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Tailoring care for older adults

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1.

General introduction

MULTI-MORBIDITY RATES RISE DUE TO DEMOGRAPHIC AND HEALTH CARE CHANGES

Care for older adults presents with a lot of challenges in the coming decades. A growing number of home-dwelling older adults are currently receiving dispersed treatment by numerous care professionals. One of such case is illustrated in Box 1.

Box 1. Case emphasising the dispersed care older adults with multi-morbidity experience

Mrs. Blue is an 89-year old community-dwelling woman, diagnosed with osteoporosis and recurrent depressive moods with anxiety, and receives professional household support. Next to weekly visits from her son, and daily telephone contact with her daughter, she keeps in contact with her six grandchildren via social media. For several weeks she has suffered from intense pain in her right hip and leg. The pain impairs her movement and activities of daily living (ADL). At night she ruminates about the cause of this pain, like cancer of which her husband died from. Her **general practitioner (GP)** tries to improve her sleep by prescribing melatonin and referring her to a **psychologist**. The referred **orthopedic surgeon** tells her that surgery will not be possible because of her osteoporosis, while the **anesthesiologist** acknowledges the severity of her pain by prescribing transdermal morphine. The **communality nurse** offers ADL support. Mrs. Blue accepts all the help and referrals as she is desperately wanting to know what causes her pain. Since she really wants to stay physically active, she keeps her daily home-trainer routine as recommended by her **physiotherapist**. She, however, is too scared to take the prescribed medication, after talking with her neighbour about the side effects of morphine. One night she called for an ambulance due to fainting and chest pain. The **emergency doctor** diagnoses her with hyperventilation. The psychologist refers her to mindfulness therapy. Meanwhile, Mrs. Blue's pain experience is taking over her life and she quit her choir and bridge club. Her children are worried, but do not know which of the seven care providers to contact for further care planning. The difficulties in providing the right care for older adults emerge in the context of demographic changes and curative developments. These changes give rise to a growing older adult population with an increasing disease burden. After outlining these changes we will describe the ways in which care is developing to face these challenges.

Ageing population

In the Netherlands, the proportion of people aged 65 years and over has risen from 7% of the total population in 1960, to 14% in 2000, and is expected to be over 26% of the total population in 2040.¹ This is due to a double demographic development: an increased life expectancy coinciding with a decreased birth rate (in Dutch: *de dubbele vergrijzing*).

Hence, not only the number of older adults is rising, there is also a decrease in the number of possible care professionals (i.e. the working population). This old age-dependency ratio (i.e., the rate of individuals aged 65 years and over relative to the population of people aged 20 to 64 years, in Dutch: *de grijze druk*), will change dramatically between 2015 and 2040 from 1:4 to 1:2.¹ The demographic numbers reported here are based on the Netherlands, but show a comparable trend in other Western regions and even in developing countries.²

Multi-morbidity due to curative developments

Although life expectancy is increasing, not all of these years are lived in good health. Paradoxically, the years lived without disease even decrease.³ Both life expectancy and health state are influenced by curative developments.

The chances of surviving until old age have partly increased as a result of health care developments. First the mortality of communicable diseases decreased tremendously in the last century due to better understanding and application of hygienic strategies, the introduction of intravenous fluids and the use of antibiotics. Thereafter, in the previous decades, the survival rate of acute diseases like myocardial infarction and stroke has increased with the introduction of highly effective medical-technical interventions. The top ten causes of mortality in high-income countries is now abundant with chronic diseases, like COPD, malignancies, dementia and diabetes.⁴

However, these chronic diseases are already prevalent years before the end of life. The *years in good physical health* increase much slower than the life expectancy,³ and the *years living with disease* therefore rises, especially for women. For example, between 1981 and 2017 the life expectancy for Dutch women increased by 4 years to 80.1, whereas the years living without disease decreased by 12.5 years to 41.4.⁵ During these 'years living with disease' people often experience multiple diseases, called multi-morbidity. These conditions are partly caused by degeneration processes and accumulated damage, like chronic kidney disease, osteoporosis, osteoarthritis, and atherosclerosis. Earlier diagnosis of these conditions contributes to the further rise in multi-morbidity rates and the further increase of medication and health care usage.⁶

OLDER ADULT CARE NEEDS AND DEVELOPMENTS

With increasing morbidity, care complexity increases...

Due to the high prevalence of chronic diseases among the growing older adult population, patients with multi-morbidity are highly prevalent within primary care.⁷ Multi-morbidity is a complex phenomenon with an almost endless number of possible disease combinations, having a large variety of implications on functioning, dependence and quality of life. Multi-morbidity increases the risk for, and co-occurs commonly with frailty,⁷ a condition which entails an expectation of increased risk of adverse health outcomes due to a decreased ability for compensation of losses.^{8,9} In general, multi-morbidity is associated with high healthcare utilisation and costs such as frequent hospitalisation, and mortality.^{10,11} Patients with multi-morbidity have a more complex health care usage than just an accumulation of the common care usage for each single disease.¹² Their encounter with different care services and providers often results in difficult and conflicting pharmacological and non-pharmacological recommendations¹³ which can result in patient confusion, unnecessary costs, and treatment burden.¹⁴ Care professionals also experience multi-morbidity as challenging because multiple conflicting disease-oriented guidelines are applicable, evidence for patients with multi-morbidity is absent, care services are disease-oriented, and coordination within this care landscape is lacking.¹⁵ So, traditionally organised health services are often unable to meet the heterogeneous needs of older adults with multi-morbidity.¹⁶

To conclude, with increasing morbidity, care complexity increases. This implies a necessity for a tailored approach.¹⁷ Yet, current health care systems are largely built on an acute episodic model of care which is ill equipped to meet the long-term and fluctuating needs of older people with complex chronic health problems.^{7,16}

... demanding a tailored approach

In search for an answer to the increasing multi-morbidity needs, the care landscape for older adults, especially those experiencing multi-morbidity, should be re-designed to align care with needs, goals and capabilities of the individual. This is a totally different paradigm to the current disease-oriented approach, which results in contradicting and complicating therapies.¹³

In search for an optimal approach, care is currently encouraged to become more proactive, integrated and person-centred.^{7,18} Integrated care aims to connect the curative health care system with other care and social service systems to improve various outcomes (e.g., clinical, satisfaction and efficiency).¹⁹ The aim of person-centred care is to match the person's needs and preferences in a holistic way.^{20,21} Therefore, it uses methods to assess a person's individual needs and goals, align with these needs and goals and enhance a person's involvement in their own care.²² Next to the development of person-centred integrated care, policy makers often endorse the need for proactive care.^{23,24} This seems to result from the frailty

paradigm. Frailty entails increased risks of adverse health outcomes due to a decreased ability to compensate for losses.²⁵ Therefore, it makes sense to timely address these risks and promote this ability. However, evidence for the effects of pro-active care for community-dwelling older adults is scarce.²⁶

Examples of services designed to deliver proactive integrated person-centred care are home visiting case management programs²⁷ and proactive outpatient assessment services.²⁸ These services commonly involve strategies such as population screening, frailty (self-)assessment, a comprehensive geriatric assessment (CGA) into unmet needs, and tailored care planning.

Even though older adults, as well as care professionals, advocate for the integrated and person-centred approaches,^{29,30} there is still scarce and inconclusive evidence that these approaches really improve health or patient outcomes. Integrated care shows variable results in reducing health resource usage and improving clinical outcomes.^{31,32} Interventions to promote patient-centred care within clinical consultations show mixed effects on patient satisfaction, health behaviours and health status.³³

However, political reforms are already aiming at care transition stimulating these approaches. In the Netherlands financial legislation for care support was recently changed and incentives for integrated care research and network development was funded, shown in detail in Box 2.

Box 2. Examples of primary health care reforms from the last decade to promote proactive, integrated, person-centred care for older adults in the Netherlands

- To stimulate proactive care, health insurers provide GPs with funding to incorporate case finding of frail older adults and proactive care planning into daily practice routines.
- For promoting person-centred care, long-term care was reformed comprehensively to shift from residential to non-residential care, based on the assumption that older adults prefer to 'age in place' and are better cared for in the community at lower costs. The provision of non-residential care was decentralised to municipalities.
- To stimulate integrated care, the National Care for the Elderly Program funded research and implementation programs to redesign care services and improve regional cooperation between care services (budget: € 80 million).

As the optimal way to develop and deliver tailored care is not researched nor understood in detail, more insight is needed into “what should be done by whom, for which target group and at what moment” to improve current practice in older adult care.²⁷

Studying mechanisms and context to understand care development

Despite numerous developments, initiatives and policies to promote proactive integrated person-centred care for older adults, the understanding of crucial elements or preferred implementation strategies remains suboptimal. Effects on dependency, quality of life, caregiver burden, and costs of recently re-designed Dutch care programs are disappointing.³⁴ We need an in-depth understanding as to whether these developments contribute to tailored care before designing new programs. Instead of looking for causal descriptions (i.e. what effect does this cause), we need to look for causal explanations (i.e. why and how does this happen).³⁵ Thereto we can use methods from the realist evaluation approach.³⁶

Realist evaluation starts from a so-called ‘program theory’, a theory based on existing models, concepts and knowledge by which a study setting is expected to result in effects. This theory is adapted by addressing not only the outcome but also the mechanisms and the context. It thereby enhances understanding of a studied program. In this way it provides insight into “what works, for whom, in what respects, to what extent, in what contexts, and how”. This context-mechanism-outcome configuration is used as the main structure for a realist evaluation. A description and an example of each element of this configuration is detailed below.

Outcomes are the changes a program aims for in order to work, i.e. to have effect. Mechanisms are the combination of ‘reasoning and resources’ that enables a program to ‘work’. Reasoning encompasses values, beliefs, attitudes, and the logic that professionals apply to a particular situation. For example, information, skills, and support can all be considered resources. The contexts in which programs operate make a difference to the outcomes they achieve. Program contexts include features such as the program participants’ social, economic and political opinions and conditions. All of these features influence the ease with which the program is able to alter a situation, and the extent to which the program theory applies to the context. Contextually relevant measurements are therefore much broader than locality and demographic characteristics of participants.³⁷

These elements can easily be applied to the older adult care practice as all current initiatives for care reform can be seen as programs which are expected to work by a presumed theory. When studying the program, the focus is almost always on outcomes, mostly health- or disability-related.³⁴ However, mechanisms influencing this outcome are increasingly receiving attention and are studied

within implementation science,³⁸ and process evaluations are increasingly performed alongside effect evaluations.³⁹ However, in these, mostly process measures like implementation rates are studied. Since non-quantifiable matters, like professional reasoning, are also considered mechanisms, the actual practice needs to also be taken into account to further clarify how and why certain program elements were implemented, and whether this, for example, depends on care professional's skills or differs between participant groups. And lastly, the local context in which programs are implemented are rarely studied in depth, despite the impact on implementation rates and effect rate.²⁴ As the programs aim to deliver tailored care for older adults, their context is pre-dominantly determined by the individual older adults themselves and their preferences.

In conclusion, the increasing amount of people with multi-morbidity and increasing care complexity calls for tailored care. The way to deliver this care is, however, not fully understood. Therefore, not only outcomes, but also mechanisms and the context should be studied to adapt care to older adults' needs.

THESIS STRUCTURE

Thesis questions

This thesis has emerged from the desire to address the challenges and pitfalls with the re-organisation of older adult health care. To further understand the mechanisms and context of current practice, we developed the following theory:

"tailored care, by means of goal setting and enhanced patient involvement, improves well-being for older adults experiencing frailty and multi-morbidity."

In line with the realist evaluation approach, we addressed the research questions on the level of outcomes, mechanisms and context within current practice. The coherence between these realist evaluation components in this specific thesis is shown in Figure 1. The older adult is the context, for which care planning is organised, of which goal setting is a central part with the aim of goal attainment and the improvement of well-being. As shown in Figure 1, starting at the centre (outcome), we researched the diverse mechanisms (goal setting within a proactive care setting) and the preferences of the older adult (context) influencing the outcome.

The questions answered within this thesis are therefore as follows:

- Outcomes: What are the effects of goal setting for older adults within an integrated person-centred care setting? (Chapter 2 on well-being and Chapter 3 on goal attainment)
- Mechanisms: How can the effects of goal setting within a proactive assessment

service be explained from the older adult's and care professional's perspective? (Chapter 4 and 5)

Context: Can the preferences and needs of older adults explain the effects of and experiences of with a proactive assessment service? (Chapter 4 and 6)

By answering these questions we aim to increase the understanding of the extent to which current care developments align with the needs, goals and preferences of older adults. The relevance of goals and preferences for developing tailored care for older adults is illustrated in Box 3.

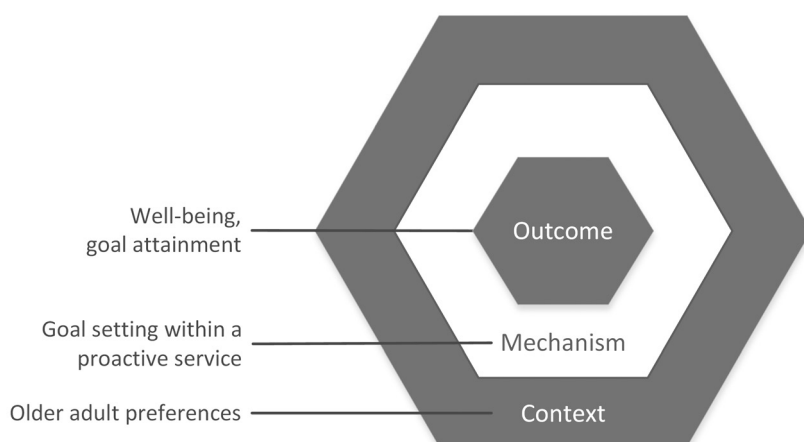


Figure 1. Graphical outline of the realist evaluation elements' coherence and their application for this thesis

Box 3. The three thesis questions translated into the individual care Mrs. Blue experiences

The seven involved care professionals, as well as the children of Mrs. Blue, are aiming for more comfort and a better quality of life for Mrs. Blue. But they are unaware of her goals, such as finding the cause of the pain and staying physically active. They did not discuss her preferences, like being involved in decisions when starting drug therapy and discussing side-effects. Neither did they discuss nor align their (implicit) therapeutic goals with each other. Whilst being unaware of the non-adherence of Mrs. Blue, everybody is wondering themselves what the next step should be.

Research settings, samples and questions

To address these aims, three older adult samples from different settings were studied. All populations were recruited from the northern, rural part of the Netherlands. A short description of each setting is written below and outlined in Table 1.

Table 1. Short description of study settings plotted against the realist evaluation elements.

	Context	Mechanism	Outcome
<i>Sage-atAge</i>	65+ community-dwelling, frail	<ul style="list-style-type: none"> • Population screening • Individual assessment • Goal setting (Sage-atAge+) 	Well-being
<i>Embrace</i>	75+ community-dwelling, frail	<ul style="list-style-type: none"> • Population screening • Individual assessment • Goal planning • Case management • Goal evaluation 	Goal attainment Goal progress
<i>Care networks</i>	65+ community- and institutional-living, frail and highly frail		

Grey highlighted: studied elements

Sage-atAge

Sage-atAge (in Dutch: *Wijs Grijs*) is a proactive outpatient assessment service for frail community-dwelling older adults. It offers comprehensive geriatric assessments, combining a population screening strategy with an interdisciplinary multi-domain approach.²⁸ Assessments were performed by a geriatric nurse, an elderly care physician, pharmacist, dental care worker and allied health professionals (physiotherapist, psychologist, occupational therapist, dietician).

In order to promote the chance of an effect on well-being, Sage-atAge+ was developed. By adding goal setting to the Sage-atAge service, the involvement and central perspective of the older adult was intended to increase. We studied the additional change in well-being after this program adaptation as an outcome of a proactive goal setting service. We also studied the experience of participating older adults and professionals to improve insight into the mechanisms behind such services.

Embrace

Embrace (in Dutch: *SamenOud*) is an integrated and person-centred care and support service for community-living adults aged 75 years and older developed within the Dutch National Care for the Elderly Program (in Dutch: *Nationaal Programma Ouderenzorg*).⁴⁰ The starting point in the development of Embrace is the wellbeing of older adults. The ultimate goal of Embrace is to prolong the ability of older adults to continue living in their own homes. It combines two evidence-based models, the Chronic Care Model and a Population Health Management Model.^{41,42} These models were translated to the Dutch health care situation and specified for older adults. In this way, the intensity of care is adapted to the frailty and care complexity of individual older adults. Older adults with frailty or care complexity received case-management for one year to formulate and attain their health-related goals. We studied the extent to which they attained their goals and made progress on their goals as an outcome of a person-centred care program.

Care networks

The third setting addresses a sample which represents the total Dutch population of persons aged 65 and over, including very frail older adults living in residential care homes. To ensure that the frailest subgroup was represented, we first used active sampling strategies by sampling throughout healthcare and welfare organisations instead of general practitioners. In this way, residential care inhabitants were also reached, who in the Netherlands receive care from elderly care physicians.⁴³ Secondly, support for questionnaire completion was actively offered. We studied the preferences of these older adults to derive insight into an important contextual factor for the improvement of older adult care.

Thesis outline

This thesis describes, in two sections, the realist evaluation context-mechanism-outcome proposition in reversed sequence, to align with the sequence in which the questions emerged.

In the first section goal setting practices are examined on the outcomes. In **Chapter 2** the Sage-atAge setting is examined, in which goal setting is added to an existing proactive assessment program. The effect of adding goal setting on well-being is then tested. In **Chapter 3** goal setting is combined with goal planning by case managers within the Embrace program. The goal content is examined, as well as goal progress and goal attainment.

In the second section of the thesis, mechanisms and context that could explain the obtained outcomes in the first section are explored. We studied the mechanisms of the program by considering the impact of several program components on the reasoning and experience of care professionals and older adults. First, in **Chapter 4** the experience of older adults with Sage-atAge+ is explained regarding three

mechanisms: the pro-active approach, the multi-dimensional assessment and the integration within existing care. Secondly, the care professionals' assessment and goal setting performance, and their perspective on this performance within the pro-active setting are studied in **Chapter 5**. Then in **Chapter 6**, we consider the context by studying older adult preferences. We study the diversity and distribution of two different health preferences: health decision involvement and health behaviour which both are important when considering goal setting.

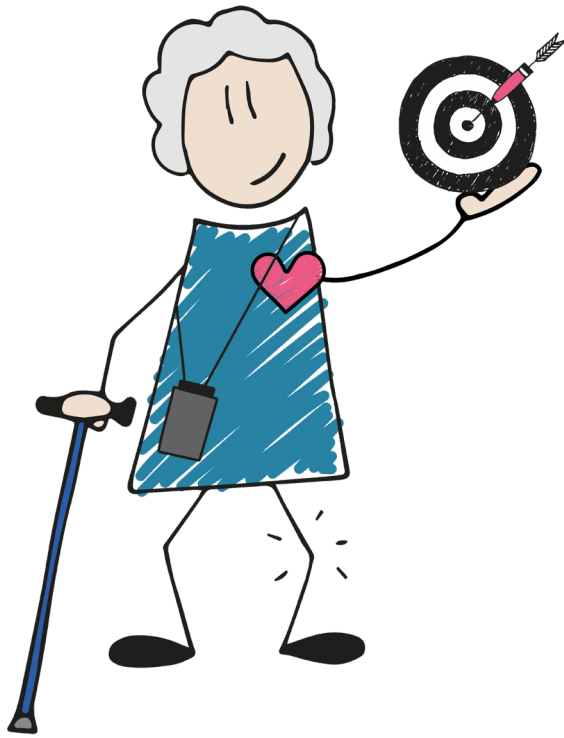
Finally, in a general discussion in **Chapter 7** we reflect on all of the findings, outline the concordance of the outcome-mechanism-context configuration for goal setting within older adult care, and the impact on future care service developments for policy makers as well as care professionals.

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Part I:

Outcome of goal setting within proactive
care services



Sage-atAge



Sage-atAge+

