **(Chapter 3)**.

Factors associated with both physical and mental HRQOL included frailty and a higher score on ADL limitations. Frail older adults are at increased risk of poor health outcomes resulting from falls, disability, and hospitalisation, which may negatively impact HRQOL (15, 16). In addition, due to the strong relationship between a person's ability to perform activities and the PCS score, this result was to be expected (17). It has been shown that loss of independence in general, and dependency regarding eating, bathing and toileting specifically, is associated with a decline in mental HRQOL (17, 18).

In our study, female sex, multimorbidity and a high risk of medication-related problems were associated with physical HRQOL. Consistent with findings from previous studies, women were more likely than men to have reduced physical HRQOL (19-21). A possible explanation is that women are more prone to musculoskeletal diseases (22, 23). This may result in pain and disability, which in turn is associated with worse physical HRQOL (20). Furthermore, the results showed that multimorbidity was associated with poorer physical HRQOL, which is in line with previous findings (24, 25). Finally, a high risk of medication-related problems was associated with low physical HRQOL (26, 27). However, no association was found between medication-related problems and mental HRQOL; this is in contrast to the results of a previous study (26). Further research is recommended to gain insights into the association between specific medication-related risk factors and HRQOL.

Loneliness, higher age and living alone were associated with mental HRQOL. Loneliness was associated with a lower MCS score. A possible explanation is that participants classified as lonely miss an intimate or emotional relationship increasing their risk of poor mental HRQOL (28). More research is needed to explore the specific factors contributing to poor mental HRQOL among older adults who are lonely. Remarkably, the multivariate regression models for 'higher age' (≥80 years) and 'living alone' showed a positive association with mental HRQOL. These results were not reported in the literature (21, 29). Gooding et al. (30) suggest that older adults (≥80 years) have a better-developed capacity for resilience compared to younger-old adults (65-79 years) which could explain these findings. Moreover, according to Burnette et al. (31) those who live alone have high levels of social interaction and participation which can have a positive effect on their mental HRQOL. Future studies are recommended to explore these findings in more detail.

The findings presented in Chapters 2 and 3 showed an association between sociodemographic factors and health outcomes. Further research is recommended to explore associations between sociodemographic factors, including gender, age, household composition, and health outcomes in more detail. Moreover, the results showed an association between indicators of functional decline and adverse health outcomes. In general, the World Health Organization (32) has suggested that functional ability allows people to be and do what they value in life, including the ability to be mobile, perform daily activities, build and maintain relationships and contribute to society. Environments that support a person's intrinsic capacity and independence could, therefore, contribute to improved health and well-being.

Part II: Stakeholder perspectives regarding person-centred integrated care supported by digital health technology

In Part II, a qualitative study design was undertaken to explore stakeholder perspectives. A semi-structured interview study as part of the 'Value-based methodology for person-centred integrated care supported by Information and Communication Technologies' (ValueCare) project was conducted to gain an in-depth understanding of stroke patients' perspectives **(Chapters 4 and 5)**. Furthermore, the readiness of the Dutch health system to adopt digital technologies for health and care was explored by conducting a stakeholder analysis and health system assessment **(Chapter 6)**. This study included several rounds of interviews with stakeholders and a focus group with chronically ill patients.

Values, needs and preferences of stroke patients

Chapter 4 described the values, needs, and preferences of stroke patients across the continuum of care. Patients' values about health care included being treated as a unique and autonomous individual, and a professional who is a good communicator, compassionate and responsive. Expressed needs were information and education, psychological services, proactive follow-up care, and continuity of care. Linked to their needs, patients preferred tailored information provision, counselling by a social worker or peer support, a coordinated and timely follow-up by one professional, and flexible services and professionals.

The aspects that patients valued in health care practices were mainly related to the skills and attitudes of professionals, such as good communication skills and being compassionate. Consistent with previous studies, patients valued a professional who is easily approachable and communicates clearly (33, 34). This may be particularly important regarding providing information to patients.

Information tailored to their diagnosis and needs was one of the expressed needs among patients. Tailoring information can enhance patient-centred communication which is associated with increased patient participation (35). Previous studies have reported that information can be difficult to assess for stroke patients (36, 37). It is recommended to use short sentences, to define technical terms and to use visuals which represent older people in a positive way (38).

In our study, patients emphasised the need for psychological support after discharge, preferably counselling by a social worker and/or peer support. Frustration, anger management issues, emotional lability, and anxiety were commonly mentioned by the participants. Improved coordination between healthcare providers across the care continuum, such as neurologists, general practitioners, social workers, and psychologists, can facilitate the identification of unmet psychological needs (36).

Concerning follow-up care, visits by a community stroke nurse were experienced positively. However, some patients were dissatisfied with a lack of proactive follow-up from their general practitioner or hospital. Similar to the findings presented in Chapter 4, evidence suggests that patients often feel abandoned post-discharge (36, 37, 39). Patients expressed the need for a proactive, timely and coordinated follow-up, preferably by one professional.

Patients referred to a lack of communication among health care providers, affecting the continuity and coordination of their care. Consistent with the literature, a trusted relationship between the patient and health care professional may be necessary for patients to feel secure (40, 41). In our study, patients emphasised the need for long-term support in the chronic phase of care and preferred flexible services and professionals to address their needs over time.

Stroke patients' preferences regarding digital health technology

Chapter 5 explored the perspectives of stroke patients regarding digital health technology to support their self-management, as well as integrated stroke care. Three themes emerged from the analysis: (1) attitudes toward using digital health for care, (2) suggested features of digital health technologies, and (3) suggested user interface design features of digital health technologies.

The findings showed mixed attitudes of patients. Some patients viewed digital health as a product or service that can be convenient to access health information. Others considered digital health as not needed and shared the concern that technology would replace physical contact with their health care professional. A possible explanation is that some patients experience the benefits of digital health technology, while others presume or experience barriers which influence the acceptance and use of technology (42, 43).

Stroke patients mentioned credible health information, an online library with stroke-related health and care information, a personal health record, and online rehabilitation support at home as the main features to include in future digital health technologies. These findings support the importance of tailoring information to patients' needs and concerns, as described in earlier studies (35). Moreover, a personal health record and online rehabilitation support have the potential to enhance patient engagement in managing their health, which is in line with previous studies (44, 45).

Regarding the user interface of future digital health technology, patients in our study emphasised the need for easy-to-use and simple designs. New design features introduced by the developers of technology were perceived by patients as hard to cope with. Patients indicated technology should be aligned with their ability to use technology and their interface preferences, which has also been reported in other studies (46, 47).

Strategies to integrate digital health technology into care

In **Chapter 6**, strategies were explored regarding the integration of digital health technologies for chronically ill patients in primary care. More specifically, the use of mobile and wireless communication technologies (mHealth) to improve health care delivery was examined. Key barriers to integration perceived by stakeholders (e.g., patients, primary care professionals, managers, policymakers) included: (1) a lack of interoperability with existing information systems, (2) difficulties in obtaining funding for implementation, and (3) limited readiness of general practices to change. Key strategies to facilitate integration were collaboration between stakeholders and incentives for pioneers.

In our study, a lack of standardisation was identified as a potential barrier to address interoperability of existing information systems. Policymakers and the National General Practitioner Association indicated the need for regulation to facilitate information exchange between health information systems. Previous studies have shown that addressing interoperability by establishing a regulatory framework can be favourable to the success of mHealth implementation (48, 49).

Another potential barrier concerned the perceived difficulty by general practitioners to ensure financial flows for mHealth implementation. General practitioners lacked the time and resources to transform existing budgets to fit mHealth costs, while insurers were hesitant to provide funding due to uncertainty about return on investment. This tense relationship has been reported in other studies (50, 51) and can be explained by the different interests and values these stakeholders hold.

A final potential barrier identified in our study was the limited readiness of general practices to implement mHealth solutions. Overall, primary care professionals and patients were positive about mHealth adoption. However, some general practitioners lacked the motivation to adopt mHealth. Building end-user trust in mHealth solutions, preferably by providing evidence-based information on app credibility, may be an important enabler reported in the literature (51, 52).

In Chapter 6, two main strategies were discussed to steer mHealth integration. First, stimulate the co-design of mHealth technologies. It has been demonstrated that end-user involvement in developing mHealth solutions is crucial to support technology acceptance and adoption (49). Second, provide incentives for pioneers to make mHealth adoption more attractive. Several studies found strong stakeholder collaboration in which financial support is assured to initiate and energize the mHealth adoption process (52, 53).

Overall, stakeholders, including patients, have a supporting or mixed attitude toward person-centred integrated care supported by digital health technology. In this thesis, insights into the needs and preferences of patients are provided which serve as touch points that can be further explored in co-design sessions. Co-design may enable end-users (i.e. patients, their caregivers, and health care professionals) to reflect on their experiences with a service and to identify improvement priorities (54). The "co" in co-design suggests that end-users are actively contributing to the design of care (55). Based on a participatory approach, co-design may open up boundaries of designing healthcare services and include new forms of expertise from various stakeholders (56). In this regard, end-users bring experiential knowledge and participate in the design process from an early stage.

Part III: Design of a person-centred integrated care intervention supported by digital health technology

Chapter 7 presented the study protocol of the ValueCare study, which aimed to evaluate the ValueCare approach in comparison with 'usual care' practices in terms of benefits for the target groups (older adults, their informal caregivers, and health and social care professionals), and to assess implementation outcomes.

In ValueCare, the (evaluation) design of the intervention is considered as well as the conditions needed to realise its mechanisms of change. ValueCare's core elements are in line with the "Framework for developing and evaluating complex interventions" developed by the UK Medical Research Council (57), and include, for example, adaptation to the local context, the consideration of appropriate health and implementation outcomes for assessment, engagement of stakeholder perspectives, and refinement of the intervention. Moreover, the complexity of the intervention calls for the use of mixed-methods research, appropriate control, and context-specific information which has been incorporated into the design of ValueCare (58).

METHODOLOGICAL CONSIDERATIONS

Several methodological considerations regarding study design, study setting, participants, measurements, qualitative validity and confounding are relevant when interpreting the findings of the studies presented in this thesis. The studies presented in **Chapter 2** and **Chapter 3** used data from the APPCARE project. **Chapter 4**, **Chapter 5** and **Chapter 7** include studies conducted as part of the larger ValueCare project. In **Chapter 6**, a stakeholder analysis and health system assessment is presented in the Dutch context.

Study design

A cross-sectional design was used to identify the factors associated with falls (Chapter 2). A limitation of this type of design is that a causal relationship between the determinant and outcome variable cannot be inferred (59). In Chapter 3, a longitudinal design was used to determine the factors associated with HRQOL. However, due to the limited observation time of six months between baseline and follow-up, the possibility to draw conclusions on causality is limited. Moreover, the study was observational (not experimental), which means that 'residual' confounding potentially can explain observed associations. Further studies with multiple follow-up measures are needed to examine the (bi-) directional associations between determinants and outcome variables. In addition, due to the relatively small size of the subgroup with hospitalised older adults studied in Chapter 2, the power to detect reliable effect sizes is lower in this subgroup (60). It is recommended to reproduce these findings in a larger sample to generate more information regarding the factors associated with falls among this subpopulation.

The qualitative approach used in Chapters 4 and 5 was based on a sound methodology (61), providing broad insights into patient perspectives. Although pilot interviews were not performed, the semistructured nature of the interviews allowed for flexibility in asking questions. A limitation of these qualitative studies is that they were conducted in the specific context of the Netherlands; therefore, the findings may not be transferable to other settings. In Chapter 6, the integration of knowledge from multiple stakeholders was facilitated by an interactive research methodology. Ideally, studies using interactive methodologies complete several learning cycles which can be time-consuming (62). Due to the limited time available, only one learning cycle was established. Further research is recommended to build on the exploratory phase and to complete more learning cycles (62).

Study setting

The APPCARE project data included in this thesis (Chapters 2 and 3), concerned a subset of data collected in the Rotterdam region. The possibility of generalization to other contexts remains unclear. Future studies need to determine whether the associations observed within the Dutch population change in other settings and across populations.

The qualitative studies presented in Chapters 4, 5 and 6 were performed within the specific context of the Netherlands; therefore, insights might not be transferable to other settings. To increase the generalizability of the findings, variation was reached in the sample in terms of participant characteristics. It is recommended to replicate these findings in other countries to generate contextual information (e.g., natural environment of the participant, health system functioning) in various settings.

Participants

As part of the studies described in Chapters 2, 3, 4 and 5, participants received an invitation by letter to ask if they were willing to participate in the study. This may have resulted in selection bias; participants who agree to participate in a study are healthier compared to participants who do not join the study (63). To include participants in the focus group, a convenience sample was taken (Chapter 6). More extensive research is needed to gain a representative view of patient perspectives. This involves the inclusion of a diverse sample of patients based on, for example, gender, age, severity of disease, location (urban vs. rural), and socioeconomic status. In addition, it is recommended to organize multiple focus groups (64).

Measurements

Data from the APPCARE study were collected through self-reported questionnaires. To perform the analyses, some of the variables were collapsed into dichotomous categories which may have resulted in loss of information. However, this simplification increases the understanding for practice. Future studies are recommended to explore potential confounders (e.g., age, education level) in more detail.

Validity in qualitative research

Validity in qualitative research refers to the appropriate application of the methods undertaken in which the findings precisely reflect the data (65). This requires researchers to incorporate methodological strategies to enhance the credibility of a study. For example, in Chapter 6, multiple research methods were applied, including desk studies, semi-structured interviews and a focus group to help produce a more comprehensive set of findings. In addition, in Chapters 4 and 5, emerging themes were discussed with the research team members in an open process to reach consensus and reduce bias (66). Chapters 4 and 5 focused on the patient perspective because patients have gained (experiential) knowledge about their condition and the health care services they use(d). Future research could ensure different perspectives are represented and replicate the studies presented in Chapters 4 and 5 among informal caregivers and health care professionals.

Confounding

The quantitative studies presented in this thesis controlled for confounding variables (67). Confounders were chosen based on previous literature and the availability of data. Nevertheless, the possibility of unmeasured confounding cannot be ruled out. Future studies are recommended to explore important factors, including frailty, loneliness and malnutrition in more detail, particularly regarding their social dimension. These factors may have had an impact on the association between age and HRQOL, and living alone and HRQOL (Chapter 3).

RECOMMENDATIONS FOR FUTURE RESEARCH

1. Recommendations regarding the determinants of health outcomes

- Longitudinal studies with two or more follow-up measurements are needed to examine the (bi-) directional associations between determinants and outcome variables.
- Future studies among a representative sample of hospitalised older adults can generate more information regarding the factors associated with falls among this subpopulation.
- It is recommended to further explore the association between education level and falling, age and HRQOL, and household composition and HRQOL to determine underlying causes.
- Additional research is needed regarding the determinants of other health outcomes that matter to older adults such as frailty and loneliness.
- Future studies assessing the association between socioeconomic factors and outcome variables may include, for example, neighbourhood characteristics, socioeconomic factors earlier in life and social support.

2. Recommendations regarding person-centred integrated care supported by digital health technology

- Further research is needed to validate and enrich the findings on stroke patients' values.
- Future research exploring how patients' perspectives can inform practice guidelines and ultimately improve care delivery is recommended.
- The role of the community stroke nurse in improving the continuity and coordination of stroke care should be explored in more detail.
- Future studies could explore the suggested features of digital technologies more extensively. In this regard, it is recommended to use an iterative co-design approach involving multiple stakeholders such as patients, their informal caregivers, and health care professionals.

- It is recommended to improve the engagement of patients with low literacy in research by using visual and artistic methods. For example, asking participants to respond to pre-selected images.
- Future studies with a larger variety (e.g., multiple perspectives, various settings, other chronic conditions) could focus on subgroup analyses to explore patterns in the data in more depth.

3. Recommendations regarding the design of person-centred integrated care interventions supported by digital health technology

- It is recommended to explore alternative methods of recruitment for accessing 'hard-to-reach' groups to include a representative sample of older adults.
- Further research is needed to examine the usability and validity of interactive research methodologies to develop, implement and evaluate digital health interventions.

IMPLICATIONS FOR POLICY AND PRACTICE

Determinants of health outcomes in older adults

To develop effective and feasible interventions, policymakers need to have insight into older adults at risk. Findings on the factors associated with falls and HRQOL imply that future interventions could be tailored to frail or lonely older adults. Overall, the studies included in this thesis support the assumption that functional decline is a relevant determinant of falls and low HRQOL. Policies that support a person's intrinsic capacity and independence could, therefore, contribute to improved health and well-being.

Having more knowledge on the determinants of health outcomes can help clinicians and informal caregivers identify a patient or relative at risk for poor health outcomes (68). In Chapters 2 and 3, determinants of health outcomes were studied from a multidimensional perspective, including sociodemographic characteristics, health indicators, and lifestyle factors, which can help to identify possible causes of poor health outcomes. Further research could evaluate whether regular assessments (e.g. once a year) of relevant health outcomes in adults 65 years and older, including fall risk and HRQOL, are an effective way to address risk factors of poor outcomes (69). Studies should also address how such (self-)assessment could be organised (e.g., coordinated by the community nurse). Subsequently, future research should focus on how the health care professional, older adult and (when applicable) the informal caregiver can discuss the results of the assessment, potentially supported by digital health technology (70).

Person-centred integrated care supported by digital health technology

Findings on patients' perspectives in this thesis regarding person-centred integrated care supported by digital health technology imply the need for a personalised approach. Patients in our studies indicated a need for tailored information provision about stroke-related health and care issues. Shared decision-making tools have the potential to promote patients' knowledge and satisfaction by enhancing patient participation (71). In addition, mobile health applications can be used to facilitate tailored information provision for patients (72). It is recommended that clinicians communicate the concrete benefits of digital health to patients and, at the same time, reduce technology-related concerns such as challenges regarding usability (73). Furthermore, training activities can help to facilitate the implementation and use of new technologies among patients, their informal caregivers and health care professionals (54).

The varying views regarding the use of digital health technology for health and care highlighted the need for a tailored approach. It is recommended to include end-users of technology early in the design process of digital health interventions to ensure that the intervention is meaningful to the people it will serve (74). Adopting an iterative co-design process allows the tailoring of digital solutions by gathering continuous feedback and supporting interaction between designers and end-users (54). To increase the uptake of co-designed technologies, it is crucial to bring together diverse groups of stakeholders (75). Therefore, it is recommended to include "hard-to-reach" groups such as people who are frail, with low literacy, from rural areas, or from ethnic minorities to gather their experiential knowledge with the ultimate goal to extend the reach of digital health intervention and to improve their impact.

In the context of developing and evaluating a person-centred integrated care intervention, it is important to consider the appropriate methodology. These types of interventions are complex to evaluate; evaluations may benefit from mixed-methods research (76), appropriate control, and context-specific information (e.g. setting, health system context, target population) (58). A stakeholder analysis is recommended to identify the stakeholders involved in a particular setting, to assess the level of support for the intervention, and to map stakeholders' positions. The engagement of stakeholders is crucial to adapt and refine the intervention to the local context (57).

GENERAL CONCLUSION

The overall aim of this thesis was to improve the quality of care for older adults by studying person-centred integrated care supported by digital health technology. Results regarding the determinants of health outcomes among older adults showed that vulnerable people, such as frail and lonely older adults, are at increased risk of falls and poor HRQOL. The findings supported the assumption that functional decline is a relevant determinant of adverse health-related outcomes. Furthermore, studies regarding stakeholders' perspectives showed that stakeholders, including patients, had a supporting or mixed attitude towards person-centred integrated care supported by digital health technology. The aspects that stroke patients value in healthcare practices are mainly related to the skills and attitudes of professionals. Stroke patients in our studies emphasised the need for tailored information and education, psychological support, follow-up visits, and improved continuity and coordination of care. Digital health technologies can help patients manage their health and care, particularly regarding the provision of health information, a personal health record, and online rehabilitation support at home. Patients emphasised the need for simplicity of digital solutions and to tailor technology to individual preferences.

Future studies should focus on the determinants of health outcomes among vulnerable older people, explore suggested features of digital technologies more extensively, and engage "hard-to-reach" patients (e.g., older adults living with frailty, people with low literacy) better in designing interventions. This will contribute to improved quality of care for older adults by recognising the need for attention to vulnerable people, adopting person-centred care satisfying individual needs, and using digital health technology as an opportunity to manage a patient's health and care better.

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APPENDICES

Summary
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SUMMARY

The proportion of European citizens aged 65 years and older is expected to rise from 21% in 2020 to 29% in 2050. Ageing is associated with an increased risk of chronic conditions. Service provision based on disease-specific guidelines can be inappropriate for patients with two or more chronic conditions (i.e., multimorbidity). If each condition is considered in isolation, care can become duplicative and inefficient due to poor coordination and integration. Therefore, a shift is required away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive, in which people with chronic conditions are encouraged to manage their health and care. With this challenge in mind, organisations in Europe have endorsed the Chronic Care Model to deliver high-quality care to patients with multiple chronic conditions. The Chronic Care Model sets out the design of chronic care initiatives to improve the quality of care.

The ultimate goal of the Chronic Care Model is to improve outcomes at an individual level, as well as a population level. Person-centred integrated care is seen as a promising approach to delivering care that is proactive, coordinated and centred around people's needs. However, the implementation of person-centred integrated care in practice is challenging. There is a need for more knowledge on how to design and evaluate appropriate person-centred integrated care. In addition, digital health technology has the potential to involve patients better in their care process and could, therefore, support person-centred integrated care. However, barriers exist that constrain the adoption and acceptance of technology in clinical practice. There is a need to incorporate the patient's voice better into the design of digital health technology.

The overall aim of the research described in this thesis is to improve the quality of care for older adults by studying person-centred integrated care supported by digital health technology. This thesis addressed the following questions:

Part I: Understanding the determinants of health outcomes that matter to older adults

- What factors are associated with falls among hospitalised and community-dwelling older adults? (Chapter 2)
- What factors are associated with health-related quality of life among community-dwelling older adults? (Chapter 3)

Part II: Stakeholder perspectives regarding person-centred integrated care supported by digital health technology

- What are the values, needs and preferences of stroke patients across the continuum of care? (Chapter 4)
- How could digital health technology support stroke patients' self-management regarding health and well-being, as well as integrated care? (Chapter 5)
- How can digital health technologies for people with chronic conditions be integrated into the Dutch health system? (Chapter 6)

Part III: Design of a person-centred integrated care intervention supported by digital health technology

- How to design and evaluate a person-centred integrated care intervention supported by digital health technology for older adults in multiple settings in Europe? (Chapter 7)

Part I

Part I consists of a cross-sectional study about the factors associated with falls (Chapter 2) and a longitudinal study about the factors associated with health-related quality of life (HRQOL) (Chapter 3). The analyses were performed using questionnaire data from the APPCARE project.

Chapter 2 used multivariable logistic regression models to assess associations between sociodemographic characteristics, potential fall risk factors, and falls. Regression analyses for the two subsamples, hospitalised and community-dwelling older adults, were done separately. Among hospitalised older adults, participants classified as lonely were more prone to falling. Female sex, education level, multimorbidity, a higher score on activities of daily living limitations, and malnutrition were associated with falling in community-dwelling older adults. Longitudinal studies with two or more follow-up measurements are recommended to examine the (bi-) directional associations between risk factors and falls in-depth. In addition, future studies among a larger sample of hospitalised older adults can generate more information regarding the factors associated with falls.

Chapter 3 used linear regression models to assess associations between sociodemographic characteristics, health indicators, lifestyle factors and HRQOL. Regression analyses were conducted separately for the two outcome variables: physical and mental HRQOL. The study sample consisted of community-dwelling older adults. Frailty and a higher score on activities of daily living limitations were negatively associated with both physical and mental HRQOL. In addition, female sex, multimorbidity and a high risk of medication-related problems were associated with reduced physical HRQOL, and loneliness with reduced mental HRQOL. Remarkably, higher age and living alone were associated with better mental HRQOL in the multivariate models. Future studies are recommended to explore the association between sociodemographic factors (e.g., gender, age, household composition) and HRQOL in more detail, including their social dimension to determine underlying causes.

To develop effective and feasible interventions, policymakers need to have insight into older adults at risk. Findings on the factors associated with falls and HRQOL imply that future interventions could be tailored to frail or lonely older adults. Overall, the studies included in this thesis support the assumption that functional decline is a relevant determinant of falls and low HRQOL. Policies that support a person's intrinsic capacity and independence could, therefore, contribute to improved health and well-being.

Part II

Part II includes three studies that used a qualitative study design to explore stakeholder perspectives (Chapters 4-6). Interviews as part of the ValueCare project were conducted to gain an in-depth understanding of stroke patients' perspectives (Chapters 4 and 5). Furthermore, the readiness of the Dutch health system to adopt digital technologies for health and care was explored using several rounds of interviews with stakeholders and a focus group with chronically ill patients (Chapter 6).

The study presented in **Chapter 4** explored the values, needs, and preferences of stroke patients across the continuum of care. Patients valued a compassionate professional who is responsive to their needs. Stroke patients emphasised the need for information, psychological support, proactive follow-up, and improved coordination of care. Expressed preferences were tailored information provision, counselling by a social worker or peer support, a coordinated and timely follow-up by one professional, and flexible services and professionals. The findings of this study could help stroke care providers to adopt a person-centred approach. However, more research is needed to explore how patients' perspectives can inform practice guidelines and ultimately improve care delivery.

Chapter 5 explored the perspectives of stroke patients regarding digital health technology to support their self-management as well as integrated stroke care. Some patients viewed digital technology as a convenient product or service, while others expressed no desire or need to use technology for self-management or care. Digital features suggested by stroke patients included (1) information about the causes of stroke, medication, prognosis, and follow-up care; (2) an online library with information regarding stroke-related health and care issues; (3) a personal health record by which patients can retrieve and manage their own health information; and (4) online rehabilitation support to empower patients to exercise at home. Patients emphasised the need for easy-to-use and simple designs. Future studies could explore the suggested features of digital technologies more extensively by using an iterative co-design approach involving multiple stakeholders such as patients, their informal caregivers, and health care professionals.

In **Chapter 6**, strategies were explored regarding the integration of mobile health technology (mHealth) for chronically ill patients in primary care. A stakeholder analysis and health system assessment were conducted in the Dutch context. Overall, stakeholders (e.g., patients, health care professionals, policymakers) held a supporting or mixed attitude towards mHealth integration. Two main strategies emerged to steer mHealth integration: (1) stimulate the co-design of mHealth technologies, and (2) provide incentives for pioneers to make mHealth adoption more appealing. In this study, the integration of knowledge from multiple stakeholders was facilitated by an interactive research methodology. Ideally, studies using interactive methodologies complete several learning cycles. Due to the limited time available, only one learning cycle was established. Further research is recommended to build on the exploratory phase and to complete more learning cycles.

Professionals in stroke care could adopt a more personalised care approach, in order to satisfy the individual needs of patients regarding information, communication and follow-up care. In this context, digital health technologies could support person-centred integrated care and promote self-management. The adoption of an iterative, co-design process is recommended to allow tailoring of digital solutions by gathering continuous feedback from end users.

Part III

Part III consists of the design of the 'ValueCare' approach (**Chapter 7**). The ValueCare project aims to deliver person-centred, value-based integrated health and social care for older people (≥65 years) with multimorbidity, frailty, or mild to moderate cognitive impairment in seven sites (Athens, Greece; Coimbra, Portugal; Cork/Kerry, Ireland; Rijeka, Croatia; Rotterdam, The Netherlands; Treviso, Italy; and Valencia, Spain). The evaluation of ValueCare has a pre-post-controlled design in which the intervention group (using the 'ValueCare approach') is compared to the control group ('care as usual') in terms of benefits for the target groups (older adults, their informal caregivers, and health and social care professionals) and implementation outcomes.

Measurements are taken at baseline, after 12 months (the end of the 'ValueCare approach' intervention period), and at 18 months. Each site adapts the general ValueCare approach to its target group and local context. In Rotterdam, the target group consisted of people who have had ischemic stroke.

The ValueCare's Project core elements are in line with the "Framework for developing and evaluating complex interventions" developed by the UK Medical Research Council, and include, for example, adaptation to the local context, the consideration of appropriate health and implementation outcomes for assessment, engagement of stakeholder perspectives, and refinement of the intervention. In designing complex care interventions, it is recommended to include "hard-to-reach" groups to gather their experiential knowledge. For example, people who are experience frailty, with low educational literacy, from rural areas, or from ethnic minorities.

Finally, person-centred integrated care demands innovative ways of organising and thinking. However, this is a complex process that involves multiple stakeholders, requires contextual information, and appropriate methodologies for evaluation. This thesis provides a first step towards person-centred integrated care supported by digital health technology for older adults.

SAMENVATTING

Het aandeel Europese burgers van 65 jaar en ouder zal naar verwachting stijgen van 21% in 2020 naar 29% in 2050. Veroudering gaat gepaard met een verhoogd risico op chronische aandoeningen. Zorg op basis van ziektespecifieke richtlijnen sluit niet altijd goed aan bij de behoeften van patiënten met twee of meer chronische aandoeningen, oftewel multimorbiditeit. Als elke aandoening afzonderlijk wordt bekeken, kan de zorg inefficiënt worden als gevolg van een gebrek aan coördinatie van zorg. Daarom is er een verschuiving nodig van een reactief, ziektegericht, gefragmenteerd zorgmodel naar een zorgmodel dat meer proactief, holistisch en preventief is, waarin mensen met chronische aandoeningen worden aangemoedigd om regie te nemen over hun gezondheid en zorg. Met deze uitdaging in het achterhoofd, hebben organisaties in Europa het Chronic Care Model onderschreven om hoogwaardige zorg te verlenen aan patiënten met meerdere chronische aandoeningen. Het Chronic Care Model beschrijft de organisatie van zorg voor chronisch zieken.

Het uiteindelijke doel van het Chronic Care Model is bijdragen aan het vebeteren van de kwaliteit van zorg en de kans vergroten op betere uitkomsten op zowel patiëntniveau, als in de populatie. Persoonsgerichte geïntegreerde zorg wordt gezien als een veelbelovende aanpak om zorg te verlenen die proactief is en gecoördineerd wordt rond de behoeften van de patiënt. Maar hoe doe je dat in de praktijk? Er is behoefte aan meer kennis over het ontwerpen en evalueren van passende persoonsgerichte geïntegreerde zorg. Bovendien biedt digitale gezondheidstechnologie de mogelijkheid om patiënten beter bij het zorgproces te betrekken en zou daarom persoonsgerichte geïntegreerde zorg kunnen ondersteunen. Desondanks, bestaan er barrières die de adoptie en acceptatie van technologie in de zorg belemmeren. Dit vraagt om het beter betrekken van patiënten bij de ontwikkeling en inzet van digitale gezondheidstechnologie.

Het algemene doel van het in dit proefschrift beschreven onderzoek is het verbeteren van de kwaliteit van de zorg voor ouderen door persoonsgerichte geïntegreerde zorg ondersteund door digitale gezondheidstechnologie. In dit proefschrift zijn de volgende vragen beantwoord:

Deel I: Inzicht in de determinanten van gezondheidsuitkomsten die belangrijk zijn voor ouderen

- Welke factoren houden verband met vallen bij ouderen die zijn opgenomen in het ziekenhuis en thuiswonende ouderen? (Hoofdstuk 2)

- Welke factoren houden verband met de gezondheidsgerelateerde kwaliteit van leven van thuiswonende ouderen? (Hoofdstuk 3)

Deel II: De perceptie van stakeholders met betrekking tot persoonsgerichte geïntegreerde zorg, ondersteund door digitale gezondheidstechnologie

- Wat zijn de waarden, behoeften en voorkeuren van patiënten die een beroerte hebben gehad met betrekking tot de gehele ketenzorg? (Hoofdstuk 4)
- Hoe kan digitale gezondheidszorgtechnologie patiënten die een beroerte hebben gehad ondersteunen op het gebied van zelfmanagement, evenals geïntegreerde zorg? (Hoofdstuk 5)
- Hoe kunnen digitale zorgtechnologieën voor mensen met chronische aandoeningen worden geïntegreerd in het Nederlandse zorgsysteem? (Hoofdstuk 6)

Deel III: Ontwerp van een persoonsgerichte geïntegreerde zorginterventie ondersteund door digitale gezondheidstechnologie

- Hoe ontwerp en evalueer je een persoonsgerichte geïntegreerde zorginterventie, ondersteund door digitale gezondheidstechnologie, voor ouderen in meerdere contexten in Europa? (Hoofdstuk 7)

Deel I

Deel I bestaat uit een cross-sectioneel onderzoek naar de factoren die verband houden met vallen (Hoofdstuk 2) en een longitudinaal onderzoek naar de factoren die verband houden met gezondheidsgerelateerde kwaliteit van leven (Hoofdstuk 3). De analyses zijn uitgevoerd met behulp van vragenlijstgegevens uit het APPCARE project.

Hoofdstuk 2 gebruikte multivariabele logistische regressiemodellen om de associaties tussen sociaal-demografische kenmerken, potentiële risicofactoren en vallen te beoordelen. Regressieanalyses voor de twee subgroepen, ouderen die zijn opgenomen in het ziekenhuis en thuiswonende ouderen, werden afzonderlijk uitgevoerd. Onder ouderen die zijn opgenomen in het ziekenhuis, waren deelnemers die als eenzaam werden aangemerkt meer vatbaar voor vallen. Vrouwelijk geslacht, opleidingsniveau, multimorbiditeit, een hogere score op beperkingen met betrekking tot activiteiten in het dagelijks leven en ondervoeding werden in verband gebracht met vallen bij thuiswonende ouderen. Longitudinale onderzoeken met twee of meer vervolgmetingen worden aanbevolen om de (bi-)directionele verbanden tussen risicofactoren en vallen te onderzoeken. Bovendien kan toekomstig onderzoek onder een grotere steekproef van in het ziekenhuis opgenomen ouderen meer informatie opleveren over de factoren die verband houden met vallen.

Hoofdstuk 3 gebruikte lineaire regressiemodellen om verbanden tussen sociaal-demografische kenmerken, gezondheidsindicatoren, leefstijlfactoren en gezondheidsgerelateerde kwaliteit van leven te beoordelen. Regressieanalyses werden afzonderlijk uitgevoerd voor de twee uitkomstvariabelen: fysieke en mentale kwaliteit van leven. De onderzoekspopulatie bestond uit thuiswonende ouderen. Kwetsbaarheid en een hogere score op beperkingen met betrekking tot activiteiten in het dagelijks leven waren negatief geassocieerd met zowel fysieke als mentale kwaliteit van leven. Daarnaast werden vrouwelijk geslacht, multimorbiditeit en een hoog risico op medicatiegerelateerde problemen geassocieerd met een verminderde fysieke kwaliteit van leven, en eenzaamheid met een verminderde mentale kwaliteit van leven. Opmerkelijk is dat een hogere leeftijd en alleenwonen in de multivariate modellen geassocieerd waren met een betere mentale kwaliteit van leven. Het is aanbevolen om in toekomstige studies de associatie tussen sociaal-demografische factoren (bijv. geslacht, leeftijd, samenstelling van het huishouden) en gezondheidsgerelateerde kwaliteit van leven verder te onderzoeken, met name de sociale dimensie, om de onderliggende oorzaken te bepalen.

Voor het ontwikkelen van effectieve en haalbare interventies is inzicht in de ouderen die een hoger risico lopen op slechtere gezondheidsuitkomsten noodzakelijk. Bevindingen over de factoren die verband houden met vallen en gezondheidsgerelateerde kwaliteit van leven impliceren dat toekomstige interventies op maat kunnen worden gemaakt voor kwetsbare of eenzame oudere volwassenen. Over het geheel genomen ondersteunen de onderzoeken in dit proefschrift de veronderstelling dat functionele achteruitgang een relevante determinant is van vallen en een lage kwaliteit van leven. Beleid dat de intrinsieke capaciteit en onafhankelijkheid van een persoon ondersteunt, zou daarom kunnen bijdragen aan een betere gezondheid en welzijn.

Deel II

Deel II omvat drie onderzoeken met een kwalitatief onderzoeksdesign om de perceptie van stakeholders te onderzoeken (Hoofdstukken 4-6). Als onderdeel van het ValueCare project zijn interviews afgenomen om meer inzicht te krijgen in de perspectieven van patiënten die een beroerte hebben gehad (Hoofdstukken 4 en 5). Daarnaast werd onderzocht in hoeverre het Nederlandse zorgsysteem in staat is om digitale gezondheidstechnologieën te integreren in de eerste lijn door middel van verschillende interviewrondes met stakeholders en een focusgroep met mensen met een chronische aandoening (Hoofdstuk 6).

De studie die in **Hoofdstuk 4** wordt beschreven, onderzocht de waarden, behoeften en voorkeuren van patiënten die een beroerte hebben gehad met betrekking tot de gehele ketenzorg. Patiënten waardeerden een meelevende professional die inspeelt op hun behoeften. Daarnaast benadrukten patiënten behoefte te hebben aan informatie, psychologische ondersteuning, verwijder proactieve nazorg en verbeterde coördinatie van zorg. Patiënten spraken hun voorkeur uit voor informatievoorziening op maat, begeleiding door een maatschappelijk werker of peer support, een gecoördineerde en tijdige opvolging door één professional, en zorg en professionals die flexibel zijn. De bevindingen van dit onderzoek kunnen zorgverleners helpen een persoonsgerichte aanpak te hanteren. Er is echter meer onderzoek nodig naar hoe suggesties van patiënten richtlijnen kunnen verbeteren en daarmee de kwaliteit van zorg.

Hoofdstuk 5 omvat een studie naar de perceptie van patiënten die een beroerte hebben gehad met betrekking tot digitale gezondheidszorgtechnologie ter ondersteuning van hun zelfmanagement en geïntegreerde zorg. Sommige patiënten beschouwden digitale technologie als een handig product of als een handige dienst, terwijl anderen geen wens of noodzaak uitten om technologie te gebruiken voor zelfmanagement of zorg. Patiënten suggereerden de volgende digitale functies: (1) informatie over de oorzaken van een beroerte, medicatie, prognose en nazorg; (2) een online bibliotheek met informatie over gezondheids- en zorgkwesties die verband houden met een beroerte; (3) een persoonlijke gezondheidsomgeving waarmee patiënten hun eigen gezondheidsinformatie kunnen opvragen en beheren; en (4) online revalidatieondersteuning om patiënten in staat te stellen thuis te oefenen. Patiënten benadrukten de behoefte aan een gebruiksvriendelijk en eenvoudig ontwerp. Toekomstige studies zouden deze suggesties uitgebreider kunnen onderzoeken door gebruik te maken van co-design waarbij meerdere stakeholders, zoals patiënten, hun mantelzorger en zorgverleners betrokken zijn.

In **Hoofdstuk 6** worden strategieën onderzocht met betrekking tot de integratie van mobiele gezondheidstechnologie (mHealth) voor chronisch zieke patiënten in de eerste lijn. In de Nederlandse context zijn een stakeholderanalyse en een beoordeling van het zorgsysteem uitgevoerd. Over het geheel genomen hadden stakeholders (patiënten, zorgverleners en beleidsmakers) een positieve of gemengde houding tegenover de integratie van mHealth. Er kwamen twee belangrijke strategieën naar voren om de integratie van mHealth in de eerste lijn te bevorderen: (1) stimuleer co-design van mHealth technologie en (2) bied prikkels voor pioniers om de implementatie van mHealth aantrekkelijker te maken. In dit onderzoek werd de integratie van kennis van meerdere stakeholders gefaciliteerd door een interactieve onderzoeksmethodologie, daarbij werd slechts één cyclus van consultaties (d.w.z. leercyclus) voltooid. Toekomstige studies kunnen voortbouwen op het huidige onderzoek en meer leercycli met stakeholders voltooien. Zorgverleners van patiënten die een beroerte hebben gehad kunnen een meer persoongerichte benadering hanteren om tegemoet te komen aan de individuele behoeften van patiënten op het gebied van informatie, communicatie en nazorg. In deze context kunnen digitale gezondheidszorgtechnologieën persoonsgerichte geïntegreerde zorg ondersteunen en zelfmanagement bevorderen. Het gebruik van co-design wordt aanbevolen om het op maat maken van digitale oplossingen mogelijk te maken door continu feedback te verzamelen van gebruikers.

Deel III

Deel III bestaat uit het ontwerp van de 'ValueCare' aanpak (**Hoofdstuk 7**). Het ValueCare project heeft als doel persoonsgerichte, waardegedreven en geïntegreerde zorg te bieden aan ouderen (≥65 jaar) met multimorbiditeit, die kwetsbaar zijn of milde tot matige cognitieve achteruitgang ervaren in zeven steden in Europa (Athene, Griekenland; Coimbra, Portugal; Cork/Kerry, Ierland; Rijeka, Kroatië; Rotterdam, Nederland; Treviso, Italië; en Valencia, Spanje). De evaluatie van ValueCare bestaat uit een voor- en nameting waarbij de interventiegroep (onvangt de 'ValueCare- aanpak') wordt vergeleken met de controlegroep (ontvangt 'gebruikelijke zorg') in termen van het effect op de doelgroepen (ouderen, hun mantelzorger en zorgverleners) en het implementatieproces. Metingen worden uitgevoerd bij aanvang van de studie, na 12 maanden (het einde van de 'ValueCare' interventieperiode) en na 18 maanden. Elke studielocatie past de algemene ValueCare-aanpak aan naar de behoeften van zijn doelgroep en lokale context. In Rotterdam bestond de doelgroep uit mensen die een beroerte hebben gehad.

De kernelementen van ValueCare zijn in lijn met het 'Framework for Developing and Evaluating Complex Interventies', ontwikkeld door de UK Medical Research Council, en omvatten bijvoorbeeld aanpassingen aan de lokale context, het overwegen van passende gezondheids- en implementatieuitkomsten voor beoordeling, betrokkenheid van stakeholders en verfijning van de interventie. Bij het ontwerpen van complexe zorginterventies wordt aanbevolen om 'moeilijk bereikbare' groepen te betrekken om ook hun ervaringen en kennis mee te nemen. Bijvoorbeeld mensen die kwetsbaar zijn, laaggeletterd, afkomstig uit plattelandsgebieden of uit etnische minderheden.

Tot slot, persoonsgerichte geïntegreerde zorg vraagt om innovatieve manieren van organiseren en denken. Dit is echter een complex proces waarbij meerdere stakeholders betrokken zijn en waarvoor contextuele informatie en passende evaluatiemethoden nodig zijn. Dit proefschrift zet een eerste stap naar persoonsgerichte geïntegreerde zorg, ondersteund door digitale gezondheidstechnologie voor ouderen.

LIST OF PUBLICATIONS

This Thesis

Chapter 2

Esmée Bally, Lizhen Ye, Amy van Grieken, Siok Swan Tan, Francesco Mattace-Raso, Elena Procaccini, Tamara Alhambra-Borrás T, Hein Raat. Factors associated with falls among hospitalized and community-dwelling older adults: the APPCARE study. Frontiers in Public Health. 2023 Jun 29;11:1180914.

Chapter 3

Esmée Bally, Sophie Korenhof, Lizhen Ye, Amy van Grieken, Siok Swan Tan, Francesco Mattace-Raso, Elena Procaccini, Tamara Alhambra-Borrás, Hein Raat. Factors associated with health-related quality of life among community-dwelling older adults: the APPCARE study. Submitted to Scientific Reports.

Chapter 4

Esmée Bally, Demi Cheng, Amy van Grieken, Dianne van Dam-Nolen, Stefania Macchione, Mireia Ferri Sanz, Áine Carroll, Bob Roozenbeek, Diederik Dippel, Hein Raat. A qualitative study of the values, needs, and preferences of patients regarding stroke care: the ValueCare study. International Journal of Integrated Care. 2023 Jul 17;23(3):2.

Chapter 5

Esmée Bally, Demi Cheng, Amy van Grieken, Mireia Ferri Sanz, Oscar Zanutto, Áine Carroll, Andrew Darley, Bob Roozenbeek, Diederik Dippel, Hein Raat. Patients' perspectives regarding digital health technology to support self-management and improve integrated stroke care: qualitative interview study. Journal of Medical Internet Research. 2023 Apr 4;25:e42556.

Chapter 6

Esmée Bally, Tomris Cesuroglu. Toward integration of mHealth in primary care in the Netherlands: a qualitative analysis of stakeholder perspectives. Frontiers in Public Health. 2020 Jan 15;7:407.

Chapter 7

Esmée Bally, Amy van Grieken, Lizhen Ye, Maite Ferrando, Mirian Fernández Salido, Rachael Dix, Oscar Zanutto, Maurizio Gallucci, Vanja Vasiljev, Áine Carroll, Andrew Darley, Alejandro Gil-Salmerón, Sofia Ortet, Tasos Rentoumis, Nikos Kavoulis, Oscar

Mayora Ibarra, Nancy Karanasiou, George Koutalieris, Jan Hazelzet, Bob Roozenbeek, Diederik Dippel, Hein Raat, and on behalf of the ValueCare consortium. 'Value-based methodology for person-centred, integrated care supported by Information and Communication Technologies' (ValueCare) for older people in Europe: study protocol for a pre-post-controlled trial. BMC Geriatrics. 2022 Aug 17;22(1):680.

Other publications

- Lal SG, Syurina E, González LP, **Bally ELS**, Gopikumar V, et al. Vulnerabilities prompting use of technology and screen by mothers of autistic children in India: lived experiences and comparison to scientific literature. Cult Med Psychiatry. 2022 Aug 20:1–21.
- **Bally ELS**, van Grieken, A. Routines binnen het gezin en slaapproblemen op 3-, 6- en 10-jarige leeftijd. Tijdschr Jeugdgezondheidsz. 2020 Oct;52:123–124.
- Essink DR, Ratsavong K, **Bally ELS**, Fraser J, Xaypadith S, et al. Developing a national health research agenda for Lao PDR: prioritising the research needs of stakeholders. Glob Health Action. 2020 Jul;13(sup2):1777000.

ABOUT THE AUTHOR

Esmée LS Bally was born on June 10th 1994 in Emmeloord (Noordoostpolder), the Netherlands. In 2012, she started the bachelor European Public Health at Maastricht University. As part of her bachelor, she studied at Dokuz Eylül University in Izmir (Turkey) as an Erasmus exchange student and followed courses in International Relations and Policitical Sciences. She wrote her bachelor thesis about the European Union's response to the 2014 Ebola epidemic at Janssen Pharmaceutica in Beerse (Belgium). After obtaining her bachelor degree, she started the research master in Global Health at VU University in Amsterdam. During her master, she went to Lao PDR to collaborate with the National Institute of Public Health on the development of a national health research agenda. She also conducted research in collaboration with Philips on the integration of mobile health (mHealth) in primary care in the Netherlands. The results of both studies have been published in peer-reviewed journals. After her studies, she started working as a junior researcher at the Department of Public Health of Erasmus University Medical Center. Her main focus was the Horizon 2020-funded ValueCare project. In 2020, she was given the opportunity to start a PhD with a focus on person-centred integrated care under supervision of prof. dr. Hein Raat and prof. dr. Diederik Dippel. She was involved in ValueCare as a researcher, project manager and study coordinator of the local pilot site in Rotterdam.

PHD PORTFOLIO

Name:	Esmée Bally
Erasmus MC Department:	Public Health & Neurology
Research school:	Netherlands Institute for Health Sciences (NIHES)
PhD period:	2020-2023
Promotors:	Prof. dr. H. Raat & prof. dr. D.W.J. Dippel
Copromotors:	Dr. A. van Grieken & dr. B. Roozenbeek

1. PhD training	**Year**	**Workload (ECTS)**
Courses		
Value-based Healthcare	2020	0.7
Maternal and Child Health	2021	0.9
Principles of Research in Medicine and Epidemiology	2021	0.7
Regression Analysis	2021	1.9
LimeSurvey and GemsTracker	2021	0.4
Personal Leadership & Communication	2022	1.0
Biomedical Writing for PhD candidates	2022	1.5
Intervision for PhD candidates	2022-2023	1.0
Scientific Integrity	2023	0.3
International conferences		
International Conference on Integrated Care; virtual	2020	1.0
International Conference on Integrated Care; Odense (oral presentation)	2022	1.2
Conference of the International Society for Quality of Life; Prague (poster presentation)	2022	1.2
International Conference on Integrated Care; Antwerp (two oral presentations)	2023	1.4
Presentations, meetings and workshops		
Oral presentation at the Rotterdam Stroke Service Symposium; Rotterdam	2021	0.2
Oral presentations at the research colloquia of the Youth Health Care section	2021-2022	1.0
Seminars at the department of Public Health	2020-2023	2.0
Section meetings and research colloquia of the Youth Health Care section	2020-2023	2.0
Oral presentations, meetings and workshops as part of the ValueCare consortium	2020-2023	4.5
Oral presentation School of Public Health Sishuan University, China	2023	0.2
Teaching		
Train-the-trainers ValueCare	2021-2022	1.0
Supervising community projects of medical students Erasmus MC	2020-2023	2.0
Supervising student assistants for ValueCare	2021-2023	1.0
Lecturing in NIHES course 'Public Health across the Lifecourse'	2022-2023	1.0
Other activities		
Member of the research colloquia committee of the Youth Health Care section	2021-2022	2.0
Grant Writing ZonMw and Erasmus MC Trustfonds	2022-2023	2.0
Awards		
Erasmus Trustfonds – Research Visit Grant	2023	

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