Embracing the perspectives of older adults in organising and evaluating person-centred and integrated care
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General Introduction
Person-centred and integrated care may be a means to meet the health needs of older adults who are dealing with the consequences of ageing. This thesis provides insight into the perspectives of older adults on ageing, their health-related problems and associated needs, their experiences with person-centred and integrated care and support, and its impact on patient outcomes. This first chapter outlines the consequences of ageing, the challenges this poses to the current healthcare system and the possible solution of providing person-centred and integrated care. Furthermore, it describes the context of the Dutch healthcare system, models for person-centred and integrated care, the newly developed person-centred and integrated care service ‘Embrace’, and the research methods that were used. Finally, the objectives and outline of this thesis will be presented.

AGEING AND ITS CONSEQUENCES

Worldwide, the number of older adults is growing rapidly. In 2060, the number of people aged 65 years or older is expected to be equivalent to 30% of the population in the countries of the European Union, compared to 17% in 2008. In the Netherlands, the number of adults aged 65 years or older will increase from 2.7 million in 2012 to 4.7 million in 2040. It is estimated that by 2040, 26% of the Dutch population will be 65 years or older, compared to 16% in 2012. This ‘greying of the population’ is due to decreasing fertility rates and increasing life expectancy.

People often struggle with ageing as it is a progressive and irreversible process that is characterised by changes, losses and the need for adaptation. Ageing inevitably leads to physiological changes and an imbalance between damage and repair at the molecular and cellular levels. The age-related loss of muscle mass and strength, for example, leads to decreased physical functioning and mobility impairments. Cognitive abilities also diminish, resulting in, for example, memory and emotional problems. Physiological and cognitive changes may also lead to problems in performing daily activities, such as cooking, cleaning and dressing. In addition, ageing is often associated with social changes, such as the loss of friends and relatives, and declining social participation. These social losses may lead to loneliness. Ageing is also associated with psychological changes, which may lead to loss of control and increasing dependence. This prospect is feared by most older adults, as they strive to remain independent and ‘age in place’, despite having to deal with disabilities (see Box 1 for the definition of disability).
The loss of reserve capacity associated with ageing also increases the risk of developing multiple concurrent chronic diseases, or ‘multimorbidity’. More than half of the population aged 75 years and over suffer from multimorbidity, with the most common diseases including hypertension, hyperlipidemia, ischemic heart disease, diabetes and arthritis. Having multiple chronic conditions is negatively associated with poor quality of life, disability and mortality. A number of diseases are known to result in a great burden of disability, such as cardiovascular disease, chronic obstructive pulmonary disease (COPD), diabetes, osteoarthritis, sensory impairments, dementia and depressive disorders. Cardiovascular diseases and COPD contribute most to mortality in older adults.

Although ageing is inevitable, its impact on health, functioning and wellbeing differs between individuals due to genetic, socioeconomic, environmental and behavioural differences. The differences in the experiences of ageing are probably due to an individual’s compensating mechanisms, their ability to adapt and their resilience, and these determine the quality of life. Some individuals, for example, may be greatly impaired and dependent, resulting in social and psychological changes associated with poor a quality of life, whereas other chronically ill older adults may still be in control, autonomous and have a great quality of life. In addition to these inter-individual differences in ageing, the level of functioning of an individual also frequently fluctuates.

**BOX 1 • Disabilities and health according to the ICF**
As older adults frequently have to deal with multiple chronic conditions, a disease-oriented approach to functioning and health is not appropriate. The World Health Organization (WHO) therefore developed an international classification system for describing health and health-related states from a biopsychosocial perspective: the International Classification of Functioning, Disability and Health (ICF). The ICF provides a standard language for the evaluation of functioning and disability associated with someone’s health status. According to the ICF, functioning is ‘an umbrella term encompassing all the body functions, activities and participation’ (p. 3), while disability is ‘an umbrella term for impairments, activity limitations or participation restrictions’ (p. 3). The ICF comprises over 1450 categories, divided over the components: Body Functions and Structures, Activities and Participation, and Environmental Factors. Personal Factors interact with these ICF components, but are not classified, as they vary between cultures and societies.
AGEING IN PLACE

Older adults in industrialised countries increasingly remain living in the community for several reasons. First and foremost, older adults prefer to age in place and to participate in society. Second, governments stimulate independent living as a way to deal with the greying of the population and because of the economically beneficial effect on healthcare provision and costs. However, the realisation of ageing in place is threatened at both the governmental and the patient level, with governments experiencing challenges in adapting their funding and service delivery systems, and older adults experiencing increasing levels of dependence and feelings of losing control and insecurity, which leads to more service use and a higher risk of relocation to an institutional setting. Societies are therefore challenged to support older adults to better deal with the negative consequences of ageing and to age successfully.

NEED TO ADAPT HEALTHCARE SYSTEMS

Current western healthcare systems have been mainly designed to provide short-term care and support to generally young and middle-aged people who suffer from a single or an acute disease (see Box 2 for the Dutch healthcare system). However, the majority of older adults who need care suffer from multimorbidity, and may therefore be served by several different health and social care professionals. The complex and long-term care needed by older adults with multimorbidity presents a challenge to the healthcare system, which needs to organise and coordinate care. Often there is fragmented, inadequately coordinated care and support for older adults. This may have negative consequences, such as misunderstanding by the patient, adverse drug events due to polypharmacy, low treatment participation and even treatment errors. Coordination between primary care, secondary care, social care and prevention is therefore essential. Ideally, care and support for older adults has to be tailored to their situation, preferences, needs and goals. Current healthcare systems are not appropriately organised to be able to address these challenges for ageing individuals and need to be reorganised in such a way that they meet the needs of older adults and promote ageing in place.
CHAPTER 1

PERSON-CENTRED AND INTEGRATED CARE AND SUPPORT

Person-centred and integrated care services (see Box 3 for definitions) are often mentioned as a solution which can transform the healthcare system into one that meets the needs of older adults.4,31,45,50,60 Person-centred and integrated care is organised around the needs of the individual and the family. It provides a continuum of care and coordinates it across providers and settings.45

BOX 2 • The Dutch healthcare system

In the Netherlands, healthcare is divided into preventive, primary, secondary and long-term care. Municipalities are responsible for social care, population-based disease prevention and health promotion. Once a health problem occurs, patients enter the primary care system – in most cases through a visit to their general practitioner (GP). GPs act as gatekeepers for secondary care: patients need their referral to specialised medical care and hospital care. Homes for the elderly, nursing homes and home care organisations provide long-term care.55 Older adults aged 75 and over visit their GP on average fifteen times a year and medical specialists nearly four times a year.55,56 More than half of the women and nearly one-third of men over the age of 80 receive home care and 15-25% receive informal care.57 Twenty percent of those aged 75 and over also provide informal care to others.58 Nearly 5% of those aged 75 to 80 live in an institution, increasing to 57% of those above the age of 95.59

BOX 3 • Definitions of person-centred and integrated care

Person-centred and integrated care currently lack clear definitions.60,61 For the purpose of this thesis we use the definitions as proposed by the World Health Organization (WHO), which defines person-centred care as 'care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health' (p. 48). It defines integrated health services as 'the management and delivery of health services such that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services, through the different levels and sites of care within the health system, and according to their needs throughout the life course' (p. 48).45
The Chronic Care Model

A well-known person-centred and integrated care model is the Chronic Care Model (CCM), which was developed in the US to improve health outcomes of chronically ill patients (Figure 1). The CCM describes a healthcare system that is linked to community organisations and addresses the needs of patients with chronic diseases by offering proactive, person-centred and integrated care. Its goal is to achieve productive interactions between an informed and activated patient and a prepared, proactive team of professionals. To meet that goal, four key evidence-based and interdependent elements are incorporated into the model: self-management support, delivery system design, decision support and clinical information systems.

Although the CCM has become a popular aid in transforming healthcare systems, evidence on the effectiveness of the full CCM regarding clinical outcomes is still limited and mainly concerns its use in groups of patients with specific chronic diseases, such as COPD, asthma, diabetes and cardiovascular disease. Only three CCM-based studies specifically targeted older adults. A study on ‘Guided Care’ for older adults showed no significant effect on self-rated mental and physical health. The ‘frail older Adults: Care in Transition-study’ found only small intervention effects for instrumental activities of daily living. However, these two studies only focused on people who were already frail or had complex care needs. Only one study on the ‘Senior Health Clinic model’ investigated the effects of the CCM on the whole population of older adults living in the community. That study showed that older adults receiving the intervention had a stable health-related quality of life despite physical function decline, whereas the control groups showed a deterioration in their quality of life.

FIGURE 1 • The Chronic Care Model
Population segmentation by the Kaiser Permanente Triangle

Older adults can be stratified into homogeneous groups with comparable healthcare needs (i.e. population segmentation). Population segmentation may offer a means to provide effective and efficient care and support suitable for the total population of older adults living in the community, but which is tailored to the needs of the individual.71-74 This segmentation method focuses on entire populations in a community and not just on those in need of urgent care. Those older adults who are in poor health may need intense counselling with an individual-needs approach, meeting the broad spectrum of health-related problems they may experience.74,75 Older adults who are still vital should also be prepared to cope with the consequences of ageing.76 Health promotion focusing on prevention and self-management behaviour40 may decrease the risk of chronic diseases and could thus be important to all older adults.26,31 Nonetheless, inter- and intra-individual differences within groups remain, indicating a need for flexibility in the level of intensity of care and support provided.39,77,78

A first attempt to segment a patient population was done by Kaiser Permanente (KP), a non-profit organisation providing integrated healthcare.79 This segmentation model has evolved over time into the KP Triangle (Figure 2). It classifies the population into subgroups based on the distribution of risk in relation to healthcare needs, in order to adapt the care and support to the individual needs. The KP Triangle differentiates between three levels, with corresponding intervention strategies: self-management support for patients with a relatively low risk of healthcare needs; disease management or care management for patients with increased levels of risk of complex care needs; and intensive case management for patients with high complexity. Preventive care is provided at all three levels.53
Embrace
Embrace (in Dutch: SamenOud, i.e. ageing together) is a population-based, person-centred and integrated care service for community-living older adults based on the CCM 62,63 and the KP Triangle (see Box 4 for the programme that funded Embrace).53

BOX 4 • National Care for the Elderly Programme
The Dutch Ministry of Health, Welfare and Sport (VWS) launched the ’National Care for the Elderly Programme’ (in Dutch: Nationaal Programma Ouderenzorg [NPO]) in 2008, with the goal of transforming the Dutch healthcare system for older adults.80 The goal of this programme was to improve care, quality of life and self-reliance of older people by restructing care and support – from the perspective of older adults themselves – disregarding the existing rules, structures and funding. The prerequisite was that the integration, quality and costs of the care and support had to improve. All eight Dutch university medical centres started regional collaboration and launched about 75 projects and experiments. One of the experiments was ‘Embrace’.

In each general practice, a multidisciplinary Elderly Care Team – consisting of a GP, a nursing home physician81 and two case managers (district nurse and social worker) – provides care and support to older adults. Older adults are stratified into three risk profiles (see Box 5 for segmentation within Embrace). The intensity, focus and individual or group approach of the care and support depends on the older adult’s risk profile. All older adults are invited to follow a self-management support and prevention programme focusing on staying healthy and independent for as long as possible. The programme includes regular Embrace community meetings, in which self-management abilities are encouraged and during which local healthcare and welfare organisations provide information on health maintenance, physical and social activities, and dietary recommendations. In addition, frail people and those with complex care needs receive individual support from a case manager. The older adult and their case manager jointly develop an individual care and support plan that focuses on all health-related problems. The case managers monitor changes in the medical, psychosocial or living situation, and are responsible for the realisation of the plan. During monthly meetings, the Elderly Care Team discusses and evaluates the health status and social situation of the older adults. If necessary, they take proactive steps in dialogue with the older adult to prevent deterioration.
Several studies are being conducted on the impact of Embrace. They focus on patient outcomes, service use, costs and quality of care. The focus in this thesis is on the impact of Embrace from the patient perspective and on patient outcomes.

**OBJECTIVES OF THE THESIS**

The main objectives of this thesis are twofold. The first objective is to gain knowledge on the consequences of ageing and the needs of older adults. The second objective is to examine the impact of receiving person-centred and integrated care and support through Embrace and the extent to which it meets the needs of older adults. The following research questions will be answered:

1. What are the most relevant health-related problems of community-living older adults?
2. What is the prevalence, severity and change in health-related problems as experienced by community-living older adults receiving twelve months of person-centred and integrated care and support from Embrace?
3. What are the effects of person-centred care and support through Embrace on patient-reported outcomes in the domains of ‘Health’, ‘Wellbeing’ and ‘Self-management’?
4. What are the opinions and experiences of community-living older adults with respect to ageing and person-centred and integrated care and support?

**BOX 5 • Embrace risk profiles**

Participants are stratified into three risk profiles using complexity of care needs, as measured by the INTERMED for the Elderly Self-Assessment (IM-E-SA), and the level of frailty, as measured by the Groningen Frailty Indicator (GFI). The risk profiles are:

- **Complex care needs**: concerning participants with complex care needs at risk of assignment to a hospital or nursing home (IM-E-SA ≥16).
- **Frail**: concerning participants at high risk of complex care needs (IM-E-SA <16 and a GFI ≥5).
- **Robust**: concerning participants at risk of the consequences of ageing only (IM-E-SA <16 and GFI <5).
OUTLINE OF THE THESIS

In Chapter 2, we present the development and validation of a Geriatric ICF Core Set (GeriatrICS), which is currently used as a history-taking tool by Embrace case managers. In Chapter 3, we investigate the prevalence, severity and twelve-month change in prevalence and severity of health-related problems as measured with the GeriatrICS. In Chapter 4, we describe the design of the study on the effectiveness of Embrace, while in Chapter 5, we present the results of this study. In Chapter 6, we present the results of a qualitative study among older adults who received integrated care and support through Embrace. In Chapter 7, we summarise and discuss the main results and present the implications of this thesis for practice and research. The timeline of the different studies is presented in Figure 3.

FIGURE 3 • Timeline of the Embrace studies performed in this thesis
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