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## Tailoring care for older adults

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# Tailoring care for older adults

Understanding older adults' goals and preferences

**Wanda Rietkerk** 

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# Tailoring care for older adults

Understanding older adults' goals and preferences

#### **Proefschrift**

ter verkrijging van de graad van doctor aan de Rijksuniversiteit Groningen op gezag van de rector magnificus prof. dr. C. Wijmenga en volgens besluit van het College voor Promoties.

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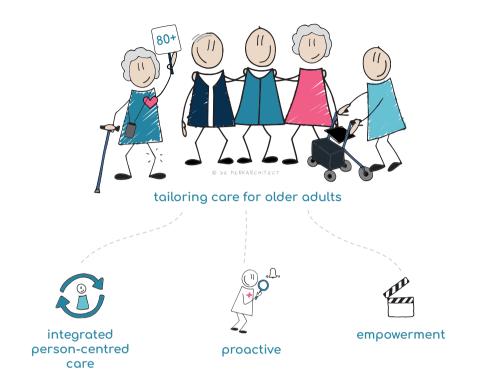
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1.

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 multimorbidity experience $% \left( 1\right) =\left( 1\right) +\left( 1\right) +\left($

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.<sup>1</sup> 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. <sup>3</sup> 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.<sup>4</sup>

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,<sup>3</sup> 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.<sup>5</sup> 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.<sup>6</sup>

# 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. 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. 10,111 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 recommendations<sup>13</sup> 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 multimorbidity 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.<sup>16</sup>

To conclude, with increasing morbidity, care complexity increases. This implies a necessity for a tailored approach.<sup>17</sup> 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.<sup>7,16</sup>

## ... 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 redesigned 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.<sup>13</sup>

In search for an optimal approach, care is currently encouraged to become more proactive, integrated and person-centred. 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). The aim of person-centred care is to match the person's needs and preferences in a holistic way. 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. Next to the development of person-centred integrated care, policy makers often endorse the need for proactive care. 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.<sup>25</sup> 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.<sup>26</sup>

Examples of services designed to deliver proactive integrated person-centred care are home visiting case management programs<sup>27</sup> and proactive outpatient assessment services.<sup>28</sup> 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,<sup>29,30</sup> 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.<sup>31,32</sup> Interventions to promote patient-centred care within clinical consultations show mixed effects on patient satisfaction, health behaviours and health status.<sup>33</sup>

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.<sup>27</sup>

#### 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.<sup>34</sup> 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).<sup>35</sup> Thereto we can use methods from the realist evaluation approach.<sup>36</sup>

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.<sup>37</sup>

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.<sup>34</sup> However, mechanisms influencing this outcome are increasingly receiving attention and are studied

within implementation science,<sup>38</sup> and process evaluations are increasingly performed alongside effect evaluations.<sup>39</sup> 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.<sup>24</sup> 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.

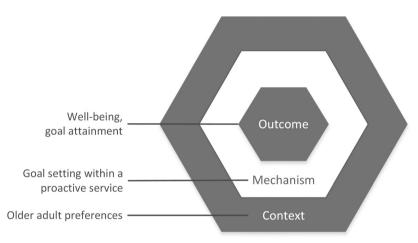


Figure 1. Graphical outline of the realist evaluation elements' coherence and their application for this thesis

# 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
Sage-atAge	65+ community- dwelling, frail	<ul><li>Population screening</li><li>Individual assessment</li><li>Goal setting (Sage-atAge+)</li></ul>	Well-being
Embrace	75+ community- dwelling, frail	<ul><li>Population screening</li><li>Individual assessment</li><li>Goal planning</li><li>Case management</li><li>Goal evaluation</li></ul>	Goal attainment Goal progress
Care networks	65+ community- and institutional- living, frail and highly frail		

Grev 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.<sup>28</sup> 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*).<sup>40</sup> 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.<sup>41,42</sup> 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.<sup>43</sup> 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-mechanismoutcome 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

#### **Chapter 1** | Introduction

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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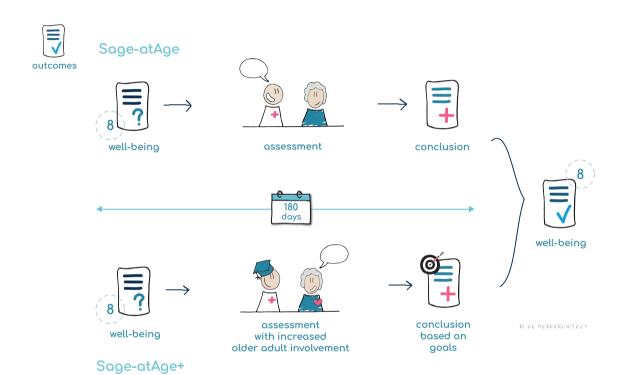
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# Part I:

Outcome of goal setting within proactive care services



# Effects of increasing the involvement of community-dwelling frail older adults in a proactive assessment service: a pragmatic trial

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#### **ABSTRACT**

#### Background

Older adults and care professionals advocate a more integrated and proactive care approach. This can be achieved by proactive outpatient assessment services which offer comprehensive geriatric assessments to better understand the needs of older adults and deliver person-centred and preventive care. However, effects of these services are inconsistent. Increased involvement of the older adult during the assessment service could increase the effects on older adult's well-being.

#### Methods

We studied the effect of an assessment service (Sage-atAge) for community-dwelling frail adults aged ≥65 years. After studying the local experiences, this service was adapted with the aim to increase participant involvement through individual goal setting and using motivational interviewing techniques by health care professionals (Sage-atAge+). Within Sage-atAge+, when finishing the assessment a "goal card" was written together with the older adult: a summary of the assessment, including goals and recommendations. We measured well-being with a composite end point consisting of health, psychological, quality of life, and social components. With regression analysis, we compared the effects of the Sage-atAge and Sage-atAge+ services on well-being of participants.

#### Results

In total, 453 older adults were eligible for analysis with a mean age of 77 ( $\pm$  7.0 years) of whom 62% were women. We found no significant difference in the change in well-being scores between the Sage-atAge+ service and the original Sage-atAge service (B, 0.037; 95% confidence interval, -0.188 to 0.263). Also, no change in well-being scores was found even when selecting only those participants for the Sage-atAge+ group who received a goal card.

#### Conclusion

Efforts to increase the involvement of older adults through motivational interviewing and goal setting showed no additional effect on well-being. Further research is needed to explore the relationship between increased participant involvement and well-being to further develop person-centred care for older adults.

#### INTRODUCTION

Multi-morbidity is common as people age, leading to increased dependency and frailty,<sup>1</sup> with older adults often fearing progressive losses during this process.<sup>2</sup> To prevent multi-morbidity,<sup>3</sup> increase well-being,<sup>4</sup> decrease care dependency,<sup>5</sup> and deliver person-centred care,<sup>6</sup> both older adults and care professionals advocate a more integrated and proactive approach.<sup>7,8</sup> Therefore, proactive outpatient assessment services have been developed. They offer comprehensive geriatric assessments (CGAs) to better understand the needs of older adults and deliver person-centred and preventive care.<sup>9</sup>

CGAs are typically provided to at-risk populations based on criteria such as age, frailty, or certain morbidities. The assessment services may incorporate personcentred care, <sup>10</sup> focusing on multiple domains, multidisciplinary care delivery, and individualized care plans. However, studies on the effects of assessment services from the last decade have produced inconsistent results. <sup>9</sup> On the one hand, studies have shown that outpatient assessment services can decrease the number of hospital admissions <sup>11,12</sup> and frailty. <sup>13,14</sup> But on the other hand, they have been shown to have no effect on quality of life. <sup>15,16</sup> Both studies failing to find effect on quality of life used a randomized controlled trial design and had little or no control over implementation of assessment recommendations.

Three reasons can be hypothesized for the lack of observing beneficial effects in earlier programs: the strict design, the role of the older adult and the outcome measure. A proactive outpatient assessment service for frail community-dwelling older adults was developed, called Sage-atAge (in Dutch: *Wijs Grijs*), to tackle the issues of previous research.

First, a pragmatic design may be preferable to the mostly used randomized controlled trial (RCT) design. Sage-atAge has an pragmatic design which allowed for an easy adaption to the local situation and experiences of professionals and older adults involved.<sup>17</sup> It is proposed as a preferable design to study the 'real world' effects of geriatric assessment programs.<sup>18</sup>

Secondly, a plausible and well-studied problem in the implementation of these programs is the poor adherence to recommendations of the geriatricians or geriatric teams and implementation of care plans. A way to improve this adherence is to increase the older adult involvement. In Sage-at Age, older adult involvement is encouraged by motivational interviewing and goal setting. Motivational interviewing is a method to encourage people to make behavioural changes to improve health outcomes. It has been proven to be effective across different health care setting for improving treatment adherence for chronic conditions. Goal setting is commonly seen as valuable in promoting the role

of patients in decision-making and is an effective way to increase motivation of older adults.<sup>25</sup> Goal setting proved feasible for older adults<sup>26</sup> and suits the heterogeneous problems older adults with multi-morbidity face.<sup>27</sup>

The third reason for the observed lack of assessment programs may be due to the outcome measures used.<sup>28,29</sup> Since these program target heterogeneous problems experienced by frail older adults, a specific outcome measure such as function dependency may not be appropriate. In the present study we used a composite endpoint (CEP) covering multiple (physiological, social, physical) domains that are associated with the (different domains) of well-being.

In this study, we evaluated both the Sage-atAge service and the potential benefit on general well-being of increasing older adult involvement by using motivational interviewing and goal setting. The evaluation had three objectives: (1) to improve our understanding of outpatient assessment services, (2) to determine why studies investigating these services produce inconsistent results, and (3) to further develop CGA in a person-centred way.

# METHODS Design

The Sage-atAge outpatient assessment service was offered by primary care practices (PCPs) to community-dwelling older adults aged ≥65 years from a rural area in the northern part of the Netherlands, aiming to promote or preserve well-being. We evaluated the service on the effect of well-being within a pragmatic trial conducted between January 1<sup>st</sup>, 2013, and April 30<sup>th</sup>, 2017. First, we used a pragmatic design to adapt the service to local needs in close collaboration with care professionals (the Sage-atAge service). Second, the assessment process was adapted during the study when we identified a potential need to increase the involvement of older adults to enhance the service's impact (the Sage-atAge+ service). The involvement of older adults in the Sage-atAge+ service was promoted by motivational interviewing and goal setting. Third, we used a composite endpoint (CEP) that combined physical, psychological, and social well-being domains. Table 1 summarizes the components of the Sage-atAge and the Sage-atAge+ services.

Table 1. The content of the Sage-atAge and Sage-atAge+ service

Service element	Content	Sage- atAge	Sage- atAge+
Start	Invitation by GP.	•	•
Triage	Care profile (based upon frailty and case complexity) or frailty level.	•	•
Assessment	Multi-domain assessment by a nurse or elderly care physician.	•	•
	Using motivational interviewing, setting goals, and filling in a goal card.		•
	Oral screening by a dental care worker.	•	•
	Medication evaluation by a pharmacist.	•	•
	Additional: consult from an allied healthcare professional.	•	•
	Using motivational interviewing, setting goals, and adding these to the goal card.		•
Actions	Actions carried out by older adult and/or GP based on recommendations sent to the GP	•	•
	and the goals and corresponding actions are written on the goal card and sent to the GP.		•

GP: general practitioner.

#### Intervention

#### The Sage-atAge service

The basic Sage-atAge service consisted of two steps: (1) proactive screening of community-dwelling older adults for frailty and case complexity; and (2) assessment of needs by CGAs, with recommendations for the older adult and their general practitioner (GP).

#### (1) Screening:

All PCPs from three neighbouring municipalities were invited to participate in the Sage-atAge service by e-mail, newsletter, and telephone. Seven PCPs (18% of those approached) agreed to participate. The most prevalent reason for not participating was enrolment in another proactive screening service for older adults in the region. After obtaining consent from GPs, a postal questionnaire and informed consent form were sent to adults aged ≥65 years in each PCP. GPs excluded patients with terminal illness or severe dementia. Respondents were classified into four care profiles based on their self-reported level of frailty and complexity of care needs, as measured using the Groningen Frailty Indicator (GFI).<sup>32</sup> and INTERMED-E-SA,<sup>33</sup> respectively. The care profiles were

as follows: (1) feeling vital, (2) psychosocial coping difficulties, (3) physical and mobility needs, and (4) difficulties in multiple domains.<sup>34</sup> These profiles were constructed in previous research by factor mixture model analysis and were used to adapt the service to patient needs. Older adults with a substantial frailty level (GFI  $\geq$ 4) and/or a high care profile ( $\geq$ 2) were invited for a CGA.

## (2) Comprehensive geriatric assessments:

The CGA was provided by a nurse or an elderly care physician, with the latter reserved for the most complex and frail older adults (i.e., care profile 4).<sup>35</sup> The focus of these assessments was well-being, including social and functional participation, physical and psychological needs, and the living situation. A pharmacist also performed a risk assessment of drug-related problems based on the triage score system<sup>36</sup> and the Structured History-Taking of Medication Use tool.<sup>37</sup> Finally, a dental care worker took an oral history and assessed the oral cavity according to the Dutch Periodontal Screening Index).<sup>38</sup> If consensus was reached between care professionals and participants, diagnostic consultations could be requested from dietitians, physiotherapists, psychologists, or occupational therapists. The problems identified, together with any recommendations, were communicated to the participant and his or her GP.

#### The Sage-atAge+ service

Based on our interviews with participants, and supported by the experiences reported in other proactive assessment services,<sup>39</sup> we identified that the involvement of older adults in the service needed to increase. Therefore, two components were added to meet this need: (1) goal setting and (2) motivational interviewing. These were developed jointly by researchers and the participating health care professionals.

#### Motivational interviewina

This is a method that can be used to encourage people to make behavioural changes to improve health outcomes.<sup>23</sup> It was developed within psychiatry and has since been applied in diverse settings, including primary care,<sup>40,41</sup> and has proven effectiveness at improving treatment adherence in chronic conditions.<sup>42,43</sup> All involved health care professionals engaged in three 4-hour training sessions to increase their skill in the provision of motivational interviewing.

#### Goal settina

This method is commonly used to increase patient involvement in decision-making and to increase their overall motivation.<sup>25</sup> It has also been proven to be feasible for use with older adults<sup>26,44</sup> in whom there are heterogeneous needs and multiple morbidities.<sup>27</sup> To address goal setting, life and health-related goals were formulated with the direct input of the older adult. Written summaries of the assessment, consisting of one or more "points of concern," corresponding goals,

and recommendations were formulated and written on a "goal card" with the input of the older adult, who was then asked to manage the implementation. The content of the goal card was recorded in the older adult's file and incorporated in the GPs letter.

To improve compliance and sustained adoption, two meetings were held for the participating health professionals during the first months after implementation to reinforce the use of goal cards and motivational interviewing.

## Sample

Older adults assessed in the Sage-atAge service were included in the analyses if they provided written informed consent and if they provided data on their well-being at least once. Those enrolled from January 1st, 2013 to August 31st, 2014, were considered to have received the Sage-atAge service. Those enrolled from September 1st, 2014, to April 30th, 2016 (after the introduction of the goal card and the use of motivational interviewing), were considered to have received the Sage-atAge+ service. Because of the pragmatic nature of the study, we used convenience sampling only.

#### **Measurement instruments**

The participating older adults completed self-administered questionnaires at baseline and at 6–12 months after their assessments. Demographic data were collected about marital status, living situation, and educational level. Inclusion was then based on the frailty and case complexity of participants. Frailty was assessed using the GFI, which comprises 15 items that cover physical, social, cognitive, and psychological domains. The total score ranges from 0 to 15, with a higher score indicating a higher level of frailty.<sup>32</sup> Case complexity was measured with the INTERMED for the Elderly Self-Assessment (IM-E-SA). This assessment tool comprises 20 items divided into biological, psychological, social, and healthcare domains by three perspectives: history, current state, and prognosis. The total score can range from 0 to 60, with a higher score reflecting a higher complexity level.<sup>33</sup>

## Study endpoint

General well-being is a concept that covers a broad spectrum of health and it is influenced by various health outcome domains.<sup>45</sup> Basically these domains were covered within the Sage-atAge assessment. General well-being was assessed at baseline and at 6–12 months after CGA using an adapted version of the TOPICS-CEP score.<sup>45</sup> This score was originally constructed with eight domains to operationalize general well-being and was considered appropriate for evaluating the effect of Sage-atAge. The TOPICS-CEP score produces a composite score, from eight clinical measures. It is a preference-weighted index ranging from 0 (worst possible state) to 10 (best possible state) that combines the data points

from all domains. The preference weights of the TOPICS-CEP were derived from a vignette study among patients and care givers. More detailed information about TOPICS-CEP, including a description of the data points, can be found elsewhere.<sup>45</sup> The TOPICS-CEP score can identify different levels of frailty, and its constructs cover well-being.<sup>46</sup> We omitted a domain for self-perceived health rating from the original TOPICS-CEP (a RAND-36 question on a 5-point Likert scale: How would you rate your current health state?).<sup>47</sup> New regression analyses were performed and regression coefficients were retrieved from the original vignette dataset to adapt the TOPICS-CEP to the new TOPICS-CEP7 used in our questionnaire (see Additional table 1). The following variables were included in the TOPICS-CEP7:

- Dependency was measured using the modified Katz activities of daily living (ADL) index. This comprised 15 items (8 physical and 7 instrumental ADLs).
   The total score ranged from 0 to 1. A higher score indicated a worse functional status.<sup>48</sup>
- Morbidity was measured by adding all diseases present from a list of chronic diseases (i.e., dementia, depression, incontinence, stroke, hip fracture, panic or anxiety disorder, dizziness with falling, vision disorder, asthma, osteoporosis, diabetes, arthritis, heart failure, cancer, complaints due to benign enlarged prostate, fracture other than hip fracture, and hearing disorder).<sup>49</sup>
- Social functioning was assessed by a single item from the RAND-36 questionnaire (Are your social activities hampered by physical health or emotional problems?) on a 5-point Likert scale from never to continuously.<sup>47</sup>
- Psychological well-being was assessed by five questions from the mental health subscale of the RAND-36 questionnaire (During the past 4 weeks did you feel [down, blue, nervous, happy, or calm]?) rated on a 6-point Likert-type scale from always to never. The scores for the negative feelings (i.e., blue, nervous, and down) were reversed. The sum of the five answers was calculated and the score could range from 5 to 30, with higher scores indicating lower psychological well-being.<sup>47</sup>
- Quality of Life was assessed by a rephrased question from the RAND-36 questionnaire (How satisfied are you with your quality of life?), which was rated on a 5-point Likert scale<sup>47</sup> with scoring options ranging from excellent to poor.
- Pain and Cognition were assessed by two items from the five EuroQol dimensions plus the cognition add on questionnaire (EQ-5D+C). Scoring options ranged from no pain to severe pain and from no cognitive problems to severe cognitive problems, both on 5-point Likert scales.<sup>50,51</sup>

## **Analyses**

All data were summarized using descriptive statistics. Categorical variables are described using frequencies and percentages. Continuous variables are described using means, standard deviations (SD), and ranges, except for skewed variables, which are described by medians, interquartile ranges, and ranges. The level of significance was set at 0.05 for all statistical analyses, which were conducted using IBM SPSS Version 23 for Windows (IBM Corp., Armonk, NY, USA).

We tested for differences in frailty and case complexity between the included and excluded participants who provided data by independent t-tests. The difference in the TOPICS-CEP7 was calculated between baseline and follow-up, and linear regression analysis was also applied to test the difference between the Sage-atAge and Sage-atAge+ groups at follow-up. Cases were excluded pairwise. In an adjusted model, propensity scores and TOPICS-CEP7 scores at baseline were included to reduce bias.<sup>52</sup> The propensity score was developed by logistic regression based on demographic and care profile characteristics (e.g., age, gender, educational level, living situation, frailty, and case complexity). We report the unstandardized (B) correlation coefficients with their 95% confidence intervals (95%Cls) for the unadjusted and adjusted regression models. Finally, to evaluate participants who received the Sage-atAge+ service as intended, a secondary subgroup analysis was performed by comparing the Sage-atAge group with the patients in the Sage-atAge+ group who received a goal card.

# RESULTS Participants

In total, 48% of the older adults (n = 1455) completed the frailty and case complexity self-assessment and 21% (n = 641) met the inclusion criteria and attended CGA (Figure 1). Of these, 29% (n = 188) were excluded from analysis due to either a lack of informed consent (n = 154) or missing well-being data at both baseline and follow-up (n = 34). Therefore, data for 453 participants were available for analysis. There were no significant differences in frailty or care complexity between the included older adults and those excluded because of missing data. The median period between assessment and follow-up was 8 months (interquartile range, 6–11).

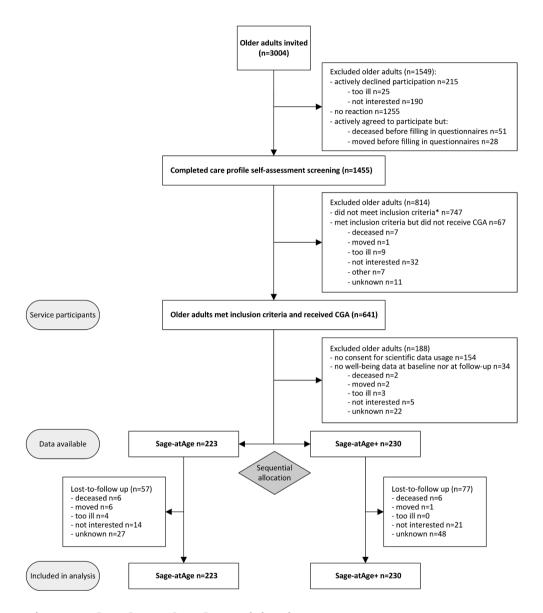


Figure 1. Flowchart of study participation

\* inclusion criteria: Groningen Frailty Indicator ≥4 and/or a care profile ≥2 Sage-atAge+ = the Sage-atAge service with the additional aim of increasing the involvement of the older adult through motivational interviewing and goal setting.

The baseline characteristics of both groups were equivalent, as shown in Table 2. Overall, the mean age was 77 years (SD 7.0), 62% were women, over half were married, one-third had a low educational level, and 96% were of Dutch ethnicity. Participants predominantly met the criteria for care profile 2 (51%). The mean well-being score was 8.1 (SD 0.9) at baseline and ranged from 8.7 (SD 0.56) for care profile 1 to 6.7 (SD 1.1) for care profile 4. Elderly care physicians performed CGAs for 6% of the participants (Sage-atAge, n = 13; Sage-atAge+, n = 15). The assessments by pharmacists and dental care assistants offered to all participants were attended by 93% (Sage-atAge, n = 203; Sage-atAge+, n = 217) and 47% (Sage-atAge, n = 134; Sage-atAge+, n = 67), respectively. Additional consultations with other allied health care professionals were attended by 18% (Sage-atAge, n = 25; Sage-atAge+, n = 57).

Table 2. Baseline characteristics

		Sage-atAge	Sage-atAge+
		n = 223	n = 230
Age (mean (SD), range)		76.5 (7.2), 65–98	77.2 (6.9), 64–94
Gender	Female	145 (65)	135 (59)
	Male	78 (35)	95 (41)
Marital status	Married	102 (51 a)	131 (60)
	Divorced	20 (10)	14 (6)
	Widowed	70 (35)	65 (30)
	Unmarried	10 (5)	9 (4)
Living situation	Alone	99 (49)	97 (44)
-	With others	103 (51)	122 (56)
Educational level b	Low	67 (33)	73 (33 <sup>a</sup> )
	medium	100 (50)	117 (53)
	High	35 (17)	29 (13)
Frailty	Possible range 0-	-15 4.7 (2.2), 0–11	4.5 (2.2), 0–11
(mean (SD), range)			
Case complexity	Possible range 0-	-60 12.7 (5.3), 1–31	12.6 (5.2), 3–35
(mean (SD), range)			
Care profile <sup>c</sup>	1. Feeling vita	28 (13 a)	26 (11 a)
	2. Psychosocia		111 (48)
	coping		
	difficulties	56 (25)	74 (32)
	3. Physical and	ł	
	mobility nee	eds 17 (8)	19 (8)
	4. Difficulties		
	in multiple		
	domains		

table continues

		Sage-atAge	Sage-atAge+
		n = 223	n = 230
Well-being <sup>c, d</sup>	Possible range 0–10	8.1 (1.0), 4.6–9.8	8.1 (0.9), 4.8–9.7
(mean (SD) range)			
Well-being distribution	Care profile 1	8.7 (0.56)	8.7 (0.48)
by care profile	Care profile 2	8.3 (0.78)	8.4 (0.64)
(mean (SD))	Care profile 3	7.7 (1.06)	7.9 (0.84)
	Care profile 4	6.7 (1.1)	6.5 (1.1)
Dependency	Range 0–15	1 (0-3) 0-11	1 (0-2.25) 0-15
(mean (SD) range)	-		
Morbidity	Range 0–17	2 (1-3) 0-8	2 (1-3) 0-8
(mean (SD) range)			
Restrictions in Social	Never or rarely	129 (64)	146 (68)
functioning	Sometimes, mostly or	73 (36)	68 (32)
	continuous		
Quality of Life	Excellent to very	54 (27)	53 (25)
	good	96 (48)	114 (53)
	Good	52 (26 a)	47 (22)
	Reasonable to poor		
Psychological	Possible range 5–30	11.5 (4.3), 5–29	10.8 (3.9), 5–24
(mean (SD), range)			
Cognition	No problems	120 (59)	126 (59)
-	Any to severe	82 (41)	88 (41)
	problems		
Pain	No pain	46 (23)	43 (20)
	Any to severe pain	156 (77)	171 (80)

Values are numbers (percentages) unless stated otherwise.  $^a$  Sum >100% or <100% by rounding.  $^b$  Low = pre-primary school or low vocational training; medium = secondary professional education; high = higher professional education/university.  $^c$  A higher score indicates better performance.  $^d$  missing data (Sage-atAge, n = 21; Sage-atAge+, n = 16).

# Outcomes

# Well-being

There was no difference in the change in well-being score between the revised Sage-atAge+ service and the regular Sage-atAge service in either the unadjusted or the adjusted analysis (Table 3, data for the total population). There were also no substantial differences between the baseline and follow-up data among the subvariables of the TOPICS-CEP7. The within-group mean difference between well-being at baseline and follow-up for the Sage-atAge sample was 0.0 (SD 0.67) and for the Sage-atAge+ sample was 0.1 (SD 0.56).

Table 3. Linear regression models of the difference in general well-being between the two service options at follow-up

	Unadj	usted m	odel		Adjus	Adjusted model 1			
	В	95%CI		р	В	95%CI		р	
Total population									
Sage-atAge vs. Sage-atAge+	0.037	-0.188	0.263	0.75	0.029	-0.118	0.177	0.70	
Participants who rec	eived the	service a	s inten	ded <sup>2</sup>					
Sage-atAge vs. Sage-atAge+	0.193	-0.065	0.452	0.14	0.063	-0.111	0.238	0.48	

General well-being was assessed by the TOPICS-CEP7; o = Sage-atAge; 1 = Sage-atAge+. ¹ Adjusted for propensity score and TOPICS-CEP7 at baseline. ² All Sage-atAge participants and the selection of Sage-atAge+ participants receiving a goal card.

## **Goal card implementation**

In the Sage-atAge+ group, 53% (n = 121) of participants received a goal card. No change in the general well-being score was found even when selecting only these participants for the second group in the unadjusted and adjusted regression analyses (Table 3, data for participants who received a goal card).

#### DISCUSSION

We found no additional benefit to the well-being of community-dwelling older adults when enriching a proactive assessment service with elements to increase their involvement. This remained the case in a subgroup that received the additional service as intended. This adds to the mixed data surrounding the involvement of older adults in earlier studies. Similar to our result, no effect on patient outcomes was found in more extensive proactive services comprising case-management and focusing on promoting autonomy, 29,53 or when using motivational interviewing.<sup>54</sup> However, in other studies, positive effects have been shown on patient health or well-being following the implementation of goal setting<sup>55</sup> and motivational interviewing.<sup>43,56</sup> These mixed results can be explained by at least two factors. First, interventions are more effective when they address homogeneous populations, such as patients with a single chronic condition, because it is easier for care professionals to adapt to a smaller scope of problems and interventions. Second, the studies with positive outcomes used more intensive strategies with more behaviour change techniques, including goal planning, an active follow-up strategy, specific goal requirements, or protocolbased interventions to act upon goals, whereas we only implemented goal setting.57

We used a pragmatic design to examine the impact of the multi-component services. However, this approach has disadvantages compared to RCT designs. An advantage of the RCT design is that differences between two groups are minimized by randomization. Even though we used sequential allocation instead of randomization, there was no difference in any domain measured between samples at baseline. This is reflected in a mean propensity score of 0.51 (SD 0.1) for the Sage-atAge group and 0.53 (SD 0.1) for the Sage-atAge+ group. A propensity score of 0.5 (SD 0.0) would indicate no difference between the groups. Despite this disadvantage, the pragmatic design has two advantages over the RCT design, namely the broader inclusion criteria and the flexibility of intervention application, and these are discussed next.

First, the inclusion criteria for pragmatic trials are typically less selective than the strict criteria used in RCTs, which aim to achieve a homogeneous group to test the efficacy of an intervention protocol. In this study, we only excluded older adults in care profile 1 and those with severe dementia or a terminal illness from the Sage-atAge service to ensure that a large heterogeneous group could benefit from a service, thereby increasing the generalizability of the study outcome. Second, the intervention flexibility permitted by the pragmatic design provided an opportunity to bridge the gap between scientific knowledge about increasing patient involvement and practical applicability in daily practice. This is highly encouraged for CGA practice. Although there is good evidence in support of CGA use, only limited data exists about its implementation in routine practice across different healthcare settings. 18 When assessing CGA programs by RCTs, it has been stated that developers failed to study local settings beforehand, so could not adapt to the requirements of those settings.<sup>39</sup> Bridging this so-called know-do gap requires moving away from restrictive RCT designs. In the SageatAge+ service, we adjusted the assessment approach based on participant experience during service delivery. This collaboration between research and care professionals can help overcome several barriers to implementation. 60 For example, it is expected to lead to better adaptation to the field, greater adoption by care professionals, and a higher likelihood of intervention sustainability. To study whether these expectations are true for the Sage-atAge+ service, we have gathered important process data from daily practice and can now perform a thorough process evaluation focusing on the effect of increased involvement by older adults.

It is worth considering the possibility of imperfect implementation of the two intervention components. Half of the older adults received a goal card to support goal attainment, yet the utility of these cards was not known. Additionally, goal setting can be hampered by unrealistic goals or a lack of familiarity with giving and receiving this method of care. <sup>61</sup> The implementation of motivational interviewing may also be limited by the skills and engagement of care professionals. Indeed,

motivational interviewing is often taught over short training periods (e.g.,  $\leq$ 12 h)<sup>62</sup> and it is questionable whether this is sufficient to provide the skill and spirit needed to execute it effectively.<sup>63</sup> Treatment fidelity should be evaluated by a thorough process analysis exploring these possible limitations. In addition to these debates, implementation of goal setting could be more intensified by adding goal planning and other behavioural change techniques to increase the impact of the service.<sup>57</sup>

Some remarks should also be made about the outcome measure. There were no differences in well-being over time in any group or sub-variable, but as shown in Table 2, the TOPICS-CEP7 could discriminate between differences in frailty and case complexity. It is therefore possible that the 1-year follow-up period was too short to detect changes in well-being and health-related patient reported outcome measures. Due to the one-off nature of the service, we preferred a maximum follow-up period of 1 year to allow well-being to change due to goal progress, but to decrease detection of changes caused by something else than the service, for example changes associated with aging.

To improve the patient-centeredness of care with such a service, it may be better to measure quality of care<sup>64</sup> and the autonomy, as experienced and preferred by patients during care. Finally, the fact that we adapted the original TOPICS-CEP by excluding the self-perceived health component was likely trivial to the outcome given that all other components showed only minor changes.

#### CONCLUSION

Efforts to increase the engagement of older adults in a proactive assessment service by using motivational interviewing and goal setting produced no additional benefits to well-being. This lack of change could be explained by poor implementation in the current setting, but given that we used a pragmatic design that facilitates implementation, we do not anticipate that results will improve in other settings. Therefore, we recommend that future efforts focus on changing the intervention itself. First, to increase program embedding within existing care, future provision should ensure that stakeholders (e.g., older adults and GPs) are involved in service development and understand its goals. In this way, knowledge translation can occur from science to practice while concurrently adapting the research design to local needs.<sup>17,18</sup> Second, interventions that are more intensive should be developed by adding other behaviour change techniques, such as goal planning, to improve the involvement of older adults in their own care. Third, outcome measures should become more patient-centred through the use of either individual goals or goal setting instruments.

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## **Chapter 2** | effects of increasing involvement

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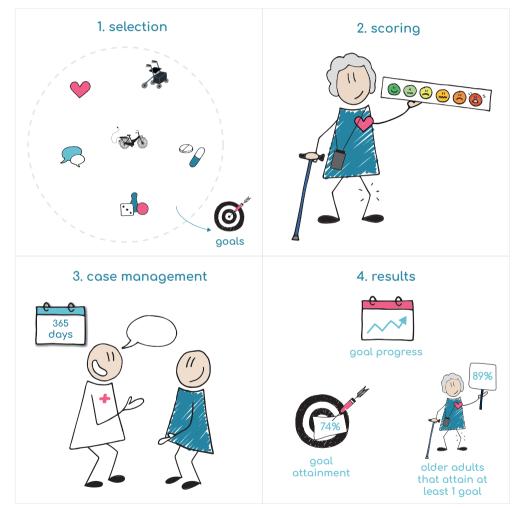
Additional table 1. Overview of regression coefficients of TOPICS-CEP and TOPICS-CEP $_7$ 

Variable	Tool	Adjustment	Regression co	efficients
			TOPICS-CEP	TOPICS-CEP7
(In)dependence	Modified Katz ADL-15	Sum	-0.12	-0.13
Morbidity	National health monitor	Sum	-0.13	-0.14
Social functioning	RAND-36	Reversed	-0.01	-0.03
Quality of Life	RAND-36		-0.02	-0.07
Psychological well- being	RAND-36	Reversed and sum	-0.03	-0.04
Cognition	EQ-5D+C		-0.14	-0.14
Pain	EQ-5D		-0.03	-0.08
Health	RAND-36		-0.17	NA

Note that the TOPICS-CEP is the original tool and that the TOPICS-CEP7 is the same tool with one less variable, as used in this study.

ADL, activities of daily living; CEP, composite endpoint; EQ-5D, five EuroQol dimensions (+C = plus the cognition add on questionnaire).





O DE MERKARCHITECT

# Goal planning in person-centred care supports older adults receiving case management to attain their health-related goals

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#### **ABSTRACT**

## **Purpose**

Care for older adults should preferably be provided in a person-centred way that includes goal planning. The aim of the present cohort study is to gain insight into the results of goal planning, in a person-centred care setting for community-living older adults.

#### Method

Within Embrace, a person-centred and integrated care service, older adults set goals with the aim to improve health-related problems. For every goal, they rated severity scores ranging from 0 (no problem) -10 (extremely severe): a baseline score, a target score and, within one year, an end score to evaluate these goals. The differences between baseline and end scores (goal progress) and target and end scores (goal attainment), and the percentage of goals attained were calculated and compared between health-related domains (i.e. mental health, physical health, mobility and support).

#### Results

Among 233 older adults, 836 goal plans were formulated of which 74% (95% Confidence Interval: 71-77) were attained. Goals related to physical health were the most likely to be attained and goals for mobility and pain the least likely.

#### Conclusions

Older adults are able to attain health-related goals through collaborative goal planning. We recommend future integrated care programmes for older adults to incorporate goal planning methods to achieve person-centred care.

#### INTRODUCTION

Many older adults experience increasing dependence, decreasing social interaction and a growing number of professionals involved in their care and support. Due to these multi-domain consequences, older adults prefer individualized care that supports their unique constellation of problems, which is generally not supported by the current traditional organization of the healthcare system. The aim of person-centred care is to put the person in the centre of the care and to match the person's needs and preferences in a holistic way. Therefore, it uses methods that meet a person's individual needs and that enhances a person's involvement in their own care. As a result, person-centred care aims to improve individual outcomes, support successful aging and reduce costs.

A common method to improve person-centeredness in health care is goal planning. Goal planning promotes a person's health by enhancing self-efficacy8 and can improve the impact of an intervention.9 Goal planning in a care setting consists of two aspects, goal setting and care planning.9 It supports communication between the patient and the care professional with the aim to capture a patient's specific values and circumstances as the basis for developing individualized goal plans.10 In this way patient autonomy11 and patient-centred care is enhanced.10,12 Another important advantage of goal planning is that it enables care professionals, patients and researchers to monitor the effects of care and support, and to quantify the impact of interventions.11 For this, various goal setting instruments are developed.13 With these instruments, people can score the severity of problems, set goals and measure the degree of goal attainment over time. Common examples of these instruments are Goal Attainment Scaling (GAS)14 and the Canadian Occupational Performance Measure (COPM).15

With these approaches the outcomes of patients with very heterogeneous symptoms can be aggregated. However, the statistical analysis and interpretation of GAS endpoints is challenging because the goals of individual patients may be unique and the number of goals across patients may vary. For the COPM, feasibility was considered limited within outpatient settings and for older adult populations. As a consequence, current practice and opinions differ substantially about the most feasible scoring instrument. Therefore we developed a goal planning method using severity scores ranging from 0 to 10, equivalent to the COPM method and to commonly used and feasible pain rating scales.

Next to the scoring instrument debate, little evidence exists about the feasibility<sup>18</sup> and effects of goal setting with frail older adults.<sup>19</sup> Within this population, very heterogeneous needs and goals can exist.<sup>20</sup> Therefore, we decided to use the International Classification of Functioning, Disability and Health (ICF) to identify health-related problems, as this classification covers all domains of human

functioning.<sup>21</sup> Because the complete classification is too broad for application within an assessment, we used the GeriatrICS, an ICF-based assessment tool, reflecting the most relevant health-related problems in community living older adults.<sup>22</sup>

We hypothesised that community living older adults, who participate in a personcentred and integrated health service, are able to address their health-related problems using a goal planning method with severity scores. Therefore, the aim of the present study is to gain insight into the results of goal planning using severity scores among community living older adults participating in Embrace, a personcentred care health service for community-living older adults. We first examined the prevalence of goals set by older adults. We then examined goal progress and goal attainment. Finally, we compared the goal attainment results for older adults with different frailty levels and differences within ICF clusters to provide possible explanations for why goals were attained or not.

#### **METHODS**

## **Design and setting**

We performed a pretest-posttest study with the intervention group of a randomized controlled trial which is part of Embrace.<sup>23</sup> Embrace (in Dutch: *SamenOud*) is a person-centred and integrated care and support service for community-living adults aged 75 years and older. The ultimate goal of Embrace is to prolong the ability of older adults to continue living in their own homes. After assessing the study protocol of the Embrace trial, the Medical Ethical Committee of the University Medical Centre Groningen concluded that ethical approval was not required under the Dutch legislation in medical trials (Reference METc2011.108). The study was conducted in accordance with the Declaration of Helsinki and the Code of Conduct for Health Research (2004). More details of the Embrace study have been published previously.<sup>23</sup>

# Sample

Participants were enrolled in the Embrace study during the first quarter of 2012. Of the 24 general practitioner practices invited, 15 decided to participate. All persons aged 75 years and older from these practices were invited to participate, of whom 1456 consented (48.7% response rate). After giving informed consent, participants provided demographic and health-related data through postal surveys. Participants were classified into three risk profiles to ensure a suitable care level. These were robust, frail or complex care needs, according to the participant's self-reported complexity of care needs (INTERMED for the Elderly Self-Assessment (INTERMED-E-SA)<sup>24</sup>) and level of frailty (Groningen Frailty Indicator, GFI<sup>25,26</sup>). The robust risk profile included older adults without complex care needs (INTERMED-E-SA < 16) and with a relatively low frailty level (GFI < 5).

The frail risk profile comprised older adults with a higher level of frailty who were at risk of developing complex care needs (INTERMED-E-SA < 16 and a GFI  $\geq$  5), while the complex care needs risk profile included older adults with care needs in multiple domains (INTERMED-E-SA  $\geq$  16, regardless of GFI score). These 1456 participating older adults were stratified into the three risk profiles. Subsequently they were randomised to the intervention or control group with balanced allocation on demographic and clinical characteristics. In total 747 older adults were randomized to Embrace intervention groups within the risk profiles: robust (n=438), frail (n=122), and complex care needs (n=187).

Older adults with the robust profile were in good health, but at risk for the consequences of aging and therefore invited to participate in the 'preventive and proactive self-management support program' with community group meetings that supported them to stay healthy as long as possible. They did not receive individual support from a case manager. Consequently, they developed no goal plan(s) and were therefore not eligible for inclusion in this study.

Older adults with the frail risk profile and those with complex care needs were eligible for inclusion in the current study because these older adults received individual support from a case manager and formulated goal plans. Included were older adults with at least one goal plan.

#### **Embrace**

Each general practice participating in Embrace set up a multidisciplinary Elderly Care Team comprising a general practitioner, an elderly care physician and two case managers. Elderly care physicians are doctors trained in, and consulted for, problems in the complex geriatric care pathway. The case managers were a social worker (for older adults with the frail risk profile) or a district nurse (for older adults with the complex care needs risk profile). Case managers were trained to give individual support in collaborative goal setting with shared decision-making, among other skills. Frail older adults were visited once a month and older adults with complex care needs fortnightly by their case manager to develop, monitor, navigate and evaluate their goal plans. One of the aims of the goal plans was to encourage the older adult to carry out activities by themselves or, if necessary, with help from a caregiver or professional. During the monthly meetings of the Elderly Care Team, the goal plans of the older adults were discussed when deemed necessary.

# **Goal-planning procedure**

The goal-planning procedure in the Embrace intervention group consisted of three steps: (1) geriatric assessment, (2) goal-plan development and (3) goal-plan evaluation. In Figure 1, each of these steps is shown and illustrated with an example.

(1) During the first consultation, a comprehensive geriatric assessment was carried out by the case manager to identify health-related problems experienced by the older adult. The Geriatric ICF Core Set (GeriatrICS) was used<sup>22</sup> to guide this assessment. It consists of 29 categories from the International Classification of Functioning, Disability and Health,<sup>21</sup> covering the four ICF-components: Body Functions, Body Structures, Activities and Participation, and Environmental Factors. Consensus on the content of the Core Set was attained during a Delphi study by an expert panel with older adults and medical and non-medical health professionals. The Core Set was validated in clinical practice with participants of the Embrace studies.<sup>22</sup> The items in the GeriatrICS reflect the most relevant health-related problems among community-living older adults without dementia.

The severity of problems identified during the assessment were rated by the older adults using a severity score. Scores could range from 0 to 10, with lower scores indicating a less severe problem. After a feasibility pilot, a ruler was added to support the older adults to determine the severity score of their health-related problem. This ruler was a 20 cm scale with images of faces (from happy to sad), adapted from the faces pain scale which is known to improve understanding of visual analogue scaling scores.<sup>29</sup>

In case of possible cognitive limitations a relevant care giver (most of the time a spouse) participated in the assessments or visits of the case manager with the older adult.

(2) Subsequently, the older adult selected from the assessment all healthrelated problems that he or she aimed to improve. Next, the older adult formulated a goal for each of the selected problems using collaborative goal setting with the case manager, and set a target score. This target score resembled the score the older adult intended to attain by performing the planned activities to address the specific problem. To reach this goal, appropriate and feasible activities that were assumed to lead to the attainment of the goal were discussed and selected by the case manager and the older adult. These activities, together with the health-related problem and the scores were considered the 'goal plan'. Finally, the feasibility of the goal plan was assessed. The older adult was asked by the case manager to provide a feasibility score per goal, with scoring options ranging from totally unlikely (score 0) to certainly feasible (score 10). The case managers were instructed to support the older adult to revise the target score or the selected activities if feasibility was insufficient (rated below 6) - in other words, with a low feasibility score, the goal seemed too difficult to achieve. To improve feasibility, either the target score was lowered or the selected actions were adjusted to improve feasibility. In this way expectations of older adults were made explicit, discussed and adjusted accordingly.

(3) Each goal plan was evaluated with the older adult within a predetermined time-frame or at the very least before the end of the 12-month intervention period. The severity of the health-related problem at that given time is the end score. The older adult rated this end score using the faces scale.

Each goal plan thus ultimately concerned a health-related problem with four scores (three severity scores (baseline score, end score and target score) and a feasibility score) and activities and interventions required to obtain the target score. All goal plans were registered in an electronic client registry system.

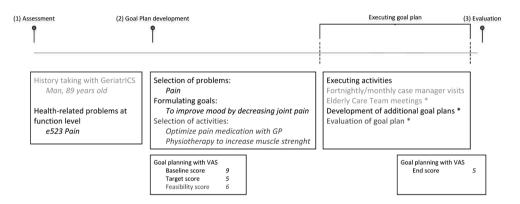


Figure 1 - Overview of the goal-planning process within Embrace, with two goal plan examples

GeriatrICS = Geriatric ICF Core Set.

Baseline score: The severity of a problem identified during the assessment.

Target score: The score the older adult intended to attain by performing the planned activities to address the specific problem.

End score: The severity of the health-related problem after at evaluation.

Baseline score, target score and end score are severity scores and range from 0 to 10 with higher scores indicating more severity.

Feasibility score: The likeliness of a goal to be attained was rated to make older adult expectations explicit, discussed and adjusted accordingly. Score ranges from o (totally unlikely) to 10 (certainly feasible).

Black: older adult in charge; Grey: older adult and the case manager mutually in charge; light grey: initiated by the case manager

In italic: example of care and goal plan

#### Measurement instruments

At baseline, before the assessment with the case manager, older adults provided health-related information with validated self-assessment questionnaires.

Frailty was assessed using the Groningen Frailty Indicator (GFI). It comprises 15 items, divided over four domains: physical, social, cognitive and psychological. The total score can range from 0 to 15, a higher score indicating a higher level of frailty.<sup>26</sup>

Care complexity was measured with the INTERMED for the Elderly Self-Assessment (IM-E-SA). It comprises 20 items, divided over four domains: biological, psychological needs, social needs and healthcare, approached from three different time perspectives: history, current state and prognosis. The total score can range from 0 to 60, a higher score reflecting a higher level of complexity.<sup>24</sup>

Activities of daily living (ADL) were measured by the modified Katz ADL index. It comprises 15 items and measures 8 physical and 7 instrumental ADL. The total score can range from 0 to 15, a higher score indicating worse functional status.<sup>30</sup> Health status was measured by the EQ-5D-3L.<sup>31</sup> It comprises 5 items, divided over 5 dimensions of health: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Scoring options ranged from 'no problems' to 'severe problems' on a 3-point scale. Every score was aggregated to one score with the Dutch value set created by time-trade off principle.<sup>32</sup> Possible scores in this value set can range between -0.33 and 1, with 1 indicating the best health status.

# **Analysis**

Health-related problems were classified into the most suitable ICF category by the case managers using the ICF categories in the GeriatrICS or by using the ICF browser (http://apps.who.int/classifications/icfbrowser/). Two researchers (WR, RB) independently checked the classification of the health-related problems into the ICF categories using the descriptions of the perceived problems given by the case managers and following the ICF linking rules.<sup>33</sup> In case of disagreement between the researchers, a third researcher (KW) was consulted. When a health-related problem could not be classified by the case manager, two researchers (WR, KW) independently classified the problem into the most suitable ICF category following the ICF linking rules.<sup>33</sup> If there was no immediate agreement between both researchers, consensus was reached by discussion. Subsequently, to gain insight into the domains of health-related problems, the ICF categories were grouped into one of the six corresponding clusters: Mental Health, Physical Health, Mobility, Personal Care, Nutrition or Support <sup>34</sup>.

A goal plan was included in the analysis when it was complete, meaning that there were a description of the health-related problem, a baseline score, a target score as well as an end score available. By calculating the difference between the target score and the end score, we determined the extent to which the goal was attained. Goal plans with end scores equal to or lower than target scores (differences? zero) indicated goal attainment. The proportion (with 95% confidence intervals (CI)) of

goals attained for the total sample, for each risk profile and for each ICF cluster were calculated. Goal progress was calculated by subtracting the baseline score from the end score. Differences ? zero indicated goal progress.

The baseline characteristics of the older adults were described for each risk profile and difference were tested between risk profiles. Baseline differences were also assessed between the included older adults (i.e. older adults with at least one evaluated goal plan) compared to all older adults with at least one formulated goal plan. Nominal baseline characteristics were assessed with Chisquare test using continuity correction. Differences in linear and ordinal baseline characteristics, target scores and proportions of goals attained between the risk profiles were assessed with Mann-Whitney U test. Non-parametric statistical tests were used in light of the discrete level of data obtained with the severity scores. The significance level was set at 0.05. Statistical analyses were conducted using SPSS 23 (Released 2015. IBM SPSS Statistics for Windows. Armonk, NY: IBMCorp.)

#### **RESULTS**

## Data available for analysis

Of the 747 older adults in the intervention group, 309 older adults were frail or had complex care needs, and were therefore eligible for inclusion (Figure 2). In total, 288 of these older adults had at least one goal plan. Of these 288 older adults, n=55 did not evaluate any of their goal plans. Of the total 920 goal plans, 84 goal plans were not evaluated within the evaluation period of 12 months. Goal plans were mostly not evaluated due to loss to follow-up of the older adult, for example due to admission to a nursing home or conversion to the robust profile (in which they received no case management nor follow-up assessments anymore). In addition, goals were sometimes not evaluated because the older adult was not able to rate the severity scores (n=2 and 8 goal plans), not able to assign a goal (n=4 and 12 goal plans) or had too severe cognitive impairments (2 goal plans). Therefore, 233 older adults were included in the study and 836 goal plans were included in the analysis.

# **Baseline characteristics of participants**

The baseline characteristics of the 233 participants are shown in table 1. The mean age of participants was 81.5 years, one third were male and half were married. The most common educational level was (uncompleted) primary school or low-level vocational training. Older adults with the complex care needs risk profile had - as a result of the stratification - more chronic conditions, used more medications, had more (I)ADL constraints and a lower health-related quality of life compared to older adults with the frail risk profile. All these differences between the strata were statistically significant (p 0.001).

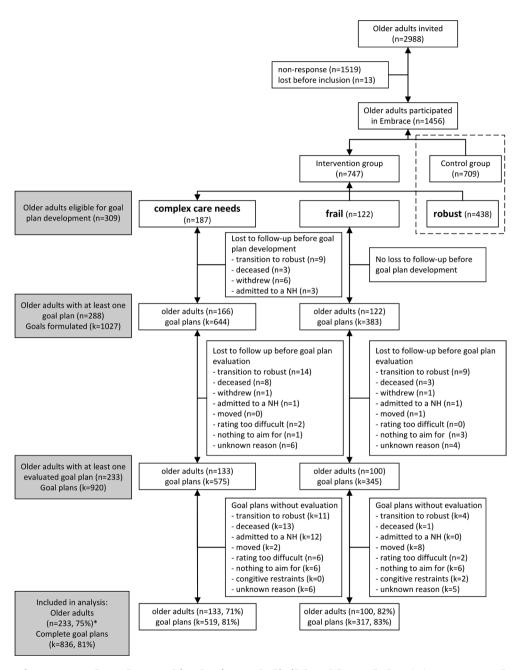


Figure 2 - Flowchart of inclusion of eligible older adults (n), separated for the complex care needs and frail risk profiles, and their goal plans (k) \* proportion of older adults (and goal plans) included in analysis of the sample eligible for goal

plan development. NH = nursing home; n: number of older adults; k: number of goal plans; Within grey box: older adults from control group and robust care profile: they did not receive individual support from a case manager and therefore formulated no goals plan

Table 1: Baseline characteristics for the total older adult sample and for each risk profile

	Total	Complex care needs	Frail
	n=233	n=133	n= 100
Age, mean (SD)	81.5 (4.7)	81.5 (4.6)	81.5 (4.8)
Male gender	75 (32)	41 (31)	34 (34)
Married	115 (49)	70 (53)	45 (45)
Living situation			
Community-living with others	119 (51)	71 (53)	48 (48)
Community-living single	109 (47)	58 (44)	51 (51)
Residential care	4 (2)	4 (3)	1 (1)
Educational level			
(less than) primary school or low vocational training	127 (54)	72 (54)	55 (55)
Secondary professional education	85 (37)	52 (39)	33 (33)
Higher professional education / university	20 (9)	8 (7)	12 (12)
Using more than 3 medications	182 (78)	111 (84)	71 (71)
Number of chronic conditions, median (IQR)	3 (2-4)	4 (2-5)	3 (1-4)
Frailty <sup>a</sup> , median (IQR)	6 (5-8)	7 (5-8)	6 (5-7)
Care complexity <sup>b</sup> , median (IQR)	16 (12-20)	19 (17-22)	12 (10-14)
(I)ADL constraints <sup>c</sup> , median (IQR)	3 (1-5)	4 (2-6)	1 (0-3)
Health Status <sup>d</sup> , mean (SD)	0.68 (0.17)		0.76 (0.12)

Data are expressed as numbers (percentage) unless stated otherwise

IQR = Inter Quartile Range, ADL = Activities of Daily Living,

# Prevalence and classification of goal plans

The median number of goal plans for each older adult was 3 (IQR 2-5). There was no significant difference in the median number of goal plans between older adults with the complex care needs profile (median 3 IQR 2-5) and older adults with the

<sup>&</sup>lt;sup>a</sup> GFI = Groningen Frailty Indicator (range 0-15), a higher score indicates more frail

 $<sup>^{\</sup>rm b}$  INTERMED SA – E = INTERMED for the Elderly Self-Assessment (range 0-60), a higher score indicates more case complexity

<sup>&</sup>lt;sup>c</sup> Modified KATZ ADL/IADL (range 0-15), a higher score indicates more (I)ADL constraints

d EQ-5D (range 0-1), a higher score indicates a better health-related quality of life

frail profile (median 3 IQR 1-4, p-value 0.06).

Three quarters of all goal plans could be classified using the ICF categories from the GeriatrICS and were grouped into one of the six predefined clusters. Three highly prevalent health related problems were not captured in the GeriatrICS and therefore not part of any predefined cluster. These health-related problems could be classified using the ICF and were clustered into the ICF categories Pain (25% of all older adults), Looking after One's Health (7%), and Recreation and Leisure (7%). Most older adults formulated goal plans within the Physical Health (64% of all older adults), Mobility (50%) or Support (49%) clusters, while problems in the Personal Care cluster had the lowest prevalence (3%). Figure 3 shows the prevalence of goal plans of each cluster or (new) ICF category among the total sample and for each risk profile. The prevalence of each ICF category within the clusters is shown in Additional table 1.

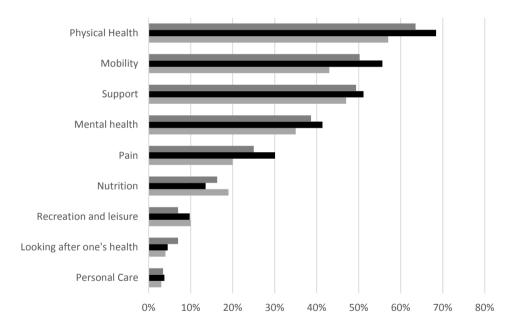


Figure 3 - Prevalence of goal plans (n = 836) among older adults (n = 233) and for each risk profile, categorized into six predefined clusters and three other highly prevalent ICF-categories

Dark grey: total sample; Black: complex care needs; Light grey: frail

# Results of goal planning for the total sample

Table 2 presents the goal-planning results for the total sample and for each risk profile. The mean baseline score for the health-related problems in the total sample was 6.0 (SD 2.0), while the mean target score was 3.3 (SD 2.0). In total, 619 of the 836 goals (74%, CI 71-77) were attained. Of all the older adults, 89% (CI 84-92) were able to attain at least one goal. The end scores were, on average, 0.2 points higher than the target score (SD 1.9). The mean goal progress (difference between end score and baseline score) was 2.5 (SD 2.3).

The median length of a goal time-frame was 283 days. 77% of goal plans were closed during the intervention year (in contrast to at the end of the intervention year). There was no difference in proportion of goal attainment between the goals closed during the intervention year compared to the goals closed at the end of the intervention year.

# Differences between the risk profiles and between goal clusters

The mean baseline scores at the start of the intervention were similar for both risk profiles (see table 2). However, older adults with the complex care needs profile had lower target scores, meaning that a larger improvement was intended, compared to the frail older adults (p <0.001). Nevertheless, the same proportions of goals attained (74%) were found in both risk profiles.

When comparing the results for the ICF clusters and ICF categories, the most severe health-related problem was Pain (mean baseline score 6.7, SD 1.7), followed by Mobility, Mental Health and Personal Care. Lowest severity at the start was rated for Recreation and Leisure (4.8 SD 2.2). The highest proportions of goals were attained within the clusters of Personal Care and Physical Health (resp. 88% CI 53-98 and 78% CI 72-83), while the lowest proportions of goals were attained within the Mobility cluster and the Pain category (resp. 69%, CI 62-76 and 68%, CI 56-78). Supplementary table S1 shows a description of the results of the goal-planning process for each ICF-category within the GeriatrICS.

**Table 2: Goal-planning results** 

Tuble 21 Gour	Pidiiii	ing resum						
	Goal plans,	Baseline score,	Target score,	End score,	Δ End - baseline score	Δ End - target score	Goal attainment	
	n =	mean (SD)	mean (SD)	mean (SD)	mean (SD)*	mean (SD)*	% (CI)	
Overall sample	836	6.0 (2.0)	3.3 (2.0)	3.5 (2.4)	-2.5 (2.3)	0.2 (1.9)	74 (71-77)	
Risk profile:								
Complex care needs	519	6.0 (1.9)	3.1 (2.0)	3.4 (2.3)	-2.5 (2.6)	0.3 (1.7)	74 (70-78)	
Frail	317	6.1 (2.2)	3.7 (2.1)	3.6 (2.4)	-2.6 (2.1)	-0.1(2.1)	74 (69-79)	
p Value for		0.25	< 0.001	0.19	0.37	0.016	0.96	
difference between risk profiles								
<b>GeriatrICS clust</b>	ers							
Mental health	110	6.1 (1.9)	4.0 (1.9)	4.1 (2.3)	-2.1 (2.3)	0.1 (1.9)	75 (66-82)	
Physical Health	233	5.9 (1.9)	3.2 (2.0)	3.1 (2.3)	-2.8 (2.2)	-0.1 1.8)	78 (72-83)	
Mobility	176	6.1 (1.9)	3.7 (1.9)	3.9 (2.4)	-2.3 (2.2)	0.2 (2.0)	69 (62-76)	
Personal Care	8	6.1 (1.6)	2.5 (1.8)	2.4 (1.7)	-3.8 (2.8)	-0.1(1.1)	88 (53-98)	
Nutrition	42	5.3 (2.1)	2.9 (1.8)	3.1 (2.1)	-2.2 (2.1)	0.1 (2.2)	74 (59-85)	
Support	165	5.9 (2.3)	2.7 (2.2)	3.0 (2.4)	-2.9 (2.5)	0.4 (1.9)	75 (67-81)	
Other ICF- categ	jories							
Pain	68	6.7 (1.7)	3.9 (1.9)	4.3 (2.2)	-2.3 (2.0)	0.4 (2.0)	68 (56-78)	
Looking after one's health	17	6.0 (2.6)	2.4 (2.2)	2.9 (2.5)	-3.1 (2.8)	0.6 (1.3)	76 (53-90)	
Recreation and leisure	17	4.8 (2.2)	2.2 (2.0)	2.2 (2.0)	-2.5 (2.4)	0.0 (0.9)	76 (53-90)	

Scores are rated by the older adult and can range from 0 to 10 with higher scores indicating more severity

 $<sup>\</sup>Delta$  End - baseline score (goal progress): a difference below zero represents goal progress;

 $<sup>\</sup>Delta$  End - target score: a difference below zero represents a goal more improved than aimed for. Goal attainment: the prevalence of goals with a  $\Delta$  End - target score  $\leq$ 0

<sup>\*</sup> difference between the result for the ' $\Delta$ -columns' and extracting the respective scores is due to rounding off the results to the first decimal;

#### DISCUSSION

The aim of this study was to gain insight into the results of goal planning using severity scores in a person-centred care setting for community-living older adults. We found that older adults who were frail or had complex care needs and participated in a person-centred and integrated health service were able to attain almost three quarters of these goals, while the mean differences between target scores and end scores were trivial. Goal progress was at mean 2.5 points, which is commonly seen as an clinical important change on a 0-10 scale.<sup>35</sup>

Most older adults formulated goal plans within the Physical Health, Mobility or Support clusters, and the least within the Self-care cluster. The high prevalence of goal in the first three clusters is not uncommon in the literature. For example, older adults who formulated life-goals mainly preferred maintenance of health, increased physical activity and increased socialization.<sup>36</sup> Health is thus an important goal, even when seen in a broader life-goal perspective. Indeed, in the study of Waldersen et al.<sup>37</sup> among community-living older adults receiving occupational therapy at home, goals were mainly focused on mobility and the least on self-care. Similar to our results, in this study it was found that 72% of goals were attained.

Goals in the Physical cluster were the most likely to be attained and goals in the Pain and Mobility clusters seemed the most difficult to attain. Again, Waldersen et al. also found that goals related to mobility (walking) and pain (within body functions) had the lowest attainability.<sup>37</sup> There is little evidence explaining the difference in goal attainability across clusters. The relatively good attainability of goals in the Physical cluster is possibly due to the central role of the general practitioner in the Elderly Care Teams in this study. As they feel most able to solve problems in the physical domain compared to other domains.<sup>38</sup> Another explanation might be the persistent or stubborn character of pain.<sup>39–41</sup> and psychological complaints<sup>42</sup> in contrast to physical complaints.

An important finding was that pain, although it was a prevalent (29%) and the most severe health-related problem, was not included in the GeriatrICS. It is known that pain is an important health-related problem among older adults<sup>40,43,44</sup> and it is more often overlooked within geriatric assessments.<sup>45</sup> In a thorough meta-analysis of qualitative literature, the 'adaptation of older adults to the inevitable' and 'the reluctance to pain medication' seems a barrier to report pain. This may be an explanation for why it was not included in the GeriatrICS after a Delphi procedure with expert panels of older adults and care professionals.

## **Methodological considerations**

Important strengths of this study are the large sample of participating older adults and the large number of goal plans included in the analysis. By using the GeriatrICS, that is based in ICF classification, we covered the broad scope of functioning and disabilities experienced by the individual participants.<sup>21</sup> By classification of the health-related problems in ICF clusters we created a beginning of a categorisation of health-related goals for older adults.<sup>46</sup>

Our goal setting method using severity scores considers many aspects of goal attainment, as proposed by Krasny-Pacini et al.<sup>47</sup> The most important aspect we covered was the central role of the client in prioritising, judging the relevance and evaluating goals. This is very important when the aim is to develop person-centred care. Other proposed aspects we applied were training the case managers in goal setting, classification of health-related problems using ICF categories, providing a goal example in this paper and accounting for feasibility.<sup>47</sup>

However, there were aspects which are considered important for the quality of goals and goal setting we were not able to investigate. For example, time-specificity and measurability were not studied. Uni-dimensionality, meaning that a goal is solely about aiming to improve one aspect of a problem, is considered very important for fair evaluation of goals. This was, however, difficult to achieve. Despite the fact that case managers were trained to avoid formulating multi-dimensional goals, not each goal plan was uni-dimensionally formulated.

Lastly, examiner bias could have been introduced, for the older adult rated the severity scores twice themselves. However we tried to minimize this by asking the older adult to rate the end score using the ruler without reminding them at their baseline score. Keeping the person-centred aim in mind, this was the best way to capture true person reported and relevant outcomes.<sup>48,49</sup>

Commonly used goal setting instruments all have their feasibility issues.<sup>13</sup> By introducing severity scoring from 0 to 10, we aimed for a clinometric measurement instrument which focusses on older adults' preferences to capture relevant outcomes.<sup>50</sup> The methodology is known for its easy adoption, also for people with cognitive impairments.<sup>13,17</sup> Nevertheless, case managers of Embrace indicated that older adults had difficulty judging the severity of their problems.<sup>51</sup> We are not aware of studies comparing different goal setting instruments for older adults. It is therefore interesting to study the difference in feasibility of our scoring method with other instruments.

We were not able to compare our results on the extent in which older adults in the intervention group attained their individual goals compared to the control group from the RCT of Embrace that received care as usual without assessments and

goal planning. This might be seen as a potential limitation, as we were not able to account for the possibility of response shift, which is caused by the adaptive strategy that allows someone to feel good about their actual health status despite chronic illnesses.<sup>52–54</sup> However, studies concerning goal setting commonly lack control groups<sup>55</sup> or experience methodological problems.<sup>56</sup> Because goal setting is suggested to be effective in itself<sup>57</sup> it is difficult to create control groups with goal plans. Current literature lacks high quality evidence on the effects of goal setting for older adults on quality of life.

Another potential limitation is the exclusion of older adults with non-evaluated goal plans, which might mean that goal attainability was overestimated. However, the risk of selection bias seems minimized, as the older adults who were excluded after the goal setting procedure, did not differ from those who were included (concerning the variables in table 1). Furthermore, the relatively low number of excluded goal plans was too small to have impact on the study results.

## **Future research and clinical implications**

Future research should examine the effect of goal planning in person-centred care on quality of life, healthcare consumption and costs. In this way, the added value of goal planning to person-centred care can be substantiated. Next to demonstrating this pragmatic value of goal setting, further work is required to explain the theoretical goal setting mechanism.<sup>58,59</sup>

An important implication for clinical practice and future research results from the heterogeneity of the goal plans. This not only indicates that the range of problems experienced by older adults is broad, but also reinforces the importance of a broadly skilled case manager. To increase the rate of goal attainment it is advised to get insight into the deployed interventions and raise the evidence–base of these interventions.

#### CONCLUSION

Older adults are able to formulate and attain health-related goals in a person-centred care setting by collaborative goal planning with their case manager. We therefore recommend that future person-centred and integrated care programmes for older adults incorporate goal-planning methods with severity scores to support person-centred care.

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Additional Table 1 - Results of goal-planning. Baseline score, target score, end score and the proportion of fully attained goals for the total sample per GeriatrICS cluster and subcategory

Prevalence <sup>b</sup>		Baseline score,	Target score,	End score,	Δ End - target score,	Goal attainment
	%	mean (SD)	mean (SD)	mean (SD)	mean (SD)	с % (СІ)
GeriatrICS clusters						
Mental health			-			
b110-b139 Global mental functions *	6	6.8 (1.7)	3.8 (1.2)	4.4 (2.5)	0.6 (2.1)	43 (21-67)
b144 Memory functions	12	5.4 (1.9)	4.1 (2.2)	4.6 (2.2)	0.5 (1.6)	79 (60-90)
b140-b189 Specific mental functions *	3	5.1 (2.7)	3.0 (2.2)	3.9 (2.5)	0.9 (1.8)	43 (16-75)
b152 Emotional functions	24	6.4 (1.8)	4.0 (1.9)	3.7 (2.3)	-0.3 (1.9)	84 (72-91)
Physical Health						
b210 Seeing functions	14	6.2 (1.6)	3.6 (2.1)	3.6 (2.4)	-0.03 (1.8)	66 (48-80)
b210-b229 Seeing and related functions *a	2	6.0 (1.7)	3.5 (1.1)	3.3 (1.8)	-0.2 (1.2)	83 (44-97)
b230 Hearing functions	13	5.8 (1.9)	3.5 (1.9)	3.3 (2.4)	-0.2 (2.2)	70 (52-83)
b250-b279 Additional sensory functions *	1	4.7 (2.1)	3.3 (2.3)	3.3 (2.3)	0 (0)	100 (44- 100)
b310 Voice Functions *	<1	8	5	7	2	0 (0-79)
b410 Heart functions	8	6.2 (2.1)	3.6 (2.1)	3.7 (2.9)	0.2 (2.5)	61 (55-91)
b420 Blood pressure functions	10	4.7 (2.3)	2.3 (2.2)	2.4 (2.6)	-0.1 (1.8)	84 (65-94)
b430-b439 Functions of the haematological and immunological systems *	2	6.3 (1.3)	4.8 (1.0)	5.8 (2.5)	1.0 (2.7)	75 (30-95)
b510-b539 Functions related to the digestive system *	2	6.0 (2.2)	2.2 (2.1)	1.8 (2.5)	-0.4 (1.7)	80 (38-96)
b525 Defecation functions	14	6.1 (1.9)	3.6 (1.8)	3.3 (1.9)	-0.3 (1.2)	91 (76-97)
b620 Urination functions	15	5.8 (1.9)	3.3 (1.8)	2.8 (1.9)	-0.5 (1.7)	89 (74-95)
b810 Protective functions of the skin	6	5 (1.4)	2.5 (1.9)	2.1 (1.7)	-0.5 (1.1)	92 (67-99)
b810-849 Functions of the skin *a	12	6.8 (1.4)	2.8 (1.9)	3.1 (1.9)	0.3 (1.9)	71 (53-85)

table continues

Prevalence <sup>b</sup>		Baseline score,	Target score,	End score,	Δ End - target score,	Goal attainment
	%	mean (SD)	mean (SD)	mean (SD)	mean (SD)	с % (СІ)
Mobility						
b240 Sensations associated with hearing and vestibular functions	25	5.8 (2.0)	3.6 (1.9)	3.7 (2.0)	0.1 (1.6)	73 (61-83)
b455 Exercise tolerance functions	12	6.8 (1.6)	4.0 (1.8)	4.3 (2.7)	0.4 (2.6)	77 (59-88)
b450-b469 Additional functions and sensations of the cardiovascular and respiratory systems *a	2	5.2 (2.7)	2.6 (2.1)	2.8 (2.7)	0.2 (1.5)	60 (23-88)
b710 Mobility of joint functions	9	6.2 (1.3)	4.1 (2.2)	4.1 (2.6)	0.1 (1.0)	81 (60-92)
b730 Muscle power functions	3	6.6 (2.2)	3.7 (2.9)	4.7 (2.1)	1.0 (1.9)	43 (16-75)
b750-b789 Movement functions *	<1	4	2	2	0	100 (21- 100)
d410 Changing basic body position	6	6.1 (1.5)	3.6 (1.7)	4.1 (2.9)	0.5 (2.6)	67 (42-85)
d450 Walking	12	6.4 (2.0)	4.1 (1.5)	4.2 (2.2)	-0.1 (2.1)	67 (48-81)
d465 Moving around using equipment *	3	5.5 (1.4)	2.3 (1.6)	2.8 (2.7)	0.3 (1.4)	67 (30-90)
d470 Using transportation	1	6 (2.6)	5 (4.0)	1.7 (2.9)	-3.3 (4.9)	100 (44- 100)
d470-d489 Moving around using transportation *a	<1	2	0	2	2	0 (0-79)
Personal Care						
d510 Washing oneself	1	7.3 (1.2)	1.3 (1.2)	1.0 (1.0)	-0.3 (0.6)	100 (44- 100)
d520 Caring for body parts	<1	5	5	5	0	100 (21- 100)
d530 Toileting *	1	6.0 (1.7)	3.0 (2.6)	2.3 (1.2)	-0.7 (1.2)	100 (44- 100)
d540 Dressing	<1	4	2	4	2	0 (0-79)
Nutrition						
b530 Weight maintenance functions	11	5.4 (2.0)	3.2 (1.9)	3.4 (2.3)	0.2 (2.7)	70 (52-84)
						table sentinue

table continues

**Chapter 3** | Goal planning in person-centred care supports older adults

Prevalence <sup>b</sup>		Baseline score,	Target score,	End score,	Δ End - target score,	Goal attainment
	%	mean (SD)	mean (SD)	mean (SD)	mean (SD)	с % (СІ)
d550 Eating	1	4 (1.4)	1 (0)	1 (0)	0 (0)	100 (34- 100)
d560 Drinking	6	5.2 (2.3)	2.6 (1.5)	2.6 (1.7)	0.0 (0.9)	85 (58-96)
Support						
d610-d629 Acquisition of necessities *	<1	8	4	0	-4	100 (21- 100)
d760 Family relationships	5	7.6 (2.1)	4.6 (2.6)	5.0 (2.9)	0.4 (1.9)	69 (42-87)
e115-119 Products and technology for personal use in daily living *	2	8.0 (1.7)	3.0 (2.5)	1.8 (2.0)	-1.2 (1.8)	100 (57- 100)
e120 Products and technology for personal indoor and outdoor mobility and transportation *	5	5.7 (2.4)	2.7 (1.9)	2.5 (1.5)	-0.3 (0.8)	91 (62-98)
e310 Support and relationships: Immediate family	11	5.7 (2.1)	3.0 (2.2)	3.4 (2.5)	0.4 (2.2)	70 (52-84)
e125 Products and technology for communication *	6	4.7 (2.8)	0.9 (1.5)	1.3 (1.8)	0.3 (1.5)	73 (48-89)
e320 Support and relationships: Friends	4	5.9 (2.2)	3.8 (2.0)	3.8 (2.2)	0.0 (1.0)	78 (45-94)
e325 Acquaintances, peers, colleagues, neighbours and community members	6	5.4 (2.1)	3.9 (2.5)	4.3 (2.2)	0.4 (0.9)	71 (45-88)
e340 Support and relationships: Personal care providers and personal assistants *	1	7.3 (1.2)	3.3 (2.9)	3.0 (2.6)	-0.3 (0.6)	100 (44- 100)
e525 Housing services, systems and policies *	2	6.6 (1.5)	1.8 (2.1)	3.8 (2.7)	2.0 (2.8)	60 (23-88)
e540 Transportation services, systems and policies *	1	5.7 (1.5)	1.3 (0.6)	1.3 (0.6)	0.0 (1.0)	67 (21-94)

table continues

Prevalence <sup>b</sup>		Baseline score,	Target score,	End score,	∆ End - target score,	Goal attainment
	%	mean (SD)	mean (SD)	mean (SD)	mean (SD)	с % (СІ)
e570 Social security services, systems and policies	7	6.3 (1.9)	2.6 (1.7)	3.7 (2.6)	1.1 (2.6)	63 (39-82)
e575 General social support services, systems and policies	11	5.6 (2.5)	1.8 (1.7)	2.1 (1.8)	0.3 (1.4)	77 (60-89)
e580 Health services, systems and policies	5	5.9 (2.0)	2.3 (1.8)	3.3 (2.5)	1.1 (2.4)	75 (47-91)
Other highly prevalent ICF-categories						
b280-b289 Pain *	25	6.7 (1.7)	3.9 (1.9)	4.3 (2.2)	0.4 (2.0)	68 (56-78)
d570 Looking after one's health *	7	6.0 (2.6)	2.4 (2.2)	2.9 (2.5)	0.6 (1.3)	76 (53-90)
d920 Recreation and leisure *	7	4.8 (2.2)	2.2 (2.0)	2.2 (2.0)	0.0 (0.9)	76 (53-90)

Dark grey filling, white text - Categories with proportion of attained goal plans above mean of the total sample (74%)

Light grey filling, black text - Categories with proportion of attained goal plans below mean of the total sample (74%)

SD = Standard Deviation; CI = 95% Confidence Interval. Scores could range from 0 (no problem) – 10 (most severe problem).

<sup>\*</sup> not part of the GeriatrICS anamnesis set;

<sup>&</sup>lt;sup>a</sup> covers the whole category except for the sub category already included within the GeriatrICS.

<sup>&</sup>lt;sup>b</sup> Prevalence among all older adults (n = 233). Older adults may have more than one goal within each category;

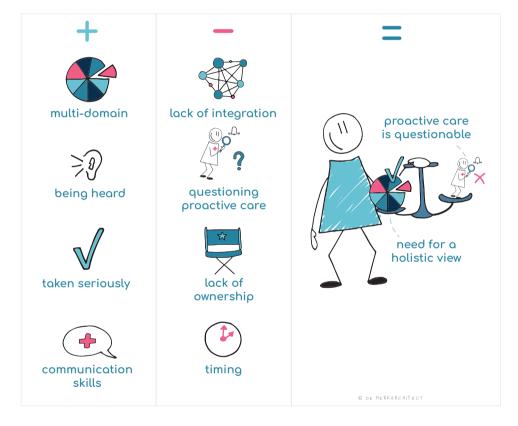
<sup>&</sup>lt;sup>c</sup> A goal is considered attained when the end score minus the target score was? zero



# **Part II:**

Mechanisms and context of a proactive care service





Explaining experiences of community-dwelling older adults with a pro-active comprehensive geriatric assessment program - a thorough evaluation by interviews

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#### **ABSTRACT**

#### Introduction

Proactive assessment programs are increasingly used to improve care for older adults. These programs include comprehensive geriatric tailored to individual patient preferences. Evidence for the effects of these programs on patient outcomes is nevertheless scarce or ambiguous. Explaining these dissatisfying results is difficult due to the multi-component nature of the programs. The objective of the current study was to explore and explain the experience of older adults participating in a proactive assessment program, to help to clarify the effects.

#### Methods

Semi-structured in-depth interviews were held with 25 participants of a proactive assessment program for frail community-dwelling adults aged 65+. This study was part of an evaluation study on the effects of the program. Transcripts were analysed with thematic analysis and cross-case analysis.

#### Results

The participants' mean age was 78.5 (SD 6.9) and 56% was female. The majority of the participants were satisfied with the program but based this on communication aspects, since only a few of them expressed real program benefits. Participant experiences could be clustered in six themes: (1) All participants expressed the need for a holistic view which was covered in the program, (2) the scope of the CGA was broader than expected or unclear, (3) the program delivered unexpected but valued help, (4) participants described a very low sense of ownership, (5) timing of the program implementation or the CGA was difficult and(6), participants and care workers had a different view on what to consider as a problem. These experiences could be explained by three program components: the degree of (the lack of) integration of the program within usual care, the proactive screening method and the broader than expected, but appreciated multi-domain approach.

#### Conclusion

Older adults' need for a holistic view is covered by this outpatient assessment program. However, their engagement and the correct timing of the program are hampered by the proactive recruitment and the limited integration of the program within existing care. Furthermore, satisfaction seems an insufficient guiding factor when evaluating CGA programs for older adults because it does not reflect the impact of the program.

#### INTRODUCTION

Traditional ways of organizing health services are often unable to meet the heterogeneous needs of older adults with multi-morbidities. Affordable solutions for organizing care are required to better meet the needs of older adults. One way of adapting care to the needs of older adults is to organize person-centred and integrated care. Affordable solutions

One common element of integrated care is the Comprehensive Geriatric Assessment (CGA).<sup>4</sup> A CGA is defined as "a multidimensional process to determine an elderly person's medical, psychosocial, functional, and environmental resources and problems, linked with an overall plan of treatment and follow-up, to improve overall patient functioning and independence".<sup>5</sup> The execution of programs offering CGA differs across settings, including community settings.<sup>6</sup> In a community setting, these programs proactively select a proportion of the homedwelling older adult population. This is often based on frailty or multi-morbidity. These individuals are then offered a multi-domain CGA with the aim of longer independence and reduction in hospitalization and institutionalization.

These outpatient assessment programs have been extensively researched, however studies have shown inconsistent effects on clinical outcomes<sup>3</sup> and scarcely any effects on functional dependency.<sup>7</sup> This inconsistency in findings can be explained through the heterogeneity of these multi-component programs.<sup>8</sup> Different programs may encompass various combinations of potentially effective and ineffective components, with the latter masking benefits to different extents. Programs can differ in many aspects: overall program aim, domains focused on in the CGA, disciplines carrying out the CGA, as well as the level of influence over the recommendations given after the CGA and follow-up period. Studying the separate components of these programs, their implementation and how they fit together has been suggested<sup>9</sup> to optimally design programs that lead to improved patient outcomes<sup>3,10</sup>).

One important perspective influencing the implementation and effects of programs is the consumer perspective<sup>11</sup> – in this case, the older adult. This perspective is often overlooked and is proven to be different from the most often used provider or organizational perspective.<sup>12</sup> Insight into the experience of older adults who have received a proactive CGA program can help understand the relevance of program components and their coherence. Therefore, the aim of this study is to explore and explain experiences of older adults who participated in a proactive outpatient CGA program.

#### **METHODS**

As part of an evaluation study into the effects of the outpatient proactive assessment program Sage-atAge, we conducted qualitative, semi-structured interviews into the experiences of older adults participating in an outpatient proactive assessment program. We complied with the COREQ checklist in conducting and reporting this study.<sup>13</sup> For detailed information about the methodology and how COREQ requirements were met, see Additional table 1.

# Setting

The Sage-atAge program is an outpatient assessment program offered to homedwelling older adults (65+) by seven general practices in a rural area in the north of the Netherlands. A postal questionnaire was distributed among 3004 older adults and completed by 1455 of them. This questionnaire captured frailty, care complexity and health-related issues. Frailty was assessed using the Groningen Frailty Indicator (GFI). GFI comprises 15 items, covering four domains: physical, social, cognitive and psychological. The total score ranges from 0 to 15; a higher score indicates higher level of frailty. 14 All older adults with a substantial frailty level (GFI >2) were invited for a CGA (n=708). The CGA consisted of a consultation with a geriatric nurse or elderly care physician 15 and focused on multiple domains (physical, functional, psychological, social and living). By protocol, the assessor was advised to extend the assessment with measurement instruments for psychological, social or functional needs. For example, when cognitive complaints or depressive feelings were expressed. Pharmacist and dental care worker assessments were also offered. A consult from an allied healthcare professional, such as a physiotherapist, dietitian or psychologist could be added to the CGA when deemed necessary by the nurse or physician. The consult aimed to reveal and formulate goals with the older adult in order to attain or preserve well-being. The healthcare workers involved were trained in using motivational interviewing - a method for encouraging people to make behavioural changes to improve health outcomes. 16 After the CGA, written recommendations were offered to the older adults and their general practitioners (GPs). The program's effects on older adults' morbidity and general well-being will be evaluated in a controlled beforeafter study. Alongside, a thorough process analysis is carried out. The current study on the experience of the older adults with the Sage-atAge program is part of this process analysis.

# Participants and recruitment

Older adults who had participated in the Sage-atAge program were invited to the interviews within four months after receiving the CGA. Between May 2015 and February 2016 older adults were purposively sampled to create a wide variation on demographics (age, sex and frailty level) and experience of diverse parts of the program (different care workers conducting the CGA). We planned for more

than 20 interviews to provide enough "information power". The sufficiency of the sample size was concluded from a diverse range of dimensions of our study: a small subject but with a heterogeneous sample, no predefined theory and a cross-case analysis technique. We stopped interviewing when we reached data saturation.

Eligible older adults were sent an information letter by post about the purpose of the interview study and practical information about the interview. Within a week after receiving the letter, the interviewer (MS or WR) telephoned the older adult to check whether they were interested and an appointment was scheduled when they expressed an interest.

#### **Data collection**

The topic list (see Additional table 2) was prepared by WR and MS, discussed with SU and DG and tested in 25 pilot interviews which were not part of this study. It consisted of the following subjects: 1) recall of and experience with the program and the CGA, 2) recall and opinion regarding the recommendations provided, 3) motivation for participation in the program, 4) goals and disabilities in life and 5) experience with health care workers in general. The topic list was adjusted following a few interviews and a discussion of the findings: the view of the participants on healthy ageing was investigated to improve our understanding of participant coping strategies.

Semi-structured interviews with open-ended questions were held, following the River Structure, i.e. personal experiences of a participant could lead to a new head course, so not all questions from the topic list would necessarily be used in all interviews.

Interviews were performed by MS (medical student) and WR (elderly care physician in training) who were trained in interviewing. Before starting the interview, participants were reassured that the transcripts would be anonymized and their health care providers would not be able to trace back any opinions to individual participants. This was done to encourage participants to express their own opinions. When the interviewer's medical background was known participants appeared to compare their health care workers with the interviewer. Therefore, in the final 15 interviews, the medical background of the interviewer was not revealed. The latter may have led to fewer 'desirable' answers being provided. 18,19 All interviews were audio-taped and transcribed verbatim.

# **Data Analysis**

This study aimed to both explore, as well as explain the experience of older adults.<sup>20,21</sup> Therefore we used thematic analysis<sup>22</sup> with a focus on a cross-case analysis using a constant comparative method.<sup>17,23</sup>

Transcripts were open-coded by two researchers (WR & MS). Experiences were explored first and allocated to themes. Subsequently, experiences were matched to program components in order to provide an explanation for the experiences. Thematic analysis was conducted in thorough steps: a within-case analysis was carried out first to cross-check the interpretation of the older adults' stories and experiences between the researchers. Once subthemes emerged the focus was shifted to an inter-case analysis in which these themes were compared. This enabled a multidimensional typology to be drawn from the older adults' potential viewpoints of the CGA program. The observations and themes were regularly discussed by three researchers (WR, MS, DG). The coherence and connections between themes were visualized multiple times in a coding tree and network view, and then discussed within the whole research team (WR, MS, DG, JS, KW, SZ). The literature was extensively searched to help explain and understand relationships between themes.

# **Data presentation**

Individual details of the participants and their CGA were listed in table 1. Ages have been presented in ranges and recommendations have not been described into detail in order to the minimize the risk of patient identification. Participants have been numbered successively. The identified themes have been described and an illustrative primary quote is provided with every theme in the Results section to support and clarify themes. Secondary quotes were gathered per theme. These have been listed separately in table 2 to improve readability and accessibility of the results.<sup>24</sup> The number and gender of the participants has been provided with every quote. These are referred to with successive codes (e.a. A1). All quotes have been translated into English by a professional translator. Finally, the relationship between relevant themes is visualized in figure 1.

# RESULTS Participants

Twenty-five participants were interviewed about 2.5 months (range 1.5 - 5.5) after the CGA for 60 minutes on average (range 30 - 106). Almost all interviews were held at the participants' home; sometimes with the spouse present. Table 1 lists the characteristics of each participant showing a broad range of frailty levels, ages ranging from 67 to 95; almost half of them were married and more than half of them had a low educational level.

Table 1 – Demographic and program characteristics of the interviewed older adults (N=25) who participated in Sage-atAge

1	Jran		bar as a mandran and						
	Demographics	aphics				Intervention	Intervention characteristics		
						CGA by			
□	Gender	Age	Marital	Educational GFI <sup>2</sup>	GFI <sup>2</sup>	initial	additional C	GA at	CGA at Domain of Recommendations
		range	status	level <sup>1</sup>		professional	assessment		
-	V	95-100	married	medium	5	Nurse	Physio- therapist	Home	physical (risk of falling)
7	M	85-90	married	medium	9	Nurse/Ph/D	)	Centre	functional, dental, (vision)
m	Ь	80-85	married	medium	8	ECP	1	Home	physical, psychological (fitness)
4	M	80-85	widower	medium	11	ECP	1	Home	physical, social (lung condition)
2	M	75-80	married	medium	7	ECP	1	Home	NA
9	Ь	75-80	married	medium	3	Nurse/Ph/D	)	Centre	physical, dental (fitness)
7	Σ	80-85	married (to P8)	medium	9	Nurse/ Ph	O	Centre	physical, social (leisure activities)
∞	ш	80-85	married (to P7)	low	8	Nurse/ Ph	J	Centre	physical, social (side-effects)
6	ш	85-90	divorced	low	4	Nurse/ Ph		Centre	physical, psychological, medication (coping)
10	ш	65-70	married	medium	9	Nurse/ Ph	J	Centre	physical, dental (fitness)
	Σ	70-75	widower	high	2	Nurse	Τ	Home	physical, psychological (depressed mood)
12	M	75-80	married	high	9	Nurse/Ph/D	)	Centre	physical (fitness)
13	ч	80-85	widow	medium	9	Nurse	<b>T</b>	Home	NA
14	Ъ	65-70	widow	low	2	Nurse/Ph/D	)	Centre	functional, medication (vision)
15	M	75-80	married	high	4	Nurse	<b>-</b>	Home	NA
16	M	80-85	married	low	3	Nurse/ Ph		Centre	physical, psychological, social, medication (coping)
									table continues

	Demographics	aphics				Intervention	Intervention characteristics	S	
						CGA by			
17	ш	80-85	married	medium	3	Nurse/Ph/D		Centre	physical, psychological, dental (pain)
18	Ь	70-75	divorced	low	7	Nurse/Ph		Centre	physical, social (leisure activities)
19	ш	75-80	married	low	9	ECP		Home	physical, functional, medication (pain)
20	F	85-90	widow	low	2	Nurse/Ph		Centre	psychological (coping strategies)
21 M	×	75-80	married	medium	3	Nurse	Psy- chologist	Centre	functional, psychological (care giver support)
22	ш	75-80	married	medium	80	Nurse/Ph/D		Home	psychological, functional, social (vision)
23	×	70-75	married (to P24)	medium	6	ECP	Physio- therapist	Home	physical, functional, social (leisure activities)
24	ш	02-59	married (to P25)	medium	5	Nurse/ Ph		Centre	psychological (coping with family problems), dental
25	ш	75-80	married	medium	10	ECP		Home	physical (physiotherapy), psychological (care giver support), social, living (home adaptation)

M = male, F = female, ECP = elderly care physician, Ph = pharmacist medication review, D = dental care worker, Y=yes, N=no. NA = 1 low = primary school (or less) or lower vocational training; medium = secondary school/vocational training; high = Higher vocational training or university not applicable

<sup>2</sup>GFI = Groningen Frailty Indicator (range 0-15), a higher score indicates more frail

When asked, all participants were able to remember their experiences with SageatAge; sometimes after being assisted with prompts, except for one woman. She had recently moved to a residential home and could not recall the CGA nor completing the guestionnaire (P13).

# **Exploring the experience of participants**

None of the participants could recall the separate parts of the program and their coherence: the questionnaires, the CGA, the recommendations for them and their GPs and their own responsibility in these components.

"I: what was the Sage-atAge program to you? P: an inventory of how the GP works, whether I am satisfied with the general practice, that was what I understood from it." P25 F

For additional citations for all described themes, see Table 2.

All of the participants expressed satisfaction when referring to the program. Further analysis suggested that levels of satisfaction related to communication with the CGA workers, and not about the value of the program (B1).

"I immediately felt comfortable with her. I could speak with her in an easy way. You were able to ask anything. That was very good. {} I sat there and had a very nice feeling afterwards and was not nervous or anything at all, not at all. {} Oh well, nothing else has happened, I mean I have asked questions, she has asked questions ... other than that nothing special." P9 F

Further examination of the participants' experience of the program, revealed six main themes.

# Need for a holistic view

Participants appreciated the CGA and questionnaires for their focus on a broad view on their lives and health complaints (C1).

"Because it has to do with being seen. That you really see the other person as a whole individual. That you are not just that pelvis, or that arm that is broken, or whatever, but that you see the human being. That is the most important thing for me. I: and how do you notice that you are being seen? P: looking at someone, not directly behind the computer, but making eye contact, I think that's very important. And that you also feel that someone is listening. That you are not just an ailment that needs to be resolved. But that you are seen as a human being." P25 F

Some participants had not discussed these aspects previously with other health care workers (C2). They expected that their own GP or medical specialist would

not have time to discuss these aspects (C3), or they experienced a lack of interest from doctors in their problems (C4). Participants considered the CGA as reassuring in terms of the fears they experienced in daily life (C5, C6).

"You could talk about anything, she was very attentive and - perhaps that is the most important – just the very idea that she said "Well, if something is wrong you can always call me". {} I think that is the most important thing. That you know that you are not on your own." P6 F

Table 2 – Overview of sub-themes supporting all main themes and secondary quotes grounding the subthemes.

Main themes	Supporting subthemes	Relevant secondary quote
Experience		
	Recall and understanding of the intervention	A1 "The GP has a lot of elderly people in his practice, do they all get a letter? I: Yes, they do. P: So everyone so not that you say we will pick out a few? I: Yes {} But you tell me that you did not receive the invitation [to fill in the questionnaire] P: No, I did not get it. I: What kind of invitation did you receive? P: Well, just an invitation to come here [to the centre], that was the only invitation I got." P9 F
		A2: "Because I think you had to turn to the GP as well, didn't you? The GP had then indicated which people were eligible for this. So in that respect the doctor played a part in it, didn't she? So that's, well, yes, people do have a lot of illnesses or whatever, right? In that way, it's been brought into action you might say, hasn't it? But otherwise she has nothing to do with it, I think. She probably won't have time for that" P6 F
	Satisfaction is not about the effect of the program	B1 "I have been treated nicely. Otherwise, I can't say anything negatively about it. I wouldn't advise against it to someone else either, but recommend it, oh well, I don't know. Anyway, there's nothing that I wasn't happy with. That you say like, well, I would rather not have done it. {but} I don't know what's in it – there's nothing in it. Not for me." P21 M

Main themes	Supporting subthemes	Relevant secondary quote
Need for a ho	listic view	
	Appreciation with the broad view of the program	C1 "My blood was also just checked again this week, because they doubted the thyroid gland, which was only slightly on the edge [the doctor] thought. Then, I went to be checked again, I'll just wait for [that result] again. You can be very tired of that, too. But then again, we have been very tired for a very long time. And then [the nurse from Sage-atAge] said: "But that's only logical, woman, you have so much going on in your head, that alone should get you tired". I think: well, you are right. That was true enough." P24 F
	Other care workers are not meeting this need	C2 "but I hope that they [care workers] can do something quickly. You always hope for that and yes, also in hospital. I don't get anything there either. [there they say]: "You may come back in a year", just like that. They just don't give a moment's thought to anything." P4 M
	and they are not expected to meet this need	C3 "we only visit the GP when it's very much needed, right? If you really have problems Or, yes, real problems If you're really ill, say, then you'll visit the doctor." P6 F
	Participants experience a lack of interest into this need with other care workers	C4 "Sometimes I also notice that with GPs: They just listen to your heart for a moment: "Oh yes, it's still beating." And then they listen to your lungs for a moment, "yes they are also still working. Well now, so you are not dead." And for the rest, you may just figure it out. So no feeling with the human being behind the patient at all. [The GP can't take care of everything] He doesn't have to, but he should have an antenna for picking up someone's signals." P11 M
	Need for support	everything I'd like to [because of vision problems]. {} I don't play a part in anything anymore, do I? I listen to the radio to hear the news all day long, and if something is wrong, well But, there are also things you should just actually read, shouldn't you? So that it really sinks in. {} [with the nurse at Sage-atAge] I could at least just tell my story and I thought that in itself this was a start to set everything in motion, wasn't it?"

Main themes	Supporting subthemes	Relevant secondary quote
		P2 M C6 "Especially checking the medication is important to me as well. And nothing had to be changed about it, but that people paid attention to it. You can never know." P2 M
Scope of the O	CGA	
	Unable to recall the agenda of the CGA	D1 "I: And do you still remember what [the CGA] was about then? P: Yes, it was also all about those ordinary things. Yes, I just call it ordinary things. It was all about how you lived and what you could still do and this and that and about all of those things. But exactly, the specific details, that I don't know anymore." P20 F
		Do you still remember how that was then? {} P: Yes, I do. Talking a bit about everything, right? S: Yes, of course you start with an open mind, don't you? I: And that conversation How did that go? P: Well, it went alright. Yes, I think I could give an answer to whatever she asked." P5 M
	Uncertainty about the goal of the program	D3: "I: And before the doctor came here - did you have any idea of what she would come and do here? P: No, not at all, right? No, because we thought it was something that our doctor would help with or so. Yes, that's what I was thinking. And am I right? That she will then have a better overview of our family or something?" P3 F
	Questionnaire guided the agenda of the CGA	D4"I: Had you then thought in advance about what you were going to discuss during that conversation? P: No, I hadn't, because that had already been noted in my questionnaire, right? [The conversation] was more an explanation of what I had already said in the questionnaire. Well, she asked some additional questions about and around that and so on. So, well, I felt that it was going quite alright." P11 M
		D5 "S: At some point [the nurse] then says: "It's about time that I should deal with my questions, because otherwise it will take much too long."

Main themes	Supporting subthemes	Relevant secondary quote
		I: because what actually were her questions then? P: Well those were, they actually were related to the list that I had filled in. And so I did answer those." P15M
	Scientific design of the program	D6 "Ok, well, that conversation was not useless. But yes, I actually did, I thought, answer all sorts of questions in the questionnaires, so I believe that conversation didn't have any added value. That was not this lady's [SageatAge nurse] fault, but let's put it this way, I'm not any the wiser. Well, it was a research, so then you are not supposed to be any the wiser, but you are expected to make the researcher wiser." P12 M
<b>Expected help</b>	•	
	Unexpected problems discussed	E1 "I've also received a card from her, because it was also about some personal things with her in the end, and that was very nice, too, and well, then she had something like, then give – I'll give you my card, right, if ever you think you'll need me again, you may always call me." P24 F
	Unexpected solutions	E2 "I did speak with someone from social support. They now know what the situation is like here, so in general I benefited from it to some extent. If anything happens to me, they know about my wife's situation [for whom he is care giver]" P21 M
Ownership		
	Passive role	F1 "They really want you to. That's why I say: I'll just take part in it. {} For my doctor and for myself as well, of course." P9 F
		F2 "There's no harm in it anyway. I thought: They are launching a new project there, I'll just contribute to that. But not with a certain expectation or so." P6 F
	Initiation	F3 "Yes, she would discuss it with the GP And then you don't hear anything. Then you have to ask about it yourself. {} You would like to contribute alright, but I think the other side should come up with something as well." P5 M
		table continues

**Chapter 4** | experiences of older adults with a proactive assessment program

Main themes	Supporting subthemes	Relevant secondary quote
	Agenda	F4 "you're waiting for what that lady would say." P1 M
		F5 "I: But do you still remember what you talked to her about? P: Yes, also about, these things rather. Yes, yes, but everything specifically, she asked and then I just answered in fact. That's how you should see it." P4 M
	Actions expected by the care workers	F6 "I: So the care worker came to visit you at home. P: Yes, he did, because I could have come myself [to the research centre]. But that was not necessary." R23 M
		F7 "So I knew that [the nurse] would contact the GP. But I didn't know what would happen next, so then I already thought, yes, should I be the one to take initiative, will I have to call her later or how does that work. Oh well, I thought, just wait and see for a while. But then that [family doctor] visited, personally. {} The GP had actually signed me up to that project, so it's only logical that people from that project will give feedback to the GP about the results." P11 M
	No actions carried out by participant	F8 "That's how I found out that the cause was the diuretics that were affecting me badly. So then I said to that pharmacist like, what do you say about this? Shall I just leave them? Because I still have some problems with dizziness Never heard of anymore." P8 M
		F9: [reading out the goal card]: "'Increasing the activities around movement a bit and possibly go to [the community centre]'. You have to do that apparently because we haven't heard anything from that either. Actually we haven't heard about anything at all." P7 F
	Unsolved misconcep- tions	F10 "Yes, we would like to contribute, but we didn't really know what it means. And I actually still don't know, but I thought it was about help, for the doctor. For our family doctor, and that she would would then explore our household a bit and what was there." P3 F
		F11 "I never really understood that it was for me. I had the idea that it was part of the research." P12 M

Main themes	Supporting subthemes	Relevant secondary quote
Timing		
	Ageing is about uncertainty	G1 I: [how can we make sure we reach those who will benefit from this]? P: Well, of course at this age that may change per month, eh? So yes, that's difficult." P7 M
	Changes occurred within timeframe of	G2 "then the first time someone came here, nothing was wrong with me, but then there was during the second time." P3 M
	program	G3 "I have very bad eyesight, and then [the Sage-atAge nurse] also talked about Visio [a vision-aid centre]. And then I said to her like, "Well, I won't need that yet. I'll be fine like this." But now I do need them. {} It used to be fine, until four, five weeks ago. I suddenly got a dark spot in front of the eye {} Yes, I needed it faster than I expected myself." P14 F G4 "And I also have a sore knee and I didn't mention that {} at that moment it wasn't hurting so much and then I forgot about it." P10 F
	Synchroniza- tion with other health care	G6 "I: Has that also been discussed then [at the CGA]? P: No, it hasn't That, eh, I haven't mentioned that anymore. Because we were already working on that [with the GP]." P2 M
		G7 "I: Have you also discussed the memory with [the Sage-atAge nurse]? P: No, I haven't. {} Then we didn't know it yet. Then we hadn't visited that doctor in hospital" P16 M
	Counsellor would solve timing difficulty	G8 "{Sage-atAge} is a start I think, yes. Well, this is only just an inventory. {} I: and would you like it if that nurse would see you again? P: Well, it doesn't necessarily have to be a nurse, because there is nothing to nurse here. So it doesn't really matter who that is as long as he's part of such a project or organization. {} I: and that he will come back once in a while? P: Yes, otherwise it doesn't make sense. A one-off doesn't make sense. So that should actually become standard procedure." P11 M

Main themes	Supporting subthemes	Relevant secondary quote
		G9 "All those people [he met at a ward when he was hospitalized] could use a director. I think that would be a good addition to supporting ill people, including simple material matters. {} There are so many annoying things in life, which will be going to be one hundred percent, one thousand percent more difficult if you fall ill. {} that if they have a question about something, that they know they may call someone in confidence." P12 M
View on prob	lems	
	Questionnaire is lacking the narrative	H1 "[the Sage-atAge nurse] said:" You sometimes feel lonely, too." I said "No, not that I know of.". She said "You did fill that in." I said "Well, then that was a mistake." So therefore she has been here again and we talked about it once more. {} But yes, I'm on my own, but I don't feel lonely." P14 F
		H2 "Alright, so there may have been a few leads for [the Sage-atAge nurse] to come here, because I might have answered a bit differently from the average answer, that's possible. I was probably a doubtful case." P15 M
	Expecting physical scope	H3 [reads out problem on the goal card]: "preferably be a bit more mobile.' Yes, I do fortunately have my car, but otherwise I would be completely stuck at home! [reads out] 'Preferably be a bit more among people', oh well, I am. {} No, I can't do all that much with this [goal card]. [I only have a problem] with diabetes, which isn't mentioned on it. I: and the things that are on it, are these matters for you that were relevant at that point? P: Yes, that's private, if I want to play cards then I'll just do so. Which, it seems to me, doesn't have anything to do with that. S: That is a leisure activity." P8
		H4 "Well, we went through everything a bit. I am quite reasonably aware of how I'm put together. It isn't an examination, not a medical examination. So like ingrown toenails and so on, they are not mentioned." P12 M

Main themes	Supporting subthemes	Relevant secondary quote
	No urgency for prevention	H5 "But anyway, yes, you should try to live a bit healthily, but not at all costs. Because then I think the quality of life is losing out. Then you do have a healthy body that may want to get old, but a certain quality of life is part of it as well, and I think that is missing then. If I can't smoke my cigarette, can't have my drink, yes, then nothing will be left anymore." P11 M
		H6 "I have to exercise more but that is considerably inhibited by my heart condition {}. I can't do more than that. Things should remain pleasant, right? I think it's important to get "healthily old" but that's not an end in itself. You have to be able to grow old in a pleasant way. There's no point at all in filling your days with horizontal bar exercises in order to win another year." P12 M
	Coping / Secondary control / Acceptance	H7 We aren't getting old in a healthy way. When we get older, everything starts to crack, I sometimes say. But yes, you hear that from a lot of people {} Yes, they all suffer from it in some way." P14 F
		H8 "And I also try to walk in succession as far and as long as possible. Because sometimes I don't have any energy left. Then I walk a short distance and then I have to sit on my walker. And then walk a bit further. And then when I have walked all the way out and back, then I praise myself. I think that's so beautiful then. I did manage to walk all that. That used to be quite normal, but now everything isn't normal." P20 F
	Unfounded hope	H9 "I: [What did you expect from Sage-atAge?] R: Well, I that it could be useful to me when they could help me with this [with the oxygen therapy] {} But anyhow, I don't get any support, I don't have to count on that, no." P4 M

Corresponding code (e.a. A1) "quote" Participant number, Sex (Female/Male). S=spouse, I=interviewer, P=participant. {}: text left out to increase readability. []: text added or paraphrased to increase readability.

# Scope of the CGA

The scope of the CGA seemed unclear for the participants. They did not know what the CGA would be about beforehand, and they could not recall clearly what it had been about afterwards (D1, D2).

"I: what did you expect in advance of the appointment? P: just a conversation about the complaints we had written on [the questionnaire] and about how we looked to the future: continue to live here, to live independently. But I actually did not have an image of how that would be. Well I answered her questions, and apart from that we just talked a bit." P24 F

Though participants expected it to be broader than a consultation at the GP, they were unsure what to discuss within a CGA (D3). The program's questionnaire seemed to be a barrier to bringing up new – more important – topics. (D4, D5).

""I: Did you have any questions for her? R: No. What could I ask someone like that? I don't know. {}. Well, she just asked questions about the paper we filled in." P19 F

This can partly be explained by participants thinking the scientific goals of the project were more important than discussing their own problems (D6).

"I went into this process with the understanding of "you have been picked out. Would you like to participate in the study?" So then I thought okay, that's fine, I want to, not with the preconceived goal that they had to do something for me, or whatever, that developed in the course of the conversation." P25 F

# **Expected help**

Problems were discussed within the program for which the older adults had not yet sought or found help. This could result in unexpected revelations of (E1) and even to unexpected solutions to problems (E2).

"I went to [the ophthalmologist] and then they said "We can't do anything for you anymore". After two operations, on both eyes. {} {Then the Sage-atAge nurse advised to go to a vision-aid centre}. {} Then I thought, well, isn't this something. You go to [the hospital], and they did not know what to do with me." P22 F

#### **Ownership**

Almost all participants described their own role in the program as passive (F1, F2). They explained their role as 'wait and see', because the initiative for the assessment was not their own (F3). They tended to wait for the care workers to bring about subjects during the CGA (F4, F5).

"Well, I didn't know that [topics of conversation], you don't know those beforehand, right? I had to indicate what I had. So, that's what I did. I've just done what they asked of me." P8 F

Participants waited for Sage-atAge to schedule appointments when and whenever this was deemed necessary (F6). They expected the GP to be informed by the CGA nurse or physician (F7). Afterwards, they tended to wait for the GP to contact them about the advice given:

""And she [Sage-atAge nurse] told me what I already knew: {}" At some point I'll report to your GP how I see things." So, I assume that the report is with the GP. I have not been to the GP since this spring. And he has not been here either, so he probably won't have discovered anything disturbing." P15 M

Participants almost never acted themselves whenever the expected action had not been carried out by the GP and CGA care workers (F8, F9). Furthermore, participants tended not to resolve their own questions regarding the program design (F10, F11).

"I: Will you see [the Sage-atAge nurse] again? P: Well, that wouldn't be bad. And it may well be that we get another call, from this Sage with Age. It could be. {} I don't know how it continues. No idea, but there might be a follow-up, or maybe they will ask in a year's time how it is going." P24 F

### Timing

Participants stressed that timing of the program implementation or the CGA was difficult. They attributed this to the fluctuation of symptoms in time and concomitant health concerns (G1). The timing of the program components was therefore delicately balanced in three ways. For instance, occasionally symptoms had already changed or resolved in the time period between completing the questionnaires and attending the CGA (G2). Secondly, sometimes just after the CGA some important deterioration took place or the symptoms occurred only outside of the CGA (G3, G4, G5).

"I have not heard anything yet [no invitation for a CGA] I had also completed [the questionnaire] but then after that time I got that arrhythmia which I didn't have before. I didn't have much at the time and then all of a sudden there is something, right?" Spouse of P5 who was not invited to the CGA because of the absence of frailty on the self-assessment questionnaire.

Additionally, when symptoms had already been covered in other health appointments (or were to be in the future) this seemed to be a barrier for discussion during the CGA (G6, G7). Multiple participants advocated a personal

counsellor for this timing difficulty. The latter was described as someone who could be contacted spontaneously with no prior planning for a broader range of problems than those considered appropriate for a GP, for example for reassurance or practical help (G8, G9, G10).

"Though I might need someone next week, or this week. But then I have to make an appointment during office hours again. And I find that difficult. I would just like to have someone whom I could call and say to them 'Hey, I would like to get something off my chest' or 'Could you lend an ear to me'. I need that most and I find that with my friends {} but you know, I sometimes want something outside my circle of friends." P25 F

# View on problems

There also seemed to be a difference between the participants and the care workers in the definition of problems. The participants differed in four ways in their view on problems highlighted by the questionnaire or care worker. Firstly, they objected to problems revealed by the questionnaire (H1, H2). Secondly, it was sometimes questioned by participants whether problems on domains outside of the physical domain were part of the program scope. This meant these issues would not be expected to be seen as a relevant problem to discuss (H3, H4). Thirdly, participants seemed to stress less importance on preventive actions than care workers. (H5, H6). Finally, sometimes symptoms had been a burden some time ago and were therefore highlighted in the questionnaire, yet as participants had already adapted to them, it no longer seemed important to discuss them in the CGA (H7, H8).

"Just gradually you start to put things into perspective again and then everything becomes a bit more common again. First you have to process it and then I think like: gosh we have so much, we have healthy children, we have healthy grandchildren, what more could you wish for? Life is not endless, we [all] have to leave here in the end." P6 F

Multiple participants described problems that were overlooked by the program (both by questionnaire and care workers) in addition to the difficulty of signalling problems with the questionnaire. These problems were also neglected or not solved by care workers from existing care. They were hoping the program would offer a solution for these problems, but were also disappointed that the program was not able to address these problems. (H9, H10).

"Because sometimes there are a lot [problems]: because I always have a buzzing in my ear. They don't look further into it. And I thought, well maybe something will result from it, that's why I thought it was fine. I: You had hoped that they might investigate the ear? P: Yes, everything actually. I have a swollen hand and swollen

foot, I have pains in my legs every night. {} I went to the hospital several times, [they say:] "well there is nothing wrong with you". Well, I thought they'll look at it thoroughly and that was what I thought of the assessment. {} Yes, I really looked at it from a completely different point of view, let's be honest." P18 F

These six themes explored the participants' experience. When trying to explain the experience, the themes coalesced with three program components (See figure 1).

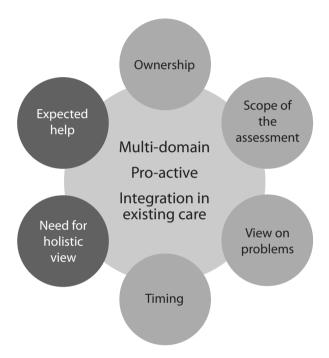


Figure 1 – Themes encompassing the experience of outpatient assessment program participants, relevant program components and their coherence

The small circles forming the outer layer are representing the themes encompassing the experience of participants of an outpatient assessment program. The big inner circle contains the relevant program components. The coherence of the program components and the experiences are marked by the colour of the small circles. The dark grey circles indicate that themes are negatively influenced by the program components and the light grey circles indicate that themes are positively influenced by the program components.

# **Explaining the participant experience - Program components**

The participant experience, was considered in light of the program design in order to provide an explanation for these experiences. We identified three program components which seemed to have a part in the participants' experience.

## Multi-domain approach

Firstly, the program's multi-domain approach attended to the *need for a holistic view* that was expressed by the older adults. Secondly, it may, however, also be used to explain the participants' confusion about the *scope of the CGA*. Thirdly, it could be a reason for the difference in the *view on problems*: the explanation why the care worker would focus more on prevention than the participant appreciated.

#### **Proactive**

Another program component which seemed to influence the experience was the proactive approach. The program was proactively offered to a(n older adult) population. This meant that the steer towards the CGA was led by answers on the screening self-assessment, more specifically, whether these answers complied with the CGA inclusion criteria. This is contrast to a consult or appointment where patients seek help themselves or are individually referred by their GP. This component had the positive effect of delivering unexpected help. Problems were discussed which had not involved a care worker to-date and where care was not expected (as yet). The proactive induction had two drawbacks though. Firstly, it was often experienced as wrongly timed because of the dynamic of symptoms related to ageing. Secondly, it seemed to amplify the passive role of participants in the program: they experienced a lack of ownership with regard to the topics to discuss and in terms of adhering to advice.

# Integration with existing care

The third program component which seemed to influence the experience of older adults was the one-off aspect of the program and the way it was incorporated in the existing care processes. Due to the lack of *ownership* and the uncertainty about *the scope of the CGA* older adults did not prepare for the CGA and did not actively engage in the agenda during the CGA. Afterwards they sometimes felt important problems had not been discussed. The single contact with the CGA care worker provided a one-time opportunity only, which also caused friction with the *timing* of the CGA. Reaching consensus on the *view on problems* in this single contact was also troublesome. The lack of integration in the existing care structure was a barrier to implementing care after the CGA. Because of the lack of *ownership* by the older adults, they did not carry out recommendations by themselves and waited for their GP.

#### DISCUSSION

In this article we described the experience of older adults with an outpatient assessment program and aimed to explain the coherence between this experience and program components. Although older adults expressed satisfaction this did not cover their whole experience with the program; they also expressed a lack of ownership in the program, experienced problems with the timing of the program, were uncertain about the scope of the CGA and their views on problems seemed to differ with the care workers. Importantly, the program seemed to address their need for a holistic view and delivered unexpected help. In aiming to explain this broad range of experiences we found coherence with three program components: multi-domain approach, proactive sampling and integration in usual care. By connecting the experiences to the program components we gained insight into potentially relevant factors for improving care for older adults.

# **Embedding in literature**

Similar to our findings, Darby et al. reported that satisfaction applied to the contact with the geriatrician within an in-patient CGA program, but it also appeared concurrently with a lack of understanding regarding the meaning of the intervention.<sup>25</sup> For out-patient CGA programs both with and without subsequent interventions, the discrepancy between satisfaction and efficacy has been underlined before.<sup>26</sup> It is also noted in other settings, like residential care<sup>27</sup> and within the concept of person-centred care.<sup>28</sup> Notwithstanding this complicated nature of satisfaction, satisfaction (with care) is still used as an outcome measure of CGA evaluation studies, e.g. by Ekerstad et al.<sup>29</sup> However, there is also a trend towards the evaluation of 'experienced care' instead of satisfaction.<sup>30</sup> Our results emphasize the importance of this development for evaluating experiences of health services.

The participants appreciated the multi-domain approach of the program as they expressed a need for a holistic view. This need is in line with other research into the experience of older adults with regular health care<sup>31</sup> and integrated care.<sup>32</sup> However, the holistic view of the CGA also hampered the participants to get a grasp on the scope of the CGA. This could be explained by the expectations of patients that interaction with care workers would mainly focus on physical complaints: the Voice of Medicine.<sup>33</sup> Another problem with the broad scope of the CGA is the dilemma in *the view on problems* between older adults and care workers. Extensive literature exists on the change in priorities given to problems experienced when ageing,<sup>34</sup> the declining need for primary prevention and goals being reset.<sup>35,36</sup> This all underlines the difficulty of really tuning in on the needs and preferences of older adults.

This program, as most outpatient assessment programs, had a preventive strategy design. Our data showed that the advantage of proactively delivered care was the experience of unexpected help. This decreases patient delay: participants were not seeking help for their needs yet because they did not expect any result from a consult with their GP or medical specialist. Reasons provided by the literature for not seeking help for problems have attributed these problems to age<sup>37</sup> or being unaware of possible solutions.<sup>38</sup>

The difficulty of the proactive strategy was the sub-optimal timing of the CGA that was experienced by participants. When disabling arises within the process of ageing, it is characterized by multiple and possibly interrelated disability episodes.<sup>39</sup> Van Houtum et al. noted that patients only have an increased need for support when they experience progression or deterioration of their disease, and care workers should be able to adjust their timing to the course of disease.<sup>40</sup>

Another finding linked to the proactive design was the lack of ownership the participants expressed. Lack of ownership is known to decrease commitment to goals and the chance of attaining goals,<sup>41</sup> decrease self-management ability<sup>42</sup> and having a negative impact on effect.<sup>43</sup> It is noteworthy that being a patient in itself seems to cause a passive attitude towards care workers and their disease-management.<sup>44</sup>

The care of Sage-atAge lacked proper integration with existing health and social care. The negative impact of this solitary aspect and (therefore) lack of control of the implementation of recommendations on the effect of a CGA was described in various research. In a long-standing meta-analysis, solitary CGA programs showed no effect, 45 in contrast to home-visiting programs with follow-up visits or programs embedded in general practice. <sup>6,46</sup> Kagan et al. demonstrated that a lower integration within primary care is linked to lower adherence to recommendations.<sup>47</sup> An explanation for this connection could be that GP need support in acting upon CGA recommendations.<sup>26</sup> Despite the overwhelming amount of literature about the importance of integration of care and the difficulty of implementing this collaborative way of working<sup>48</sup> there is still not enough attention to embedding in existing care or to the context in which outpatient programs are carried out.9 The consequence of the solitary nature of the intervention is amplified by the CGA being a solitary consult lacking follow-up. For appropriate recommendations, adapted to the goals and needs of the older adult, more than one consult is commonly needed, as has been demonstrated in the shared decision-making literature. 49,50

# Strengths and limitations and further research

The qualitative design of this paper allowed us to reveal a coherence between experiences and program components, possibly explaining contradictory findings in intervention studies within CGA-research, and a broader insight than a survey

would have provided. Two drawbacks of this qualitative study are nonetheless worth noting. Firstly, during the interviews participants repeatedly postulated a link between the interviewer and the Sage-atAge care workers. This could have introduced socially desirable answers. Nevertheless, numerous remarks and complaints about the conduction of the intervention were still voiced.

Secondly, the findings might not be generalizable to outpatient assessment programs or CGAs with a different design than Sage-atAge, for example those with only one or two of the program components discussed. Further research could study these components separately in different CGA settings considering their effects on participant experiences and health outcomes.

When the screening instrument revealed a 'problem' older adult were reluctant to considering this as a problem, even though they had marked the response on the questionnaire. There is possibly a discrepancy between the problems flagged by the questionnaire and the way older adults experience these problems. Questionnaires are increasingly used to guide care (pathways). Hence, more research is needed into these possible discrepancies.

#### CONCLUSION

An outpatient assessment program fits into person-centred care, as it is able to meet the older adults' need for a holistic view. Next to that, with its' proactive approach it is able to deliver unexpected help to some of the participants. However, the correct timing and engagement of older adults is hampered by proactive recruitment and limited integration of the program within existing care. More attention needs to be paid to these program components and implementation strategies when designing and evaluating proactive and person-centred care for older adults.

Therefore, there seems to be a need for unscheduled availability of care workers working holistically and integrated within the standard health care of older adults. This was suggested by our participants and has been concluded in other research into the older adults' perspective for improving standard care. 51,52

This study underlines that satisfaction seems an insufficient guiding factor when evaluating care programs for older adults as it appears to have no link with the experienced effects of the assessment program. Conversely, three program elements appeared to be of importance for explaining this experience: The multidomain scope, the proactive approach and the integration with existing care. These factors should be addressed when developing outpatient assessment programs and evaluation studies.

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# Additional table 1 - Detailed applied methodology following the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist

No. Item	Guide questions/ description	In our research:
Domain 1: Res	search team and reflexivity	
Personal Chara	cteristics	
1. Interviewer/ facilitator	Which authors conducted the interview?	MS/WR
2. Credentials	What were the researcher's credentials?	MS: BSc. WR: MD
3. Occupation	What was their occupation at the time of the study?	MS: Master student. WR: Phd student
4. Gender	Was the researcher male or female?	Female
5. Experience and training	What experience or training did the researcher have?	MS: Medicine WR: Medicine. Elderly Care physician
		Research team: The researchers have diverse backgrounds; medical (SZ, JS), health sciences (KW) and psychological (DG) and are all specialized in elder care.
Relationship wi	ith participants	
6. Relationship established	Was a relationship established prior to study commencement?	The Sage-atAge program is initiated by an older adult care organization. Researchers carrying out the scientific evaluation are not explicitly involved in the program development and implementation.
		MS twice observed the CGA of a participant before interviewing. She did not know the care workers. WR knew the care workers and gave them training-on-the-job. She had no acquaintances with study participants before the interview.

No. Item	Guide questions/ description	In our research:
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	They were aware of the reasons for doing the research as part of the evaluation of the Sage-atAge program. In the invitational letter it was also noted that the researcher was a medical students (MS)
		In the latest interview rounds, respondents were not informed about the medical profession of the interviewer (WR) which helped elicit more critical views on health care providers.
	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	It was written in the invitational letter and orally stated that the researchers had no conflict of interest with the outcome of the conducted CGA
Domain 2: stu	dy design	
Theoretical fran	nework	
9. Methodo- logical orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic analysis <sup>1</sup> , cross-case analysis
Participant sele	ction	
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	By conducting purposive sampling, a sample of older adults was created with variation in their care complexity and experience of diverse parts of the program (i.e. assessment by nurse, elderly care physician, location of assessment at home or in the centre, additional assessment by pharmacist and follow-up visits).

No. Item	Guide questions/ description	In our research:
		Participants were invited 1-3 months after CGA. This time range was thought to warrant older adults still remembering details of the assessments, and would have had time to act on their formulated goals. The latest two samples were invited shorter after their assessment to improve recall of details of the communication with the care worker.
11. Method of approach	How were participants approached? e.g. face-to- face, telephone, mail, email	Four sets of a maximum of ten older adults were selected, to make sure no additional participants would be invited after achieving data saturation.  Participants first received an explication letter in which the invitation by telephone was announced. Within a week they were contacted by telephone to ask for consent and – when consented – an appointment was made.
12. Sample size	How many participants were in the study?	25
13. Non-participation	How many people refused to participate or dropped out? Reasons?	In total, 42 older adults were invited of whom 27 consented to be interviewed. Reasons for not participating were severe illness (6), no apprehension with the research purpose (3), did not receive the assessment (1), no interest (1), died (2), not available by phone (2). One participant was not at home at the appointment and not available by phone afterwards and one withdrew before the interview took place.
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	All interviews were carried out at home except for one, in which the participant preferred to come to the intervention centre. She preferred speaking alone (without her spouse for whom she was the informal care giver)

No. Item	Guide questions/ description	In our research:
15. Presence of non- participants	Was anyone else present besides the participants and researchers?	Yes, a spouse was present in 14 of the 25 interviews. Two of the spouses were participants themselves and were interviewed afterwards (interviews 8 and 24). Present spouses were instructed not to respond except when asked for.
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	See baseline table
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	A semi-structured interview guide was used, most often only to check at the end of the interview whether all topics were discussed.  The interview topic list was pilot tested by 2 students who carried out a pilot study among 25 participants. This pilot study focused on the experienced effects after Sage-atAge. After this pilot study, the topic list was adapted for the current study: the description of the program Sage-atAge in the participants' own words was added to the topics, to improve our insight in the understanding of the participants with regarding the program design.  Prompts used during the interview were: pictures of the care worker who carried out the CGA, the invitation letter of the CGA and the goal card. <sup>2</sup>
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/ visual recording	Did the research use audio or visual recording to collect the data?	All interviews were audio-taped and transcribed (by medical students MS, ED and SAR) using the same instructions. All transcripts were checked against the tape recordings (WR).

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No. Item	Guide questions/ description	In our research:
20. Field notes	Were field notes made during and/or after the interview or focus group?	During the interview, prompts were used to improve recall of the assessment and the program (i.e. picture of the care worker, questionnaires, goal card, invitational letter of the GP). After the interview, field notes were written and together with a summary added to the transcripts.
21. Duration	What was the duration of the interviews?	Mean duration was 64 minutes, with a range from 30 to 106 minutes
22. Data saturation	Was data saturation discussed?	The research group discussed findings and data saturation multiple times. Data saturation was reached after 25 interviews. This is mentioned in the manuscript as well
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Receiving a summary of the interviews was offered after every interview, only one participant approved to this. She did a minor suggestion after returning the summary.
Domain 3: ana	lysis and findings	
Data analysis		
24. Number of data coders	How many data coders coded the data?	WR, MS, DG
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from data
27. Software	What software, if applicable, was used to manage the data?	Analysis was done with Atlas.ti 7.5.15 (Atlas.ti Scientific Software Development, Berlin, Germany).
28. Participant checking  Reporting	Did participants provide feedback on the findings?	See 23.

table continues

No. Item	Guide questions/ description	In our research:
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes, see Results section and Table 2
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes, see Results section and Figure 1
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

<sup>1.</sup> Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006 Jul 21;3(2):77–101.

<sup>2.</sup> DiCicco-Bloom B, Crabtree BF. The qualitative research interview. Med Educ. 2006;40(4):314-21.

# Additional table 2 – Topic list for semi-structured in-depth interview with Sage-atAge participants

Topic	Sub-topic	Interview questions	Additional sub-questions
Experience	Experience	How do you recall your experience at Sage-atAge?	What components of the program do you recall? Prompts used: picture of the professional who performed the assessment and/or self-assessment questionnaire used for screening for eligibility and/or location of the assessment centre was described. Did you discuss the program with your relatives?
	Expectation	What did you expect from the assessment? Did you had topics in mind to discuss?	Why was this (not) discussed? What made this happen? Or what did you need to discuss this?
Communica- tion (quality)	Trust and confidentiality	You did not know [nurse] beforehand	What made you feel (un) comfortable?
	Quality of goals and recommen- dations	Were goals formulated or recommendations given at the assessment?	Did you receive a goal card? And what was on the goal card? If applicable, a goal card was used as a prompt What did you do with these recommendations and goal card? Did you discuss it with your GP/relatives
Needs	Added value of (a program like) Sage-atAge	What makes you feel better?	What bothers you in daily live? Can you describe an ordinary day?
		How can needs of older adults preferably be addressed?	How would ideal care for you look like? What can you/ your GP / other relevant care professional do to help to reach this?

table continues

Topic	Sub-topic	Interview questions	Additional sub-questions
		What kind of needs do you have?	What did you discuss recently with your GP? Was this also discussed in the assessment? Why (not)? What kind of help do you need? Was this dependency discussed in the assessment?
	Cope with age	What does ageing imply for you?	What questions do you have for your GP? Can you discuss
	Healthy ageing	What does healthy ageing mean to you?	this with your GP? Why (not)? Does this bother you? How do you take care of your own health? What decisions do you make about your lifestyle? How do you know what is best for you?
Involvement	Self- management preference	Can you describe a recent consultation with your GP (or other care professional involved)?	What do you discuss with your children, friends, neighbours about health? What kind of advice do you give to them?
	Disease- management preference	and what happened after this consultation?	Who do you expect to take the lead? Why?

GP: general practitioner





non-specified, status quo goals



motivational interviewing: high adaption, lack of time and proficiency





proactive goal setting requires follow-up

# Increasing older adult involvement in geriatric assessment: a mixed-methods process evaluation

Submitted

W Rietkerk JM de Jonge-de Haan K Wynia JPJ Slaets SU Zuidema DL Gerritsen

#### ABSTRACT

# **Background and objectives**

Motivational interviewing and goal setting may increase well-being by promoting healthy behaviour. However, we failed to show improved well-being in a proactive assessment service for community-dwelling older adults applying these techniques We therefore aimed to study the implementation process to identify reasons for these results.

# **Research Design and Methods**

Adherence to motivational interviewing was assessed by reviewing audiotaped interactions and goals were reviewed on four characteristics lowering the potential for behaviour change. The application of motivational interviewing and goal setting was studied by content analysis of interviews with care professionals.

#### Results

All four expert-driven *fair* thresholds for motivational interviewing were reached in only one of eleven interactions. Overall, 280 goals were set with 230 older adults (mean age  $77 \pm 6.9$  years, 59% women). Among these, 91% were set at the outcome level, 96% did not specify the time or magnitude, and 21% used desire talk. Most effort during interactions was spent on the *engaging* and *focusing* processes of motivational interviewing, with little time spent on *evoking* and *planning*. Application was hindered by the context (e.g., the proactive approach and once-only set-up) and the proficiency of care professionals.

# **Discussion and Implications**

Implementation was suboptimal for motivational interviewing and goal setting. Few goals incorporated the potential for behaviour change, only one motivational interview reached minimum accepted thresholds, and little time was spent on evoking and planning. Unsurprisingly, these decreased the potential for behaviour change and improved well-being in the older adults who participated.

#### INTRODUCTION

It is recommended that clinicians should strive to provide integrated care for older adults.<sup>1</sup> Such care can be provided within proactive comprehensive geriatric assessment services that combine a population screening strategy with an interdisciplinary multi-domain approach.<sup>2</sup> Next to the need for integrated care, older adults and care professionals each advocate the need for a more person-centred approach to care that increases well-being<sup>3</sup> and decreases care dependency.<sup>1</sup> Motivational interviewing (MI) and goal setting are established methods for delivering these goals.

MI is a well-researched person-cantered care communication strategy used by professionals to promote healthy behaviour and achieve health benefits.<sup>4</sup> It involves a care professional exploring and resolving individual ambivalence to behaviour change<sup>5</sup> rather than merely giving a diagnosis and advice. Four overlapping processes are involved: *engaging* (establishing a trusting relationship), *focusing* (determining the target for change), *evoking* (eliciting change talk; i.e., motivational statements about change), and *planning* (increasing commitment to change and formulating an individualized plan of action). The care professional should use adherent strategies for MI (i.e., affirmation, seeking collaboration, and emphasizing autonomy) and avoid non-adherent strategies (i.e., confronting and persuading).

Although MI was developed within psychiatry, it has since then been applied in various care settings, including primary care.<sup>6</sup> The technique has been shown to be effective in increasing healthy behaviour, treatment compliance, motivation, and emotional well-being,<sup>7</sup> including in elderly people.<sup>6</sup> A key element of MI is to identify goals during the focusing process. Indeed, the identification and setting of goals is considered key aspect to delivering true person-centred care.<sup>8</sup> Goal setting is also commonly used to increase patient involvement in decision-making and to increase their overall motivation.<sup>9</sup> It has proven feasibility for use with older adults<sup>10</sup> and is effective as a behaviour change technique.<sup>11</sup> The addition of MI and goal setting techniques to existing care could, therefore, help to enhance person-centeredness.

Previously, we incorporated MI and goal setting in a proactive outpatient assessment service for frail community-dwelling older adults, called Sage-atAge+ (in Dutch, Wijs Grijs 2.0). Although we had sought to increase patient-centred care, the inclusion of these techniques had no additional effects on the physical, psychological, or social well-being of older adults. However, before concluding that these strategies were ineffective, it is necessary to determine the extent to which they were actually applied. This is because it can be difficult to implement a multi-component trial into daily practice, because the extent of performance

cannot always be known, and because performance of different components may vary. Studying the extent of performance is crucial to preserve both the internal and external validity, and it can provide invaluable insights into the reasons for an intervention's success or failure. In this ensures that results are interpreted accurately to facilitate the successful translation of evidence-based interventions into practice.

The implementation of separate study components should be evaluated alongside the effect evaluation, <sup>15</sup> thereby allowing conclusions to be made about the efficacy of components and to understand the results of a multi-component intervention. Understanding the reasons for inadequate implementation rates is important for two main reasons. On the one hand, the components can seem promising, but implementation (strategies) or components may need to be further adapted to the local context to improve implementation. <sup>16</sup> On the other hand, it may be that further implementation of the intervention and its components add no benefit. Measuring the quality of the extent to which MI is performed, known as treatment fidelity, is already recognized to be a key factor when appraising trials of MI. <sup>5</sup> For goal setting, it is important to determine the extent to which goals have the characteristics needed to promote the potential for behaviour change. <sup>17</sup>

Given that further development of MI and goal setting during outpatient assessments could be beneficial, we aimed to study the extent to which these strategies were adopted within Sage-atAge+ and to identify the factors that influenced their use.

# METHOD Design

We performed a mixed-methods process evaluation alongside our study into the effects of the Sage-atAge+ outpatient assessment service for community-dwelling older adults. This service was designed to increase the general well-being of participants by enhancing their involvement in resolving their unmet needs. We studied the determining the implementation rate and the MI and goal setting quality. We also searched for explanations for the extent of performance by analysing the judgments and experiences of care professionals who had used MI and goal setting. The process analysis focused on the perspectives of care professionals because the perspectives of older adults were thoroughly considered in another study. Figure 1 shows the relation between the intervention components, the questions used in the process evaluation, and the data sources.

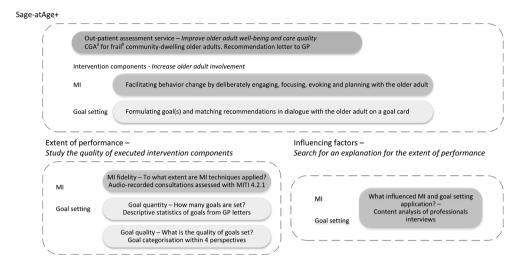


Figure 1. Study design, intervention components, process evaluation questions, and data sources

*Italic*: Component's aim. <sup>a</sup> comprising an assessment by a nurse or (for the most frail older adults) by an elderly care physician, oral screening by dental care worker, medication evaluation by a pharmacist, and, if applicable, consult from an allied care professional; <sup>b</sup> Groningen Frailty Indicator  $\geq 4$  (possible range 0-15)<sup>19</sup> and/or care profile based on frailty and case complexity  $\geq 2$  (possible range 1-5).<sup>20</sup> Abbreviations: CGA, comprehensive geriatric assessment; GP, general practitioner; MI, Motivational Interviewing; MITI, Motivational Interviewing Treatment Integrity (code).

#### **Ethical considerations**

The study was conducted in accordance with the Declaration of Helsinki and the Code of Conduct for Health Research (2004). The ethics committee of the University Medical Centre Groningen confirmed that the study did not require ethical approval based on the Dutch law for medical trials (M12.120835). Written informed consent was obtained from all older adults before they participated in the study. All care professionals consented to the publication of the final manuscript.

# Sage-atAge+ service

The Sage-atAge+ service comprised two steps: (1) proactive screening of community-dwelling older adults for frailty and case complexity; and (2) assessment of needs and goals of older adults identified as frail. We then generated recommendations for the frail older adult and their general practitioner (GP). Older adult involvement in the intervention was promoted by using MI and goal setting techniques.

Patients were selected for assessment by sending a postal questionnaire and informed consent form to 1495 adults aged  $\geq$ 65 years from seven primary care practices in the rural Northern part of the Netherlands. In total, 49% of the older adults (n = 725) returned the questionnaires. Of these, 44% (n = 322) had substantial frailty and underwent a comprehensive geriatric assessment between September 1, 2014, and April 1, 2016. Overall, their mean age was 77  $\pm$  6.9 years (range, 65–94), 59% were women, 60% were married, 33% had a low educational level, and 97% were of Dutch ethnicity. Details of the recruitment and selection procedure, as well as the participant characteristics, are published elsewhere. 12

## Comprehensive geriatric assessments

Comprehensive geriatric assessments were provided by a nurse or an elderly care physician,<sup>21</sup> with the latter only performing assessments for the most complex and frail cases. The focus of these assessments was well-being, including social and functional participation, physical and psychological needs, and the living situation. A pharmacist performed a risk assessment of drug-related problems and a dental care worker took an oral history and assessed the oral cavity. If considered necessary, optional diagnostic consultations could be added from a dietitian, physiotherapist, psychologist, or occupational therapist.

Written summaries of the assessments, consisting of one or more points of concern, corresponding life and health-related goals, and recommendations were formulated and written on a *goal card* in collaboration with the older adult. MI was used to stimulate the older adult's ability to reach the goals by deliberately improving their motivation through engaging, focusing, evoking, and planning. The content of the *goal card* was recorded in the older adult's file and incorporated in the letter to his or her GP.

Between October 2014 and January 2015, all care professionals involved in the Sage-atAge+study were invited for three 4-hour training sessions about MI. During these, didactic instruction was combined with role playing to allow practice with eliciting change talk, seeking collaboration, and goal setting. Participants received instructor and peer feedback on their performance. To improve compliance and sustained adoption of the newly acquired techniques, two booster sessions were held with care professionals that reinforced the training and provided an opportunity to discuss practical experiences.

# MI fidelity of audio-recorded interactions

The MI fidelity was rated with the Motivational Interviewing Treatment Integrity (MITI) coding system.<sup>22</sup> The MITI is a reliable behavioural coding system which assesses the extent to which MI techniques are used during interactions by coding the remarks of care professionals. We audiotaped and transcribed eleven consecutive assessments by care professionals during December 2016 (four

times by a nurse, three times by a pharmacist, and once each by an elderly care physician, a physiotherapist, a psychologist, and a dietitian). The median assessment length was 32 (range, 16–65) minutes. Following the MITI, a 20-minute segment of each session was coded independently by two students studying for a master's qualification in a health field. Whenever the audio-recorded assessments exceeded 20-minutes, a segment of that length was selected that focused on a target change behaviour. Both coders had received 20 hours of training in coding with the MITI by an expert from the MI network of trainers (JJ) who also provided supervision while they performed the coding.

First, we scored four global MI qualities (i.e., partnership, empathy, cultivating change talk, and softening sustain talk) on a Likert scale that captured the coder's overall judgment of the global qualities of an interaction. Summary scores were calculated with these and checked against expert-derived *fair* thresholds, which is considered the minimum extent of MI application needed to obtain the desired effects:<sup>23</sup>

- 1. The relational score is the average of the partnership and empathy global scales. Higher scores indicate clinicians trying to foster a collaborative approach and genuinely seeking to understand a patient's perspective. The possible range is 1–5, with the fair threshold set at 3.5.
- 2. The technical score is the average of the softening sustain talk and cultivating change talk global scores. Higher scores indicate clinicians actively eliciting the patient's arguments in favour of positive change (i.e., change talk) and decreasing the patient's arguments for no change (i.e., sustain talk). The possible range is 1–5, with the fair threshold set at 4.
- 3. The *reflection to question ratio* is calculated, with the fair threshold set to a ratio of one reflection to one question. Higher scores indicate that the clinician centres on engagement and evocation. The *fair* threshold is set at one or more reflections to one question.
- 4. We calculated the *percentage of complex reflections* compared to the sum of complex and simple reflections. The fair threshold was set as >40%.

Each relevant utterance of a care professional was counted as an adherent (i.e., affirming, seeking collaboration, and emphasizing autonomy) or a non-adherent (i.e., confronting and persuading) behaviour category of MI.

# Goal setting: quantity and quality based on medical records

The recommendation letter to the GP was extracted from all participants' medical records and any goal(s) were recorded, if applicable. *Goal quantity* was described by the median number of goals per participant with the interquartile range (IQR) and total range. *Goal quality* was classified into four categories: desire language, goal level, magnitude specification, and time frame specification.

**Desire language**. We coded this language element because it is known to be associated with the potential for behaviour change.<sup>24</sup> Every goal using the words "want," "desire," "like," or a synonym of those words, was coded as desire language (e.g. "would like to improve walking").<sup>25</sup>

**Goal level**. We classified goals at the behaviour or the outcome level based on an adaptation of a taxonomy for behaviour change techniques.<sup>17</sup> Goals at the *behaviour level* were those targeting behavioural solutions (e.g. "playing billiards again; going outside with the mobility scooter"), whereas goals at the *outcome level* were defined in terms of an expected consequence of one or more behaviours, without being a behaviour in itself (e.g., "decrease in abdominal discomfort"; "stay independent for as long as possible"). In addition to the taxonomy of Michie et al., to improve our agreement on this discrimination, we coded as the behaviour level when a goal could be a task that could be added to a to-do-list. Whenever this seemed impossible or if we needed to give more specification on the next step (e.g. "being among people more frequently"), we coded at the outcome level.

**Specification categories.** Specificity was coded because it is considered to increase the potential for behaviour change by increasing commitment to that change.<sup>26</sup> These elements were adapted from a taxonomy of important goal elements for people with dementia.<sup>27</sup> *Magnitude* was coded into three categories: *magnitude or volume specified* if the goal was objectively measurable (e.g., "having a daily walk"), *mentioned but not quantified* if the goal was specified without the amount (e.g., "stabilize weight loss"), and *not mentioned* if the evaluation criterion for a goal was unknown (e.g., "decrease stress"). *Timeframe* was also coded into three categories, as follows: *specified* if the time to attain the goal could be measured on a calendar, *mentioned but not specified* if a vague time period was used (e.g., "soon or as long as possible"), and *not mentioned* if no time period was given.

# Interrater agreement

The interrater agreement for MITI coding was assessed on five recordings between the two coders with a two-way mixed effects model, absolute agreement, average measures intra-class correlation coefficient. The mean interrater agreement for coding between the reviewers was excellent (interclass correlation coefficient  $0.81 \pm 0.15$ ). All interclass correlation coefficients ranged between good for complex reflections (0.64) and excellent for affirmations (0.95), except for giving information, which was only fair (0.44). When applicable, the average of both raters' scores was calculated. Finally, we calculated the means, standard deviations, and ranges for the behaviour counts and summary scores. The number of interactions reaching the *fair* threshold was counted.

Two researchers (WR and CN) independently applied the taxonomy for goal setting, and their allocation was similar in 94% of categories (range 92%–95%). Cohen's kappa was 0.48 for the goal level, and the linear Cohen's kappa values were 0.79 for *magnitude* and 0.83 for *timeframe*. Whenever there was disagreement over categorization, consensus was reached after discussion between WR and CN.

# **Identification of influencing factors**

Influencing factors were identified by MI and goal setting based on interviews. Semi-structured interviews with all care professionals were held by WR, a physician and researcher, within three months after the Sage-atAge+ program had ended. The topic list comprised questions about the feasibility and acceptability of the program and its intervention components, and experience with various elements of the program (e.g., training, MI, goal setting, and goal cards). All interviews were audiotaped, but technical problems resulted in two tapes being unusable. These interviews were transcribed in detail by the interviewer and checked by the interviewee within a week. All other tapes were transcribed verbatim.

We used inductive content analysis to derive findings by focused evaluation of questions phrased by WR and DG.<sup>29</sup> The analysis of transcripts was supported by the software package Atlas.ti 7. WR analysed all interviews, and discussed themes, and corresponding quotes with JJ and DG regularly. All identified experiences and influencing factors were substantiated with relevant quotes.

#### **RESULTS**

# Sample: care professionals and assessments

Overall, 322 comprehensive geriatric assessments were performed as part of the Sage-atAge+ program. Of these, 29% (n = 92) were excluded from analysis due to a lack of informed consent (n = 79) or missing medical record data (n = 13). Thus, the medical records of 230 participants were available and included in the analysis. All assessments were executed by three specialist geriatric nurses, except for 7% (n = 15), which were performed by the elderly care physician. Additional assessments by the pharmacist and the dental care assistant, which were offered to all participants, were attended by 94% (n = 217) and 29% (n = 67), respectively. Consultations with other allied health care professionals were attended by 25% (n = 57). Finally, a *goal card* was provided for 53% (n = 121) of the assessments.

Among the ten professionals involved in the Sage-atAge+ program, four attended all training sessions, one attended only one session, two attended no sessions (logistical reasons), and three reported that they had already received training in MI. All participants were interviewed, except for the occupational therapist due to logistical reasons. An overview of data about the care professionals, the number of assessments, and their attendance at MI training is presented in Appendix 1.

# **Extent of performance: MI fidelity**

The results of the MITI assessment are shown in Table 1. Adherent behaviour was expressed twice on average per interaction (SD 1.2, range 0.5–4): specifically, affirmation was expressed once on average per interaction (SD 1.0, range 0–2.5), whereas seeking collaboration or emphasizing autonomy were counted a maximum of once. Non-adherent behaviour was more common, occurring up to a maximum of 13 times (mean 5.1, SD 4.1): confronting was never seen, but persuasion without permission occurred to a maximum of 13 behaviour counts in one interaction.

Concerning the summary measures, one interaction met none of the four thresholds and only one interaction met all four thresholds. The threshold on the *relational scale* was met in eight interactions, whereas that on the *technical global scale* was met in all but one. The *reflection to question ratio* was above the threshold in four of eleven interactions. Only in one interaction was the threshold for the *complex reflection ratio* reached.

Table 1. MITI coding results of audiotaped interactions (n = 11)

	Mean	SD	Range, min– max	Possible range	Threshold <sup>a</sup>	Threshold reached, n (%)
Behaviour counts		-				
MI adherent behaviour, total	2.0	1.2	0.5-4			
Affirm	1.1	1.0	0-2.5	≥0		
Seek collaboration	0.5	0.5	0-1	≥0		
Emphasize autonomy	0.4	0.4	0–1			
MI non-adherent behaviour,	5.1	4.1	0-13.5			
total						
Confront	0.0	0.0	0-0	≥0		
Persuade	5.1	4.1	0-13.5	≥0		
Summary Measures						
Relational	3.4	1.0	1.3-4.5	1–5	≥3.5	8 (73)
Technical	3.2	0.6	1.5-4	1–5	≥3	10 (91)
Reflection to question ratio	0.8	0.6	0.1–2	>0	≥1	4 (36)
% complex reflections	20	2.0	0-50	0-100	≥40	1 (9)

MI, Motivational Interviewing; MITI, Motivational Interviewing Treatment Integrity (code) 4.2.1; SD, standard deviation. <sup>a</sup>The fair threshold was used<sup>22</sup>

Extent of performance: goal setting

In 206 of the 230 assessments (90%), 280 goals were formulated by the geriatric nurses or the elderly care physician and presented in a recommendation letter to a GP. The median

goal count per adult was 1 (IQR, 1-2; range, 1-4). Goals mostly aimed to preserve the status quo (51%, n=144), with the most common goals being to preserve independence or self-sufficiency for as long as possible (n=30) and to preserve mobility for as long as possible (n=28). The allocation of all goals among the four characteristics is shown in Table 2. Desire talk was used in 21% of the goals, the behaviour level was specified in 9%, and the *magnitude* was specified in 4%. *Timeframe* was specified in only one goal.

Table 2. Goal quality from four different perspectives (n = 280)

Used	60 (21)
Not used	220 (79)
Behaviour	26 (9)
Outcome	254 (91)
Specified	10 (4)
Mentioned but not quantified	28 (10)
Not mentioned	242 (86)
Specified	1 (0)
Mentioned but not quantified	142 (51)
Not mentioned	137 (49)
	Not used  Behaviour Outcome  Specified Mentioned but not quantified Not mentioned  Specified Mentioned but not quantified

NA, not applicable

# Influences on applying MI and goal setting

The interviews revealed that the extents to which MI and goal setting were applied were influenced by the context and the care professional's proficiency. Moreover, not all MI processes were sufficiently applied and are described in Figure 2 and in detail in the following text.

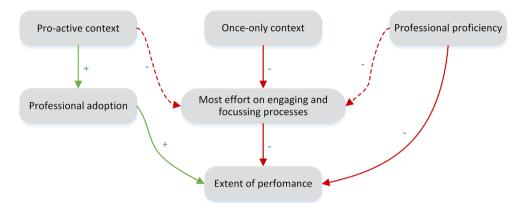


Figure 2. Factors influencing the extent of performance of MI and goal setting within a proactive assessment program

green lines = positive influence; red lines = negative influence; solid line = strongly substantiated within our data; dashed line = moderately substantiated within our data.

**Context:** Sage-atAge+ was proactive and once-only. Care professionals expressed the need to increase participant motivation because of the proactive approach. However, because the older adults did not volunteer for the service, they experienced low ownership, did not expect benefit, felt no urgency, and started with a passive attitude. This resulted in care professionals needing to focus on overcoming significant motivational barriers.

"Since you start from scratch in this visit, both for yourself and the one in front of you, one hour might not be enough to create internal motivation. So, during the conversation something will come up, but they also need to be motivated. "." Only when it is something urgent, something they would have wanted to do for a long time, it will succeed." (Elderly care physician)

Thus, there was high motivation among the care professionals to adopt MI techniques and goal setting. They believed these techniques could be of real benefit in engaging older adults and helping them to formulate and reach their goals.

"[Sage-atAge+] is a supplement for frail older adults since they take their frailty for granted most of the time, or they don't see it. By having a conversation with them, many things will come up. Things that they do not discuss with their [GP] or that just had slipped in." (Dental care worker)

The proactive approach not only influenced the motivation of care professionals but also made engagement a delicate process. This was because the professionals often felt less authority and experienced friction during the engaging process.

"At a certain moment you feel when people are having resistance, that you are meddling some one's autonomy. I don't think that is ok. ".." As a screener, without having a relationship with the patient, I should not cross that line." (Nurse B)

The once-only context negatively influenced whether MI and goal setting were applied, often leaving the professionals feeling reluctant to engage in depth, specifically regarding psychological topics.

"At some moments I was wary to get an intimate discourse by asking a certain question. And then I would never see them again. Yes, that is definitely a disadvantage." (Nurse A)

The once-only context also made it difficult to reflect on earlier attempts and engagement with health behaviour change, which hampered the evoking process.

"That is also a disadvantage of seeing them only once. Otherwise you could ask them whether they succeeded or what challenges they experienced, since that is something we can work on together." (Nurse C)

**Care professional's proficiency.** Suboptimal proficiency in MI negatively influenced effective delivery. For example, the evoking process was hampered because some care professionals feared achieving an opposite result when triggering sustain talk.

"It could be a sensitive issue for people, especially if you give them the feeling they are not performing well. "." And since I did not know how to deal with that, I avoided the topic, to prevent saying the wrong things and making them grab their cigarettes. I did not feel familiar with that, so I preferred to avoid these topics." (Nurse C)

Most care professionals expressed a need for ongoing training or booster sessions to improve their knowledge and to exchange their experiences (e.g., dealing with barriers).

"And we also discussed the way we wrote stuff down [on the goal cards]. "." You can consult each other ... that would have been good, and I think it has been done too little, since that is something you can learn from." (Nurse A)

**Most effort was spent on the engaging and focusing processes.** Professionals felt they lacked the time to execute all MI processes because of the need to overcome the barrier of low participant motivation during assessments.

"You need to become acquainted with people, you need to win their trust, you are talking about what they have raised in the questionnaire, and you hope that they will find some motivation to start working on things that might have been considered obvious but could become a problem. That is a lot to do within a one-hour visit." (Nurse B)

When mentioning a follow-up context, however, less time was spent on the engaging and focusing processes of MI.

"And you notice, when people come for a follow-up visit, they will get back to the first conversation, and then it is easier to continue with what has been discussed before. It is easier to step in, so to speak. Because you have already won their trust." (Nurse B)

The limited proficiency with MI of care professionals, especially with the evoking process, meant they felt more comfortable with the engaging and focusing processes.

"For example, a man who is smoking and does not consider this an issue. At these moments I think 'never mind, who am I to say something about this?" (Nurse C)

Overall, the extents of performing MI and goal setting were positively influenced by the high motivation and attempted adoption by professionals. However, although the Sage-atAge+ context contributed to this motivation, it also hampered the extent of performance, mostly because a lot of effort needed to be spent on the engaging and focusing processes. We found that the proficiency of participating care professionals was insufficient to overcome these barriers.

#### **DISCUSSION**

Implementation research is essential for the successful translation of evidence-based interventions into practice. Using a mixed-methods strategy, we studied the extent to which MI and goal setting were performed within the Sage-atAge+proactive assessment program for home-dwelling older adults (65+) to identify why we failed to show the hypothesized effect on well-being. In the current study, we showed that goal setting was prevalent, but that MI fidelity and the quality of goals were suboptimal, despite high motivation and adoption by care professionals. Overall, the proactive and once-only context of the service, as

well as the limited proficiency of the care professionals, were the main factors hindering successful implementation.

MI fidelity was low in our research, with only one in eleven interactions reaching all thresholds for which effect on behaviour change was expected. Adherent behaviour was also infrequent during the motivational interviews, despite its known effectiveness for improving healthy behaviours.<sup>24</sup> When compared to GPs without training in M,<sup>30</sup> the consultations in our study had much better scores on the *relational* and *technical summary scores*, implying these care professionals performed better at engaging with their patients and in delivering patient-centred or patient-friendly consulting. However, the professionals did report limited proficiency, especially when evoking change talk, which is consistent with reports that it is the most difficult MI skill to acquire.<sup>31</sup> Limited proficiency is often seen in trials of MI<sup>32</sup> and can be attributed both to limited training and the need to update and consolidate skills over time through booster sessions.<sup>5</sup>

Goal setting was highly implemented, with 90% of all letters to GPs containing at least one goal for which desire talk was prevalent. The mapping of these individual needs and wishes within goals is central to person-centred care<sup>8</sup> and was reflected in the positive attitudes of participants toward the service<sup>18</sup> However, only a minority of the formulated goals contained aspects that were expected to increase the potential for behaviour change. The fact that professionals spent most effort and time in engaging and focusing participants meant that less time was available to specify goals further or to elaborate on goal planning.

Most goals that we identified were aimed at maintaining the status quo and not at delivering tangible improvements, which is in line with other recent research on proactive goal setting with community-dwelling older adults.<sup>33</sup> The fact that we detected preventive or long-term needs rather than urgent needs likely results from the use of the proactive approach. However, to achieve the actual benefits of preventive behaviour change, much more effort is needed for goal planning compared to the requirement of goals that seek to achieve short-term benefits, especially for older people.<sup>34</sup>

The proactive and once-only context of Sage-atAge+ was probably the main reason for care professionals spending most of their interaction time on the engaging and focusing processes of MI, and having very little time for evoking and planning. This represented the care professionals adapting to the needs of older adults, who often first required to set goals, before discussing their ambivalence for behaviour change and starting action planning. However, by failing to complete all processes, the necessary tools to achieve meaningful change were not delivered. If a professional is to complete an assessment after only achieving engagement and focus, follow-up will be needed to specify goals through evoking and planning. This could explain the limited effect of any outpatient assessment

service that lacks direct influence over the implementation of recommendations.<sup>35</sup> The modifying effect of this influence has also been reported in earlier reviews on the effects of outpatient assessment services.<sup>2</sup> To date, we are unaware of any studies describing the role of failure to execute the goal planning process on the limited impact of those services.

# **Methodological considerations**

Some remarks can be made about the methods and validity of the current study. The mixed-methods strategy allowed us to explain the results of implementation, with the quantitative results complementing the qualitative results. Together, they formed the basis of our conclusion that suboptimal MI and goal setting explained the failure to achieve the hypothesized outcomes of the Sage-atAge+ program.

We complied with the criteria proposed by Jelsma et al. when coding and reporting the MI fidelity,<sup>36</sup> but not with the minimum recommended collection of 20 interactions. Although this could have hampered the validity of our assessment of MI fidelity, it should be noted that we substantiated our fidelity findings by including the experiences of care professionals and by assessing the quality of goal setting. Consequently, we expect our conclusion about suboptimal MI to be valid.

We are not aware of a feasible goal taxonomy for coding full-scale goal quality, consistent with an existing report that currently available goal setting evaluation tools are inadequate.<sup>37</sup> Therefore, we combined several existing goal characteristic classifications from the literature. By doing so, we created a taxonomy that was feasible and had high agreement and reasonable kappa scores. The discussions between raters led to full agreement. With this taxonomy, we could provide insights into the characteristics and quality of goals, the proficiency of care professionals in goal setting, and the potential of goals to result in desired effects. However, external validation is needed before we can advocate further usage of this taxonomy.

It should also be noted that the care professionals who participated in this research did not receive specific training on the goal characteristics we reviewed with the taxonomy, which may have contributed to the low quality we found. In addition, this gives a useful insight into the reality of adding goal setting to daily practice without specific training.

# Recommendations for future research and practice

Our current study results help to explain not only the extent of performance (i.e., how the older adult involvement was enhanced within the outpatient proactive assessment service) but also the factors that influenced that extent of performance. This may lead to service enhancements and adaptations, including the addition of

behaviour change techniques.<sup>17</sup> For example, by allowing for follow-up to deliver goal planning services, we may improve participant engagement and motivation. Equally, the implementation of MI could be enhanced to increase fidelity: this may involve extending the initial training, offering booster sessions, or better adapting to the needs of professionals by focusing on the process of evoking. Fidelity could even be monitored during service delivery to control for whether MI thresholds are reached.

In terms of future research goals, the impact of proactive approaches on participant engagement requires further study. It could be tested whether this is a key barrier in other integrated proactive programs for older adults. Such research into implementation may improve our understanding of the additional value of MI strategies within person-centred care for older adults. Designs can be improved to overcome the barriers to motivation and goal planning, such as implementing case management instead of once-only assessment strategies. However, if we are to deliver true person-centred care, we must avoid striving blindly for behaviour change if it is at the expense of recognizing the goals of the older adult, who may not want behaviour change.

#### **CONCLUSIONS**

In this mixed-methods implementation study to identify the reasons for failure to achieve the expected outcomes in a previous study, <sup>12</sup> we found MI fidelity and goal quality were suboptimal despite a high prevalence of goal setting. Several issues contributed to these problems. It is true that care professionals lacked some proficiency with MI, especially with the evoking process, resulting in less time being spent on evoking and planning, and decreasing the opportunity to resolve ambivalence to behaviour change among the older adults. However, our findings indicate that this was not the full extent of the problem. Perhaps of even greater importance was the proactive and once-only context of the Sage-atAge+ service. To improve MI and goal setting implementation in the future, we should not only seek to focus on adding booster training sessions but also on adopting a case management approach that allows for adequate patient follow-up over multiple session. Lessons learned from implementation studies that are conducted alongside effect evaluations can help both to improve care and to develop effective and efficient care programs.

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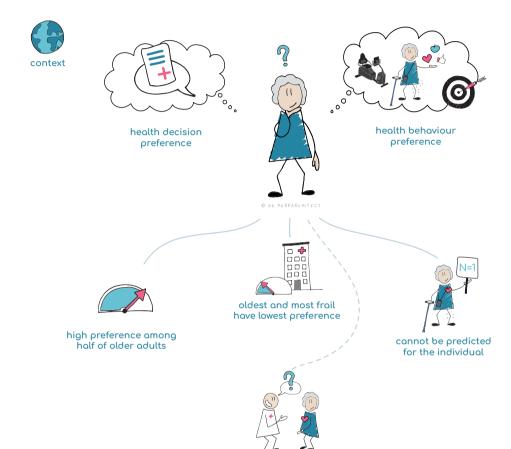
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Appendix 1. Overview of data provided by care professionals and the implementation reach

Care professional	MITI au- diotape	Interview	Assess- ments (n)	Attended Sage- atAge+ MI training sessions	
Nurse A	-	•	48	3/3	
Nurse B	4	•	113	3/3	
Nurse C	-	•	54	0/3*	
Elderly care physician	1	•	15	3/3	
Pharmacist	3	•	217	0/3*	
Dental care worker	-	•	67	1/3	
Allied health care professionals			57		
Physiotherapist	1	•		3/3*	
Psychologist	1	•		0/3*	
Occupational therapist	-	-		1/3*	
Dietitian	1	•		0/3	

<sup>\*</sup> Care professional had previously attended training in MI elsewhere MI: Motivational Interviewing; MITI, Motivational Interviewing Treatment Integrity (code)



verify preferences

# Older adult preferences for health decision engagement and health behaviour

Submitted

W Rietkerk, JPJ Slaets MA van Offenbeek SU Zuidema DL Gerritsen

#### ABSTRACT

### Objective

Adapting to patients' preferences is important to improve patient outcomes. Preference levels for engagement and health behaviour are expected to decrease when ageing. As little empirical data exists for older adult preferences, we examined whether these preferences can be identified in clinical practice.

#### Methods

Older adult preferences for health decision engagement and health behaviour were measured with multiple Likert-scales. Combining dichotomized preferences for low versus high level of decision engagement and low versus high level health behaviour led to four preference types. Differences in demographic and clinical characteristics between preference types were non-parametrically tested.

#### Results

Among 1408 older adults (mean age 79.9 years  $\pm$  7.8; 62% women) the types' prevalence ranged from 13% (low-low: low decision engagement and health behaviour) to 50% (high-high). Type low-low was related to older age, single marital status, assisted-living situation, low education level, higher frailty, and lower quality of life (all p<0.0001).

#### Conclusion

Half of the older adults prefer both health decision engagement and health behaviour. The other half varied, with a substantial percentage showing ambivalence in their preferences. Despite statistical differences, demographic and clinical characteristics insufficiently predict these preferences.

# **Practice Implications**

Care professionals should verify and discuss patient preferences separately.

#### HIGHLIGHTS

- Half of older adults prefer both health decision engagement and health behaviour
- An individual's health decision engagement and behaviour preferences can be opposed
- Preferences are associated with other patient characteristics to a limited extent
- Care professionals should explicate these preferences with older adults individually

#### INTRODUCTION

Patient participation and patient empowerment receive increasing interest in the scientific literature and clinical practice.<sup>1</sup> Patient participation is related to health decision engagement while patient empowerment is related to the individual's health behaviour, by taking responsibility for one's own health.<sup>2</sup> Preferences vary across studied populations for health decision engagement<sup>3</sup> as well as health behaviour,<sup>4</sup> depending on specific morbidity and demographic characteristics.

Care professionals should preferably match their approach to the patient's preferences to improve patient outcomes.<sup>5</sup> For example, optimal matches between the preference for health decision engagement and the actual enacted or experienced engagement results in higher treatment satisfaction and emotional well-being, and more effective treatment.<sup>5</sup> However, matching the care professionals' consultation strategy to patient preferences was found to be difficult and often results in mismatches.<sup>6</sup> Such matching between the consultation approach and a patient's preferences would be easier when patient preferences could be predicted a priori based on their demographic or clinical characteristics.

Older adults tend to have a relatively lower need for health decision involvement.<sup>7</sup> Moreover, they tend to show less health behaviour engagement due to long-term (health) goal disengagement.<sup>8</sup> While on the one hand preference levels seem to decrease with age, the need for optimal preference accommodation increases with age, at the individual as well as the societal level. For the individual, due to co-morbidity and frailty, the complexity of interventions increases, and the importance of aligning therapy with individual norms and values increases to maintain quality of life.<sup>9</sup> From a societal point of view, health care expenditure per capita is the highest for older adults,<sup>10</sup> implying that optimizing therapeutic chances in this population has the highest impact on societal costs. However, older adult preferences have not been studied frequently.

We studied the preferences for health decision engagement and health behaviour in a broadly sampled older adult population. The research aim was twofold. We wanted to determine the preference combinations for health decision engagement and health behaviour among older adults, and test to what extent these combinations can be predicted by demographic and clinical characteristics.

#### **METHOD**

Using a cross-sectional survey design, we explored the existence of different preference types and tested for demographical and clinical differences between these types with self-reported data in a sample of older adults.

Each older adult, or an authorized representative, provided written informed consent for data usage. The study complies to the ethical prerequisites of the declaration of Helsinki and the contemporary Dutch legislation for medical research.

### Sample

Preferences were collected within an older adult sample (aged 65 years or over) from the North-Eastern part of the Netherlands. To ensure that frail older adult subgroups were also included, stratified sampling on living situation was performed through 25 diverse healthcare and welfare organizations in urban and rural areas. This survey was performed between 19 May 2011 and 30 December 2011. Detailed information on recruitment, selection procedure and participants is published elsewhere.<sup>11</sup>

#### **Measurement instruments**

Data were collected through postal surveys. Support by volunteers for filling in the survey was offered to all respondents. The volunteers were trained to uniformly support the older adult through the clarification of the questions and response options and facilitating the appropriate pace. The survey contained questions on preferences for health decision engagement and health behaviour and included amongst others demographic and clinical characteristics.

Health decision engagement preference was defined as the extent to which autonomy in health decisions was favoured. It was measured with the following three items: 1) How much influence would you like to have on decisions about personal care? 2) How much influence would you like to have on medical decisions? 3) How much influence would you like to have on decisions about psycho-social problems? For these three items the following five scoring options were available: 1 I would prefer to leave that decision entirely to others; 2 Others may decide, but I want to be informed; 3 Others may decide, but I want them to take my opinion into account; 4 I want to decide with others; 5 I want to decide completely independently.

Health behaviour preference was defined as the motivation for performing behaviour with the intention to promote health. This preference was also measured with three items: 1) I want to do as much as possible to prevent or minimize problems related to my physical health; 2) I want to do as much as possible to prevent or minimize problems related to my mental well-being. 3) I want to put effort into (continuing to) seeing people and maintain relationships with others. These three items were rated on a 5-point Likert scale (1-5), which ranged from strongly disagree to strongly agree.

# **Demographic and clinical characteristics**

Next to the preferences, older adults reported on their demographic characteristics (age, gender, four-digit postal code, marital status, living situation and educational level) and on two clinical characteristics: frailty and quality of life. *Frailty* was assessed with the Groningen Frailty Indicator (GFI),<sup>12</sup> which comprises 15 items, divided over four domains: physical, social, cognitive and psychological. The total score can range from 0 to 15, a higher score indicating a higher level of frailty. *Quality of life* was assessed by Cantril's ladder: 'How would you rate your life at this moment' with a numeric rating score from 0 to 10,<sup>13</sup> a higher score indicating a higher level of quality.

# **Analysis**

Using the four-digit postal code, the socio-economic status (SES) was determined based on the calculation of the Netherlands Institute for Social Research. <sup>14</sup> The SES score is constructed from the mean income of a neighbourhood, the percentage of citizens with low incomes, low education levels and non-employment. With factor analysis these features are composed into one characteristic: the neighbourhood's SES. The SES scores from 2010 were used.

Both preference item groups were tested for being internally consistent scales using Cronbach's alpha. Alpha is considered reasonable when >.7.15 The correlation between both scales was tested with the Spearman rank correlation after calculating the mean score of three items on each scale.

After examining the descriptive data and plots, we decided to form four groups of preference types. To this end, we dichotomized both preference item groups based on the scores on each of the two scales. Participants were considered having a 'High decision engagement preference' when they scored 4 (I want to decide with others) or 5 (I want to decide completely independently) on each item of the decision preference scale. Equally, participants were considered having a 'High health behaviour preference' when they scored 'agree' or 'strongly agree' on each item of the health behaviour preference scale. In all other cases, participants were considered having a 'Low preference' on the respective dimension. Each combination of preferences was seen as a preference type, and prevalence for each type was calculated.

We tested for differences in patient characteristics between the four preference types with Kruskall-Wallis tests for continuous variables (age, quality of life and frailty) and used Pearson Chi square exact limits for the ordinal and nominal variables (gender, educational level, living situation, marital status and SES). We used non-parametric testing because of the non-normal distribution of variables. To correct for multiple testing, p-value for significance was set at 0.01. Finally, all significantly different characteristics were dichotomized and the positive predictive

value was calculated and displayed for the least prevalent preference type.

# RESULTS Sample

Data of 1408 older adults were available. More than half of the participants (54%) were assisted in completing the questionnaire. Demographic and clinical characteristics are shown in Table 1.

Table 1. Older adult sample characteristics (n=1408)

Variable		
Age	mean SD	79.9 (7.8)
Centenarian	n %	160 (11)
Gender	n %	
Female		869 (62)
Male		539 (38)
Marital status <sup>a</sup>	n %	
Married		660 (51)
Single		66 (5)
Divorced		54 (4)
Widowed		621 (44)
Living situation	n %	
Together, independent		571 (41) <sup>b</sup>
Alone, independent		364 (26)
Assisted-living		
Residential home		377 (27)
Nursing home		93 (7)
Educational level	n %	
high		157 (11) <sup>b</sup>
medium		610 (43)
low		638 (45)
SES	n %	
high		63 (5)
medium		140 (10)
low		1164 (85)
Frailty (GFI)	mean SD	5.1 (4.9)
QoL NRS	mean SD	6.8 (1.6)
QoL ≥ 9	n (%)	73 (5)
<u> </u>	V: · /	- \-/

SES: Social economic status based on postal code; GFI: Groningen Frailty Indicator, possible range 0-15 with higher scores indicating more frailty; QoL NRS: Quality of life Numeric Rating Scale, possible range 0-10 with higher scores indicating a better quality of life <sup>a</sup> Marital status: 4 missing, Living situation, educational level, frailty, and QoL: 3 missing,

SES: 41 missing

b sum < or > 100% due to rounding

The mean age of the participants was 79.9 years (SD 7.8) and 62% was female. Half of them were married, 34% were living in a home for assisted-living (comprising residential and nursing homes) and the majority (85%) lived in a low SES area. Participant's quality of life on a 11-point numeric rating scale was 6.8 (SD 1.6) on average.

# **Preference scales reliability**

Internal consistency for both scales was very good. Cronbach's alpha for decision engagement was .85 and for health behaviour preference .76. Spearman rank correlation between both scores was .22 (p <0.0001), suggesting different concepts.

# **Preference types**

The median preference for health decision engagement was 4.0 (IQR 3.3 - 4.3, min 1 – max 5) and for health behaviour 4.0 (IQR 4.0 - 5.0, min 1 – max 5).

After dichotomization, in every potential combination of preferences we found a subsample of older adults, with prevalence rates ranging from 13% (low-low preference) to 50% (high-high preference) (See Figure 1).

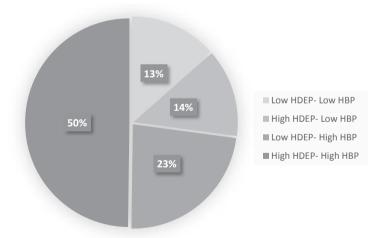


Figure 1. Distribution of preference types within an older adult population (n=1408)

HDEP: health decision engagement preference; HBP: health behaviour preference

Table 2 shows the difference in demographic and clinical characteristics between the four preference combinations. The low-low preference group (column 1) has a higher mean age (83.4 years; SD 7.8) than the high-high preference group (column 4) (78.4, SD 7.5, p < 0.001).

Table 2. Characteristics for each prevalence type and differences between preference types

Variable		Low HDEP – Low HBP	high HDEP – low HBP	low HDEP – high HBP	High HDEP – high HBP	difference between types
	N (%) <sup>a</sup>	190 (13)	192 (14)	325 (23)	701 (50)	p-value <sup>b</sup>
Age	mean (SD)	83.4 (7.8)	80.9 (7.8)	80.6 (7.6)	78.4 (7.5)	<0.0001
Female gender	n (%)	114 (60)	118 (62)	188 (58)	449 (64)	.27
Married status	n (%)	63 (33)	73 (38)	158 (49)	366 (52)	<0.0001
Living situation	n (%)					<0.0001
Together indep		37 (20) <sup>c</sup>	52 (27) <sup>c</sup>	146 (45)	336 (48)	
Alone, indep		28 (15)	62 (33)	70 (22)	204 (29)	
Residential home		81 (43)	64 (34)	89 (27)	143 (20)	
Nursing home		43 (23)	13 (7)	19 (6)	18 (3)	
Educational level	n (%)					<0.0001
high		12 (6) <sup>c</sup>	21 (11)	32 (10)	92 (13)	
medium		67 (35)	75 (39)	136 (42)	332 (47)	
low		110 (58)	95 (50)	156 (48)	277 (40)	
SES	n (%)					.09
high		4 (2)	6 (3) <sup>c</sup>	14 (4)	39 (6)	
medium		17 (9)	13 (7)	28 (9)	82 (12)	
low		163 (89)	161 (89)	279 (87)	561 (82)	
Frailty	mean (SD)	7.2 (3.6)	5.9 (3.6)	5.5 (6.1)	4.2 (4.6)	<0.0001
QoL NRS	mean (SD)	6.1 (1.7)	6.3 (1.8)	6.9 (1.4)	7.1 (1.4)	<0.0001

HDEP: health decision engagement preference; HBP: health behaviour preference; indep = independent

GFI: Groningen Frailty Indicator, possible range 0-15 with higher scores indicating more frailty; QoL NRS: Quality of life Numeric Rating Scale, possible range 0-10 with higher scores indicating a higher quality of life

<sup>&</sup>lt;sup>a</sup> percentage within a preference type

<sup>&</sup>lt;sup>b</sup> tested with Kruskal Wallis test for linear variables and Chi-square for nominal and ordinal variables.

c sum < or > 100% due to rounding

The low-low preference group is also less often married (33% resp. 52%, p <0.0001), more often living in an assisted living facility (66% resp. 23%, p<0.0001) and more often having a low educational level (58% resp. 40%, p<0.0001) than the high-high preference group. The low-low preference group also has a higher frailty level (7.2 vs 4.2, p<0.0001) and a lower quality of life (6.1 vs 7.1, p<0.0001).

No characteristic is unique for a preference type. Despite all statistical differences, for every demographic and clinical characteristic the positive predictive value for a preference type is at maximum 46% (for living in a nursing home). In figure 2 the prevalence among all preference types is visualized for the characteristics most associated with the least frequent preference type (low-low).

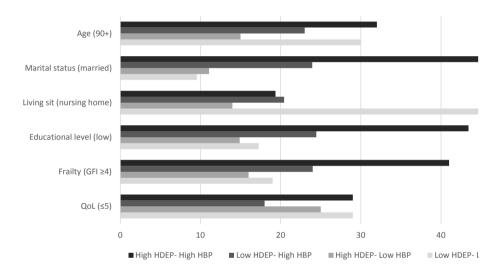


Figure 2. Distribution of demographic characteristics between preference types

HDEP: health decision engagement preference; HBP: health behaviour preference; living sit: living situation; GFI: Groningen Frailty Indicator, possible range 0-15 with higher scores indicating more frailty; QoL: Quality of life Numeric Rating Scale, possible range 0-10 with higher scores indicating a better quality of life

#### **DISCUSSION**

Within a sample of older adults, half of them prefer both health decision engagement and health behaviour. Health decision engagement and health behaviour preferences are the lowest for older adults with a higher age, who are single, reside in assisted-living, have a low education level, a higher frailty, and a

lower quality of life. The found association between age and decision engagement preference was shown before. Furthermore, a systematic review showed that decision engagement preference was lower in populations with chronic conditions, probably comparable with the frail older adults from our sample.<sup>3</sup>

However, despite the statistical differences for demographic and clinical characteristics between preference types, they have insufficient positive predictive values to predict low preferences. Next to that, a substantial percentage of older adults showed ambivalence in their preferences. Care professionals should consider this notion of different preference patterns within the older adult population. Since optimal preference accommodation has a positive effect not only on patient satisfaction but also on clinical outcomes and adherence,<sup>5</sup> accommodation is an important aspect of patient treatment. And since the demographic characteristics are not exclusively linked to a preference, care professionals should put effort into making preferences explicit to optimize preference-matching. This can be done during the consultation. However, there is a well-known reluctance of physicians to engage in explicit role clarification.<sup>17,18</sup> Goal setting<sup>19</sup> or goal oriented care<sup>20</sup> may help in eliciting preferences and establishing an effective collaboration between patient and care professional.<sup>19</sup>

So, on the one hand professionals need to optimally match these preferences. Yet, on the other hand, professionals are encouraged to enhance patient participation and empowerment, by performing health advocacy.<sup>21</sup> This is strived for within recent care developments like shared decision making<sup>22</sup> and the positive health movement,<sup>23</sup> and can be helpful in improving health outcomes.<sup>24</sup> For example, it is suggested that stimulating patient empowerment increases adherence and engagement in self-management.<sup>24</sup> However, there is a thin line in 'helping to increase someone's empowerment' and 'overriding someone's preferences' in forcing them into engagement. In this respect, the inherently normative character of the healthy ageing paradigm and the concept 'empowerment' needs to be recognized.

### **Methodological considerations**

The results of this study should be interpreted taking some methodological considerations into account. As a strength, our large sample was recruited from a diverse population of older adults. Trained recruitment volunteers put extra effort into inclusion of the very frail. In this way older adults could be included who were living in institutions and were - due to functional disabilities - relying on others for filling in their questionnaires. This sampling ensures that the sample represents a broad range of the older adult population. However, preference tendencies may vary over countries or geographical regions. Next to that, the help for filling in the questions could have introduced bias. This risk of bias was minimized by using independent volunteers who were trained to work protocolized. Lastly, the

preferences were measured a few years ago. As a time trend was found when reviewing the literature concerning increased decision involvement preferences over the past decades,<sup>3</sup> prevalence of the high-high group can have further increased since our measurement. This trend thus suggests a further declining of the positive predictive values for the preferences.

When considering our preference measurement instruments, some remarks can be made. Construct validity was not yet tested and is endeavoured, as measured preferences are influenced by the wording of questions.<sup>3</sup> Next to that, our questions did not refer to any applied or specific situation. This in line with other frequently used instruments such as the Control Preference scale.<sup>7</sup> However, it is known that preferences can change when assessed in real situations. For example, a difference in decision engagement preference was found when assessed before a clinical encounter and compared with preferences thereafter, with the latter aligning more with the enacted or experienced behaviour.<sup>25</sup> This has previously been described as the hot-cold empathy gap.<sup>26</sup> This perspective posits that it may be quite difficult for a person who is not in a situation where a decision needs to be made (cold) to imagine his or her own feelings and behaviour in those (hot) situations. This could be an explanation for the coherence we found between low preferences and high frailty, as frail patients are more likely to have experienced hot states, and could therefore adjusted their answers on the preference questionnaire.

### **Further research**

In line with the previous paragraph, older adult preferences could be further studied within a longitudinal study design, to improve insight in preference dynamics and explore the relationship between preferences and morbidity or frailty. Also, studying the way in which goal setting could help eliciting preferences will aid care professionals to align with these preferences. And lastly, the tension between striving for optimal preference-matching and stimulating one's empowerment is an interesting debate, for which ethical or psychological science could add important knowledge.<sup>27</sup>

In the current literature preferences are often viewed as a continuous bipolar concept, from high to low. However, as Cacioppo et al. proposed earlier,<sup>28</sup> the bipolar concept is probably overlooking or over-simplifying the real concept. A low preference for engagement does not reveal what is preferred instead of engagement. Thus, different combinations of engagement preference (e.g. preferring full autonomy for oneself) and support preference (e.g. preferring the other to be in full control) can exist. A preference for support is more than the mere absence of preference for engagement as it indicates what is preferred instead of engagement. Further investigation of the value and implication of 'low preference' of engagement in health decisions and health behaviour could help care professionals to optimally adapt to this preference.

### **CONCLUSION**

Among older adults a wide array of preferences exists. About half of older adults prefer both decision engagement and health behaviour. However, these preferences can also vary within an individual.

Demographic and clinical characteristics insufficiently predict these preferences. High engagement in health decisions and full health behaviour is not an aim per se. Being aware of and accommodating to this diverse array of preferences will lead to optimal person-centred care.<sup>29</sup> Care professionals should strive for explicating these preferences to optimally match their patient's preferences and improve the potential for better patient outcomes.

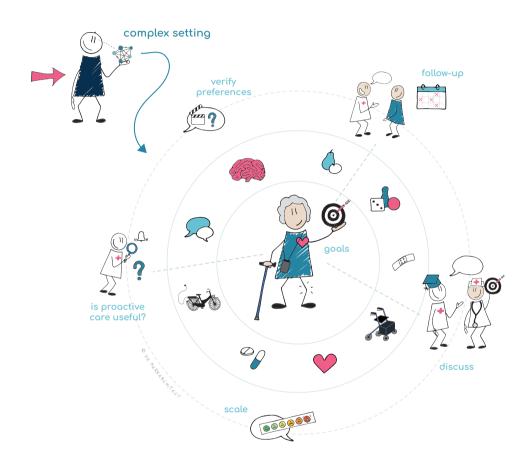
### PRACTICE IMPLICATIONS

Care professionals need to be aware that patient preferences may vary not only inter- but also intra-individually. Demographic or clinical characteristics were insufficient in distinguishing preferences. This has implications for person-centred care delivery, which aims at optimal preference-matching. Since care professionals mostly overestimate the patient's preference for involvement, 30,31 explicating a patient's preference and clarifying implications for the weighing of patient and professional responsibilities can be important during each clinical encounter. Here a moral dilemma emerges. Accepting patients' preferences to refrain from responsibility for their own health behaviour may reinforce their autonomy, but will not empower patients in terms of their health locus of control.24 It may thus go against professional values and tasks like health advocacy. Care professionals' awareness and skills for addressing this dilemma should be raised.21,27

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### **General Discussion**

In this thesis we have studied recent developments in older adult care with the realist evaluation approach. As outlined in the Introduction, tailored care is preferred for older adults. Accordingly, care initiatives have strived to develop care in a person-centred, pro-active and integrated way. Goal setting and older adult preferences are important parts of these care reforms, but it was still not well understood how these fit in with the aim of optimally tailored care. To improve our understanding of optimising older adult care, we used the realist evaluation approach. We not only addressed the outcome of innovative care approaches, but also studied the mechanisms and context in which these care programs are embedded. Our theory at the start was as follows: tailored care, by means of goal setting and enhanced patient involvement, improves well-being for older adults experiencing frailty and multi-morbidity. We evaluated three different perspectives in this regard: the extent to which recent initiatives have improved outcomes for older adults, the mechanisms behind goal setting within proactive care and the context of older adult's preferences with regards to these outcomes and mechanisms.

The proposed theory is able to be adapted as a result of our research results from the previous chapters. By doing so, we will have a better understanding into the extent to which current care developments align with the needs and preferences of older adults. We will first summarise the main findings, then reflect on these and on the realist evaluation approach, and adapt the theory accordingly. With this knowledge we are able to address questions for researchers, policy makers and care professionals. These questions should be answered before further redesigning care for older adults to align with their individual care needs.

#### MAIN FINDINGS

Outcomes: What are the effects of goal setting for older adults within an integrated person-centred care setting?

Goal setting showed no additional effect on well-being within a proactive assessment service. (Chapter 2)

Older adults were able to attain almost three quarters of their health-related goals when receiving case management within an integrated care program. (Chapter 3)

Mechanisms: How can the effects of goal setting within a proactive assessment service be explained from the older adult and care professional's perspective?

Older adult engagement and the correct timing of the program were hampered by the proactive recruitment and the limited integration of the program within existing care. (Chapter 4)

Implementation was suboptimal for goal setting within the outpatient assessment service. Few goals incorporated the potential for behaviour change and little time was spent on goal planning. Unsurprisingly, this decreased the potential for behaviour change and improvement of well-being in the older adults who participated. The proactive nature of the service emerged as an important barrier and cause for the suboptimal implementation. (Chapter 5)

Context:

Can the preferences and needs of older adults explain the effects of and experiences with a proactive assessment service?

The older adults' need for a holistic view was covered by the outpatient assessment service. (Chapter 4)

Half of older adults prefer both health decision engagement and health behaviour. The other half varied, with a substantial percentage showing ambivalence in their preferences. Increased involvement does not match the preference of all older adults. (Chapter 6)

### **REFLECTION ON THE MAIN FINDINGS**

In this thesis, by using the realist evaluation approach, we studied intervention context and mechanisms in addition to outcome. Therefore, three aspects can be addressed in the case of proactive integrated care programs not being able to work. First, the outcome measure could be insufficient at detecting change. Second, the intervention mechanisms could obstruct possible effective strategies. Third, the intervention prerequisites could mismatch the context, for instance the preference of the participants. When re-designing care, one should first take into account these last two, i.e., the context and mechanisms, before deciding on the outcome measure strategy. We will reflect on these mechanisms and context in the subsequent sections. Still, imagine a new situation where context and mechanisms are sufficiently accounted for, what outcome should be chosen to measure the effects of a tailored care program?

### Reflection on the outcome

We studied the effects of goal setting for older adults within an integrated person-centred care setting. Goal setting showed no additional effect on the average well-being of all participating older adults

within a proactive assessment service (Chapter 2). Moreover, other proactive care programs aiming to increase older adult involvement had either barely¹ or no² effect on self-reported health. However, within an integrated care program with case management, older adults were able to attain almost three quarters of their health-related goals (Chapter 3). We will outline below how these differences in effects could be explained by the outcome measures.

### Goal attainment captures heterogeneity

Within Sage-atAge we chose a composite endpoint to cover the construct of well-being. We preferred this patient-reported outcome measure above system-centred outcomes such as health care usage or costs,<sup>3</sup> and we preferred this multi-dimensional outcome over a solely health-related or other unidimensional measure to account for the heterogeneous population with needs in multiple domains. However, one can also argue against this instrument and the fit of this outcome to the program.

Firstly, the responsiveness of the instrument, as well as the underlying construct is debatable, since its subscales entail robust measures like co-morbidity or persistent complaints like pain<sup>4</sup> and memory problems. Moreover, well-being is a very difficult construct, covering a broad array of life. It is largely influenced by internal aspects such as coping mechanisms<sup>5</sup> or aspects outside the care domain, like societal circumstances such as safety and equality, or institutional aspects like autonomy.6 Therefore, one could wonder whether well-being is amendable within care services alone. A full holistic approach should include a societal viewpoint as well. Secondly, the heterogeneity of frail older adult populations causes heterogeneity in which elements of this multicomponent intervention are used, like the appropriate treatment intensity or number of referrals to allied health care professionals. Hence, since the program is designed with the aim to promote tailored care delivery, the greater the program differs between individual participants, the better it reaches its aim. Therefore, it is difficult to draw conclusions on inferences of individualised programs, adapted to personalised needs and goals when using measurement instruments with generic outcomes. Indeed, recently, in the Netherlands, the debate was raised on the applicability of these group effects on the individual.8 The Council for Public Health and Society (In Dutch: Raad voor Volkgsgezondheid en Samenleving) argued that the use of evidence-based medicine actually opposes the preferred person-centred care. However, accounting for this heterogeneity may be possible by incorporating this in measures or analysis types, for instance, with individually adapted measurement instruments, such as the SEIQol,9 or heterogeneity-of-treatment-effects analysis.10

In conclusion, older adult care innovation effects should preferably be measured with outcomes which are: a) likely to be responsive to the innovation and b) measure effects at the individual level. Goal attainment and goal progress could

possibly be considered for this in future research.<sup>11</sup>

Within Embrace we found change on both goal attainment and goal progress. However, we were unable to compare this performance with a control group (i.e. participants receiving no pro-active assessment and case management service). It is difficult to create control groups with goal plans, as goal setting is suggested to be effective in itself<sup>12</sup>. Hence, studies concerning goal setting commonly lack control groups<sup>13</sup> or experience methodological problems.<sup>14</sup> However, goal attainment measures, like goal attainment scaling (GAS) and the Canadian occupational performance measure (COPM) are widely studied instruments in rehabilitative care<sup>11,15</sup> and GAS was shown to be feasible within older adult primary care.<sup>16</sup> As can be concluded from our study, goal attainment is responsive and captures individual heterogeneous needs. Therefore, if it is possible to include control conditions in research, goal attainment seems to be a preferable patient-centred outcome measure over uniform health or well-being status measures.

### Reflection on the mechanisms

Goal setting within a proactive assessment service yielded no additional effect on the average well-being of older adults. Underlying mechanisms were studied to improve understanding of the way effectiveness of such programs could be enhanced. Thereby, we can explore insights into the way programs can be redesigned to better address specific needs of older adults.

Studies into mechanisms are recommended alongside multi-component trials to improve understanding of the mechanisms involved during hindered implementation.<sup>17</sup> For example, in a case management care program for community-dwelling frail older adults, limited adherence to the intervention protocol was found, such as a discrepancy between problems detected in the assessment and the care plans designed to resolve this problem.<sup>18,19</sup> An important mechanism here was the older adult not 'acknowledging' the detected problem and therefore 'refusing' a care plan. However, it was not further studied why care plans were refused by the older adults. We therefore dived deeper into the mechanisms that hindered the proposed implementation. We aimed to enhance insight into this hampered implementation, optimising both care design and its implementation strategies. We studied the mechanism of goal setting within proactive care from the older adult's perspective, the care professional's perspective and the actually performed interaction during the assessment.

### The proactive approach hampers goal planning and requires follow-up

Quantitative evaluation of the Sage-atAge+ implementation revealed that goals were almost always set and more than half of the older adults took home their documented goals on a goal card. Next to that, care workers experienced a high adoption rate of formulating goals and a sense of great alignment with the

aspired person-centred care (Chapter 5). This was endorsed by the older adults who approved and appreciated the holistic nature of the service (Chapter 4).

However, the older adults experienced limited integration of the service with other existing (primary) care services (Chapter 4). By studying the local context, we found that the general practitioner or other care professionals were not acting upon the assessment (pilot data Sage-atAge). Because of this, only behaviour change of the older adults themselves was expected to have an effect on well-being. With this in mind, Sage-atAge+ was developed by adding goal setting and motivational interviewing to widen the prerequisites for the older adults to act upon the assessment.

Qualitative evaluation showed two mechanisms that hindered this anticipated behaviour change of the older adults. First, the implementation of motivational interviewing was suboptimal. Second, only a few goals had the potential for behaviourchange, since they lacked specificity in time or behaviour steps (Chapter 5). Together these mechanisms underline that the older adult was insufficiently assisted to change their behaviour and therefore that the program could not be expected to be effective. Both mechanisms seemed to be in accordance with the proactive and once-only approach of the service. We discuss these mechanisms below.

By studying the experience of care professionals and audio-taping the consultations between care professionals and older adults, mechanisms for the limited application of motivational interviewing, and thus the limited planning of goals, were revealed (Chapter 5). During the assessment, most of the time was spent on the motivational interviewing processes of engaging (establishing a trusting relationship), and focusing (determining the goal or target for change). Hence, little time was spent on the remaining processes of evoking (eliciting change talk; i.e. motivational statements about change), and planning (increasing commitment to change and formulating an individualised plan of action).

The proactive approach of the program seemed to cause the need for extensive engaging and focusing, thus limiting the time for evoking and planning. For the older adults, the proactive approach resulted in limited ownership because they did not initiate use of the service, and did not predetermine or formulate their request for help. As older adults' needs and expectations were not clear beforehand, it was required to discuss these first. Engagement was therefore a delicate and time-consuming process.

Moreover, the search for the assessment focus was also experienced as time-consuming. The multi-domain approach and the lack of an explicit request for help beforehand resulted in an almost infinite range of possibilities for further focus. Thereby, although older adults were positively surprised about the multi-

domain approach, this caused uncertainty about what they were expected to address in the assessment. This, in turn, caused further delay during focusing.

With the limited time left for the process of evoking, it also seemed to be avoided, due to a lack of proficiency. It was also more difficult to apply 'evoking' in the absence of follow-up appointments, as it was not possible to reflect on earlier attempts for goal attainment. The process of 'goal planning' was almost never applied, but resulted in rushed recommendations towards the end, when the assessment time was nearly over.

So, application of the motivational interviewing processes 'evoking' and 'goal planning' was greatly hampered, partly due to the limited skills of care professionals and mostly due to the proactive and once-only approach of the service. The impact thereof is discussed below, after we discuss the quality of formulated goals.

As described above, few goals incorporated the potential for behaviour change. The majority did not contain a specified goal, nor behavioural steps to reach that goal. Next to that, goals were mostly aimed at the prevention of decline, (e.g., sustain mobility, prevent further dependency), or increasing the chance of aging in the community. This frequently pursued status quo is in line with other recent research on proactive goal setting with community-dwelling older adults.<sup>20</sup> The fact that we detected preventive or long-term needs rather than urgent needs likely results from the use of the proactive approach in combination with a well-established primary care service in the Netherlands, which seems able to tackle urgent needs.

However, to benefit from preventive behaviour change, much more effort is needed for goal planning compared to the prerequisites for goals that seek to achieve short-term benefits, especially for older people.<sup>21</sup> This is due to goal disengagement and adaptive coping strategies, which can be summarised as 'older adults have an increased precedence of short-term benefits over long-term benefits'.<sup>21,22</sup>

To improve the potential for goal attainment, care professionals can help by providing older adults with behaviour change techniques such as setting graded tasks, providing feedback on performance, and reviewing behaviour steps.<sup>23</sup> However, the proactive and once-only program insufficiently addressed these prerequisites. As a result, the one-hour assessment comprised mostly of 'engagement' and 'focusing' elements, leaving no time for the goal planning activities that are necessary for behaviour change interventions to come into effect.<sup>23</sup> This can also explain the difference in goal attainment between the Sage-at Age+program, which was a one-time meeting and showed low potential for goal

attainment and Embrace, where older adults were able to attain most of their goals and goal progress was highly prevalent. In the latter setting, case management and regular elderly care team meetings were part of the program, in contrast to the one-off Sage-atAge+ program. In this way, prerequisites for goal planning were available, like more time to focus and support the older adult during the goal planning steps.

## Differences in assessment services' approach and control over recommendations explain variation in effects

Now that the proactive and once-only approaches have been identified as opposing mechanisms of the outpatient assessment service, we are able to address long-standing questions about their variable effectiveness. First, outpatient assessment services show a lower effectiveness than inpatient assessments. Secondly, outpatient assessment services show a decreased effectiveness when these services have no control over implementation of their recommendations, when assessment recommendations are to be carried out by another person than the one who recommended them. These differences in effectiveness could be due to the varying extent to which they have a preventive approach and the existence of influence over recommendations, which will be discussed in detail below.

Inpatient assessments are mostly executed within a geriatric acute care setting where higher risks are apparent with more urgency than in outpatient settings. The addition of inpatient assessments to usual hospital care shows reduced mortality and re-hospitalisation rates, and improved functioning after discharge.<sup>25</sup> Therefore, they have been largely adopted in Western countries to supply care for geriatric inpatients. This is in contrast to the inconclusive or lack of effect of outpatient settings.<sup>25</sup> These services have a distinct approach: whereas the inpatient assessment targets an urgent and acute matter, where focus is already apparent, the outpatient assessment mostly uses a proactive approach. Since inpatient assessments are initiated around an acute problem or planned surgery, the assessment focus will be clearer for patients as well as for care professionals. This is likely to reduce the 'engagement' and 'focus' processes of motivational interviewing and hence more time can be spent on (care) planning. This seems to be a plausible explanation for the apparent, but not fully understood, difference in effect between the two settings.<sup>25</sup> Therefore, an important distinction between these service designs needs to be made, and recognition that the results for assessment programs cannot be generalised when transferred to a different setting, 26 especially when the approach is changed from a focused to proactive approach.

When assessment services (either in- or outpatient) have no direct influence on the implementation of their recommendations, limited effects are found.<sup>27,28</sup> This may be associated with the respective care professionals having different views,

goals and responsibilities.<sup>29</sup> The need for collaboration between different care professionals to create a unified view for further care alignment is underlined in a realist review within residential care,<sup>29</sup> in a primary care expert panel,<sup>30</sup> and the World Health Organization's recommendation on older adult care.<sup>31</sup> This might explain why within Sage-atAge+ older adults experienced a lack of integration with existing care, as neither follow-up nor inter-disciplinary communication was facilitated. This might also further explain the contrast in effect on goal attainment between Sage-atAge+ and Embrace, as for the latter, elderly care team meetings and case management was facilitated and goal attainment was actually reached for a majority of goals.

Therefore, the difference in effects between inpatient and outpatient assessments seems to be explainable after studying the underlying mechanisms of an outpatient assessment service. Its proactive, one-off approach without multidisciplinary collaboration, and its lack of focus, urgency, and control over implementation of recommendations, seem to reduce the effectiveness of an outpatient assessment service.

### Should we continue to strive for proactive care for older adults?

In conclusion, proactive outpatient assessment services require a lot of time to 'engage' with and 'focus' on specifying goals and goal planning. Case management guidance or multidisciplinary collaboration seem to be important prerequisites before they can be expected to have an effect on patient well-being.

Current care reforms are aiming at a more proactive strategy, likely resulting from the frailty and resilience paradigm.<sup>32</sup> Herein, frailty entails increased risks of adverse health outcomes due to a decreased ability to compensate for losses.<sup>33</sup> Therefore, it makes sense to address these risks in a timely manner and promote this adaptive ability, i.e. resilience.<sup>34</sup> However, older adults do not seem to think that anticipation of future problems will result in fewer health problems and they prefer short-term over long-term benefits.<sup>22,35</sup> So, before further development and implementation of proactive care,<sup>36</sup> we should first improve the understanding of whether resilience can be improved, and if so, how, but also what effects can be expected, and how this can be aligned with person-centred care.<sup>37</sup>

### Reflection on the context

After focusing on whether a program works, and how it works, a careful consideration of the context in which it works is imperative. Since it is the aim of the program to deliver tailored care for older adults, its context is predominantly determined by the individual older adult themselves. Therefore, we studied what care older adults need and how they prefer their role in care and will discuss the extent to which the investigated assessment services accommodate this.

# The extent to which the older adults' need for a holistic view and diversity of preferences are addressed

By studying the experience of older adults with a multi-domain assessment (Chapter 3), we found that it addressed their need for a holistic approach, integrating health with other life domains. This need is also recognised by the proposed new definition of health, the positive health approach of Huber et al.<sup>38</sup> It is addressed by the World Health Organization<sup>39</sup> and is part of the personcentred care movement.<sup>40</sup> Albeit with this awareness of holistic needs and *seeing individuals as a whole*, care is still mostly organised in a disease-centred way.<sup>41</sup>. Additionally, despite the aim of the person-centred care movement to align with patient preferences<sup>42</sup>, these preferences are frequently overlooked during the daily routine.<sup>43</sup> In that regard, we showed in Chapter 6 that preferences of older adults for health decision engagement and health behaviour differ between and within an individual. This may imply that daily practice should not focus on increased involvement and health promotion per se.

Applying this contextual knowledge in retrospect to the evaluated programmes within this thesis, this broad array of preferences for decisional involvement and health behaviour was not accounted for by Sage-atAge+ when introducing motivational interviewing with the aim to increase older adult involvement. Motivational interviewing is a communication strategy used by professionals to promote healthy behaviour and achieve health benefits.<sup>44</sup> It involves exploring and resolving individual inconsistency to behaviour change <sup>45</sup> rather than merely giving advice. It recognises differences between individuals in motivation and it requires professionals to adapt to the individual's motivation and preference. Practice nurses have been shown to apply such individual adaptation when using motivational interviewing in general practice.<sup>46</sup> However, within Sage-atAge+, combining adaptation with realistic goal planning could not be achieved due to a lack of time and proficiency.

High engagement in health decisions and health behaviour is not an aim per se; being aware of and accommodating to the diverse array of preferences will lead to optimal person-centred care.<sup>47</sup>This seems a striking paradox of the person-centred care movement, which on the one hand propagates the recognition of each patient's uniqueness regarding needs, values and preferences and on the other hand endorses patient empowerment by patient activation, education and health promotion.<sup>42</sup> This is also an important criticism on the recent positive health movement in which personal responsibility is posed as a prerequisite for good health.<sup>38</sup>

### How can we adapt to the diversity of preferences?

So, on the one hand professionals need to optimally match patient preferences. Yet, on the other hand, professionals are encouraged to enhance patient participation and empowerment by performing health advocacy.<sup>48</sup> There is a thin

line in 'helping to increase someone's empowerment' and 'overriding someone's preferences' in forcing them into engagement. In this respect, the inherently normative character of the healthy ageing paradigm and empowerment needs to be recognized.

Notwithstanding this apparent paradox, the need for optimal preference matching increases with age. Due to co-morbidity and frailty, the complexity of interventions increases, and the importance of aligning therapy with individual norms and values to maintain a good quality of life also increases.

Goal planning seems to be a good resource to resolve this issue. It supports communication between the patient and the care professional with the aim to capture a patient's specific values and circumstances as the basis for developing individualised goal plans.<sup>42</sup> In this way patient autonomy<sup>49</sup> and patient-centred care is enhanced.<sup>50</sup> The importance and benefit of goal setting is acknowledged throughout the clinical geriatric field.<sup>30,51</sup> Moreover, the World Health Organization endorses the central role of goal setting when tailoring care for older adults.<sup>31</sup>

Still, many guestions remain with this need to adapt to preferences and strive for goal-centred care planning. To begin, three of these guestions should be studied. First, how can preferences best be elicited? It is known that professionals show some reluctance to this.<sup>52</sup> The way in which goal setting can be of help here needs to be studied further. Second, to what extent are preferences amenable? For example, it was shown that decisional involvement predicts better outcomes for patients, regardless of their preference for this involvement.<sup>53</sup> Ghane et al. suggested that interventions should aim to increase patients' degree of decisional involvement when feasible and appropriate. But we still do not know when this is appropriate and what will enable this feasibility. Thirdly, when centring care around patient preferences, care professional's values are at risk of being diminished. How should care professionals act whenever patient preferences seem to interfere with patient health? And what is the societal impact when patient preferences are always respected? Can patients be the king in the care landscape? These questions are worth further studying to ensure sustainable care service developments.



## REFLECTION ON APPLYING THE REALIST EVALUATION APPROACH

After reflecting on the main findings within the realist evaluation approach, some remarks can be made on this approach itself of course. With the realist evaluation approach we were able to address the outcome of goal setting within proactive assessment care, as well as the mechanisms and context in which this care was

embedded. Through this, we improved our understanding of current older care design and can address unavoidable questions and implications for further optimising older adult care design.

### Provides important and useful insights but should be extended to a broader context

As a limitation, we solely studied the older adults' preferences and need for a holistic view. Although this is an important aspect of the context of tailored care, context can be operationalised more broadly.<sup>54</sup> Context describes those features of the conditions in which programmes are introduced that are relevant to the operation of the programme's mechanisms. This can entail participant beliefs and values, but also practical issues, like available time and money. By studying the individual needs and preferences, we focused on the micro level as most integrated care studies have done.<sup>3</sup> Since there is a relative lack of evidence regarding meso level and macro level strategies for developing integrated older adult care, these context factors deserve to be studied further.<sup>3</sup>

How can the complexity of older adult care be fully accounted for in research? Care for older adults entails case and care complexity: care is complex on the individual level as well as on the care organisation level. For example, a general practitioner can encounter difficulties when prescribing pain medication for an 89-year old woman as described in the case in the introduction. This can entail pharmacological considerations because of her increased risk of side-effects and existing medication regime. Besides, it entails being aware of her self-management ability and coping strategies, which interact with her psychological and social circumstances. Next to this case-complexity, encountered by this women with her single clinician, she encounters other professionals with their personal treatment goals. This gives rise to care complexity, postulating multi-disciplinary linkage or coordination. A new prescription will have a broader impact than the solely biological aim of this medication. As shown in the introduction, it impacts on her adherence, but can also affect other medications or her care dependency.

Therefore, it seems clear and unavoidable to consider care – and especially care for older adults – as pertaining to the 'complex' domain of the Cynefin framework (Table 1).<sup>57</sup> In this complexity perspective, no linear relationships exist between cause and effect, nor can cause and effect relations be predicted. However, studies used for evidence-based medicine are based on the 'obvious' or linear domain paradigm.<sup>58</sup> These include research strategies like the randomised controlled design and regression or prediction model analysis.<sup>59</sup> Implementation of these inflexible study protocols and inferences of these studies have a limited generalisability when accounting for the complexity perspective.<sup>60</sup>

Table 1. Four domains in which we make decisions or solve problems according to the Cynefin framework.

From left to right, complexity increases and cause-effect relationships become less clear for which applicable systems need to be adapted.

Domain	Obvious	Complicated	Complex	Chaos
Cause-effect relationship	Repeatable and predictable	Separated over time and space	•	None perceivable
Applicable policy	Linear cause- effect thinking	Scenario thinking	Pattern management	Crisis management

Therefore, when evaluating complex settings like older adult care, research designs should match and account for this type of complexity with unpredictable, changing and interfering circumstances. The realist evaluation approach accommodates for such a complex setting, which extracts context, mechanisms and outcomes and helps to combine these aspects. However, future research will require more theoretically grounded, methodologically pluralistic, flexible and adaptive study designs. Next to that, research should not only focus on understanding efficacy, but also on understanding current practice and improving implementation of known effective strategies. One way to do this is by using participatory action research, a strategy in which patients and professionals interact with researchers, and thereby have greater impact on the research set up, accounting for relevant research and improving understanding of mechanisms and context. This research strategy can even incorporate a randomised controlled design.

Next to the study design, statistical methodologies that account for the complexity within and among individuals will also improve the consideration of the complex domain. These methods entail ecological momentary assessment <sup>63</sup> by which, for example, tipping points for recovery of frail older adults can be better predicted, <sup>64</sup> and machine learning by which patterns can be better predicted. <sup>65</sup>

#### IMPLICATIONS ...

### ... for the case and theory presented in the Introduction

In this thesis we first introduced and underlined the importance of tailored older adult care, then studied the outcomes, mechanisms and context of proactive goal setting care innovations for older adults, and reflected on our findings. From this, our theory posed at the beginning of this thesis can be adapted. Our theory at the start was as follows: tailored care, by means of goal setting and enhanced patient involvement, improves well-being for older adults experiencing frailty and multimorbidity. At the present moment, we can reframe this to:

"Tailored care for older adults experiencing frailty and multi-morbidity by means of goal setting and involvement adapted to their engagement preferences, supports their need for holistic care, but can only have an impact on individual goals when embedded within a durable contact with professionals who actively align care with each other."

The implication for daily practice is detailed in Box 1, where the evolvement of the case of Mrs. Blue, introduced at the beginning of this thesis, acknowledges her goals and preferences.

# Box 1. The evolvement of the case of Mrs. Blue, taking into account her goals and preferences

The communality nurse warns the GP that Mrs. Blue seems to relapse into depression. During a house visit her GP listens to the story of Mrs. Blue, the impact of the pain and her preference to first getting to know the cause and staying active, before even starting with dizzying pain medication. Her GP proposes to confer with the anaesthesiologist about diagnostic options and the pros and cons of pain medication.

Her GP asks her whether she prefers help, and from who, to make decisions on the recommendations. In contrast to what was expected, and in spite of earlier preferences, she reveals that doing everything on her own has become a burden. She prefers to include others when making decisions, like her family. Therefore, her son accompanies her during the next consultation, and some decisions are postponed to provide the opportunity to discuss the issues within the family.

# ... for future research: adapt evaluation for setting complexity and intervention heterogeneity

With regards to the above described reflections on our findings and adapted theory, the following three suggestions for future research can be made.

First, outcomes of older adult care innovations should preferably be specified at the individual level. For example, goal attainment and goal progress measures can be considered. The optimal way of using the goals set by an individual as an outcome, while including control groups but accounting for the mechanism of goal setting as an intervention, should be further unravelled.

Second, concerning goal setting and preferences, studying the way in which goal setting could help elicit preferences will enable professionals to align with these

preferences. Older adult preferences could be further studied within a longitudinal study design. In this way, insight into preference dynamics can be improved, the relationship between preferences and morbidity or frailty can be entangled, and the possibility of amending mal-adaptive preferences can be explored through the use of behaviour change techniques. Also, the tension between striving for optimal preference-matching and stimulating one's empowerment is an interesting debate, for which ethics or psychological science could add important knowledge.

Last but not least, when evaluating complex settings like older adult care, research designs should match for this complexity with unpredictable, changing and interfering circumstances. Research designs should be able to allow for changing circumstances and to provide insight into the interplay of relevant variables.

### ... for policy makers: support sustainable care integration and collaboration

As inpatient assessment services are largely effective and widely adopted in the field, it makes sense to introduce these to the outpatient setting. However, effects of these outpatient assessment services are less clear.<sup>25</sup> In this thesis we unravelled mechanisms which can explain this difference in effect between outpatient and inpatient assessments. When further re-designing outpatient assessment services, these mechanisms should be acknowledged. As such, these services need to have more focus and urgency, and be integrated within an established and supported collaboration network. A recent development in the field in line with this recommendation is the structured funding of general practitioner referrals to elderly care physicians for community-dwelling older adults with complex needs. Because of the highly prevalent care and case complexity when caring for older adults, integrated care networks are required. To develop these networks, the collaboration between professionals is demanded and facilitated, for example by recent scientific funding of care network developments (https://www.zonmw.nl/ nl/onderzoek-resultaten/geestelijke-gezondheid-ggz/programmas/programmadetail/programma-langdurige-zorg/).

Improving integrated care is an incremental process that takes time, for which a suitable environment needs to be created. Multiple generic factors outside the clinical practice were found to be fitting in integrated care projects throughout Europe. For example, factors enabling care integration were: guaranteed or long-term funding, alignment with the political agenda, permission for different care providers to cooperate, and data sharing possibilities. 66

When designing and financing these integrated care projects, it is important to bear in mind that integration and collaboration will take time, for two main reasons. First, it will require time to develop the network, expand collaboration and define

roles, before improvement of the actual care delivery process.<sup>66,68</sup> Second, when the network is established, extra time will still be required for the professionals to collaborate, deliberate, meet, and align care with each other. This time is often not considered during negotiation of the role of professionals (in Dutch: *indirecte tijd*), and is therefore barely reimbursed. Yet, financial compensation for this time should be made available for professionals.

# ... for practice: use goals as guidance and acknowledge the diversity of preferences

To enhance tailored care for older adults, care professionals can be facilitated by creating sustainable cooperation circumstances, as outlined in the previous section. However, care professionals themselves can already enhance their practice to further align care to the preferences and goals of individual older adults. This is mostly referred to as person-centred care. Delivering person-centred care is a frequently used mission statement for policy, care institutes and professionals in the Netherlands (In Dutch: *de cliënt centraal*).<sup>69</sup> Even though professionals acknowledge its importance, translating words into deeds is experienced as difficult.<sup>70</sup> Some recommendations based on our results and experiences in practice can be made:

Preferences differ, and demographic and clinical characteristics cannot predict these. For example, there are highly educated older adults who prefer to have no control over medical decisions, as well as centenarians or nursing home residents who prefer to perform preventive health behaviour. Therefore, care professionals should engage in explicit preference and role clarification and adapt accordingly.<sup>71</sup> Setting a common treatment or care goal can help to centre care around a persons' needs, values and capabilities. Elicitation of goals can be operationalised through listening in order to get to know, uncover and understand what is meaningful for an individual. Important strategies for this are: utilising mindful listening, allowing time for a response, supporting clients in prioritising what is meaningful and viewing the professionals' role as 'being with' rather than 'doing to'. <sup>72</sup>

Goal setting also enables care professionals to cooperate and align their treatment with each other. In this process, discussing patient-centred goals when developing care plans is imperative. To ameliorate the implementation of goals into practice, whenever multiple professionals are involved, assessments need to be followed by multidisciplinary meetings. The World Health Organizations therefore endorses three steps for tailored care: (i) comprehensive assessment; (ii) a common treatment or care goal based on the individual's intrinsic capacity and functional ability; and (iii) a care plan that is shared among all care providers.<sup>31</sup> Therefore, time for goal planning and increased collaboration in aligning goals between professionals should be facilitated. Thereafter, patient follow-up is needed to further specify goals and assist in goal planning and attainment by setting graded

tasks, providing feedback on performance, and reviewing behaviour steps.<sup>23,73</sup> Such prerequisites can be provided within a case management setting.

### **GENERAL CONCLUSION**

Individualised care for older adults is worth pursuing. Accordingly, care initiatives have strived to develop care in a person-centred, proactive and integrated way. In this thesis the impact of goal setting within such care initiatives for older adult care was studied with the realist evaluation approach. We evaluated three different perspectives in this regard: the extent to which recent initiatives have improved *outcomes* for older adults, the mechanisms of goal setting within proactive care, and the context of older adult's preferences inferencing these outcomes and mechanisms. By now, we have an increased insight into the extent with which current care developments align with the needs and preferences of older adults.

Since goals capture a broad spectrum of older adult needs and applying goal attainment is highly important and feasible in daily older adult care, goal-focused outcomes seem to be important for further studying effects of tailored care.

Not all older adults prefer to adapt their behaviour nor have faith in the proactive tackling of future problems. Therefore, it takes time to engage them in proactive care approaches. Thus, follow-up is required for adequate care and goal planning, in order to achieve goal attainment. Hence, the additional value of a once-only proactive screening of older adults seems low. For improved integration and tailoring care to the older adults' needs, case management and time for collaboration appears to be a prerequisite. For further improving the insights into care for older adults, case and care complexity should be accounted for. Therefore, flexible and adaptive study designs and non-linear statistical methods should be used when evaluating the effects of these programs.

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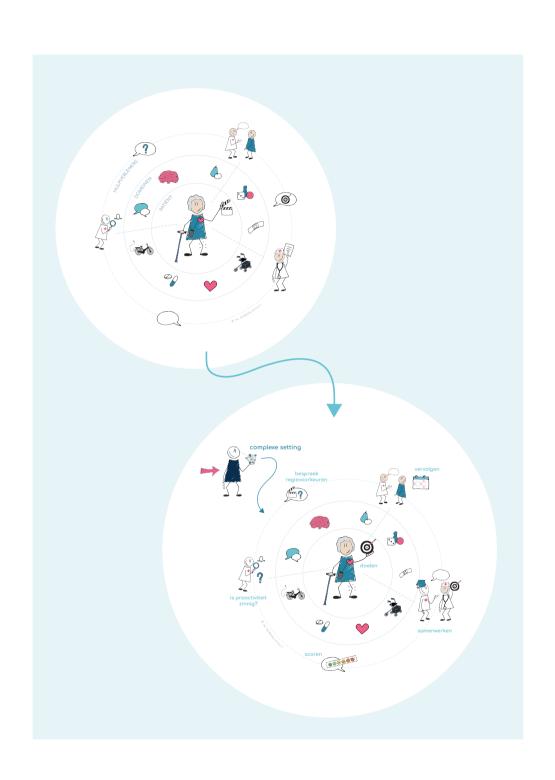
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Scientific summary
Wetenschappelijke samenvatting
List of abbreviations
Dankwoord
Curriculum Vitae

#### **SUMMARY**

Care for older adults presents a lot of challenges in the coming decades. A growing number of community-dwelling older adults are currently receiving dispersed treatment by numerous care professionals. This thesis has emerged from the desire to address the challenges and pitfalls with reorganization of older adult health care.

In chapter 1 the topic is introduced and the importance of tailoring care for older adults is underlined. The difficulties in providing the right care for older adults emerge in the context of a growing older adult population with an increasing disease burden. With this so-called multi-morbidity, care complexity increases. This implies a necessity for a tailored approach. Yet, current health care systems are largely built on an acute episodic care model which is ill-equipped to meet the long-term and fluctuating needs of older people with complex chronic health problems, as illustrated in the case below.

# Case – older adult with multi-morbidity experiences dispersed care ignorant to her goals

Mrs. Blue is an 89-year old community-dwelling woman. Despite several chronic diseases and polypharmacy, she is able to preserve her frequent family and social contacts. However, soon after she starts to experience excessive lumbar pain, seven different care professionals become involved. However, they are not able to prevent her independent functioning to quickly impair. Mrs. Blue's pain experience is taking over her life and she does not know which care professional could help her with further care planning. None of these care professionals discusses Mrs. Blue's goals nor her preferences with her or with each other.

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.

The thesis started with the following assumption:

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

With the realist evaluation approach this assumption was explored on the level of *outcomes, mechanisms* and *context* within different contemporary care practices.

# Outcomes: The effects of goal setting for older adults within a proactive care setting

Chapter 2 studied effects of goal setting for 453 frail older adults (65+) on well-being within an proactive assessment service. Halfway through the duration of the programme, we adapted the original service (Sage-atAge) with the aim to increase older adult involvement through individual goal setting and training health care professionals in using motivational interviewing techniques (Sage-atAge+). However, we found no significant difference in the change in well-being scores between the older adults receiving the Sage-atAge+ service and the original Sage-atAge service. Also, after we selected only those participants for the Sage-atAge+ group who received the service as intended, no change in well-being scores was found.

In chapter 3, we assess the results of goal planning for older adults within Embrace, an integrated person-centred care setting. Goals were set by 233 older adults (75+) with a case manager, with the aim to improve health-related problems. For every goal, they rated two severity scores ranging from 0 (no problem) to 10 (extremely severe): a baseline score and a target score. They were then supported by case management to achieve their goals. Within one year, they rated an end score to evaluate these goals. Every older adult set a median of three goals with an average baseline score of 6.0. Older adults were able to attain almost three quarters of these goals. Goal progress (the difference between severity at start and at end) was at mean 2.5 points. Goals related to physical health were the most likely to be attained and goals for mobility and pain the least likely.

# Mechanisms: The older adult and care professional's perspective explaining the effects of goal setting within a proactive assessment service

We then explored mechanisms which could explain the lack of effect on well-being for Sage-atAge+ (as assessed in Chapter 2). In chapter 4, we describe the experience of the older adults with Sage-atAge+. During in-depth interviews with 25 participants of the Sage-atAge+ service, the majority expressed satisfaction with the service. They based this on communication aspects, since only a few of them expressed real program benefits. The most redeeming feature of the service was the coverage of the older adults' need for a holistic view by the multi-domain and multidisciplinary assessment. However, on the downside, older adult engagement and the correct timing of the service were hampered by the proactive recruitment and the limited integration of the program with existing care services.

Chapter 5 explores the experience of care professionals with goal setting within Sage-atAge+. We assessed adherence to motivational interviewing by reviewing audiotaped interactions. In only one of eleven interactions, all four expert-driven fair thresholds for motivational interviewing were reached. We then reviewed the

280 goals set with 230 older adults. Most of these goals lacked characteristics which increase potential for behaviour change. From interviews with care professionals, we learned that little time was spent on goal planning and proficiency was lacking for evoking motivation. The proactive nature of the service emerged as an important barrier and cause for the suboptimal goal planning and motivational implementation. Unsurprisingly, this decreased the potential for behaviour change and improved well-being in the older adults who participated.

# Context: The older adults' preferences explain the outcomes of a proactive assessment service

We then studied an important context in which care reforms for older adults reside, namely the preferences of older adults. In chapter 6, older adult (65+) preferences are described for health decision involvement and health behaviour. These preferences were assessed with multiple Likert-scales. Among 1408 older adults, half of them prefer both health decision engagement and health behaviour. Thus, increased involvement – as strived for within Sage-atAge+ – does not match the preference of all older adults. We also show that a low preference for both decision involvement and health behaviour was significantly related to older age, single marital status, assisted-living situation, low education level, higher frailty, and lower quality of life. However, demographic and clinical characteristics insufficiently predict these preferences for an individual. Therefore, these preferences can only be identified and adequately matched to by discussing and verifying them.

# Adapting the posed assumption after studying tailored care for older adults with the realist evaluation approach

In Chapter 7, we summarise the answers to the research questions, reflect on the studies on outcomes, mechanisms and context, and describe the implications for research and practice.

We elaborate on the additional value of goal setting, for practice as well as for feature outcome measures, as they are able to capture the heterogeneity of older adult needs and are able to detect change over time. Since not all older adults prefer to perform health behaviour nor have faith in the proactive tackling of future problems, it takes time to engage them in proactive care approaches. We reflect on these findings as they seem important and cannot be overlooked when further redesigning care for older adults. Also the difference in mechanisms between outpatient and inpatient geriatric assessments are set forth. The reality of non-linear relations within older adult cases and care is discussed and adaptive research designs are suggested.

In concluding, by studying proactive care for frail older adults incorporating goal setting from the realist evaluation approach, we now have a better understanding

into the extent to which current care developments align with the needs, goals and preferences of older adults. Therefore we reframe the theory posed at the beginning of the thesis into:

"Tailored care for older adults experiencing frailty and multi-morbidity by means of goal setting and involvement adapted to their engagement preferences, supports their need for holistic care, but can only have impact on individual goals when embedded within a durable contact with professionals who actively align care with each other"

Of course, our findings demand for future research, as well as commitment of policy makers and care professionals. At this point, the implication for daily practice can already be outlined in the development of Mrs. Blue's case.

## Case – In conclusion – Taking Mrs. Blue's goals and preferences into account

The GP explores the impact of the pain for Mrs. Blue on her life, and her priorities when searching for a solution. Thereafter, the GP discusses these needs and goals with the involved care professionals, to align their implications for the right pain management in order to strive for increased well-being.

### **SAMENVATTING**

Zorg voor ouderen kent de komende decennia veel uitdagingen. Er is een groeiend aantal thuiswonende ouderen en zij ontvangen zorg versnipperd over talloze zorgprofessionals. Dit proefschrift is voortgekomen uit de wens om de uitdagingen en valkuilen te begrijpen die gepaard gaan met de reorganisatie van de gezondheidszorg voor ouderen.

In hoofdstuk 1 wordt het belang van zorg op maat voor ouderen onderstreept. De moeilijkheden bij het bieden van de juiste zorg voor ouderen ontstaan in de context van een vergrijzende populatie met een toenemende ziektelast. Voor individuen met zogenaamde multi-morbiditeit neemt de zorgcomplexiteit toe en dit vereist een individuele benadering. Het huidige gezondheidszorgstelsel en haar bekostiging zijn echter grotendeels gebaseerd op een acuut episodisch zorgmodel dat niet aansluit bij de langdurige en fluctuerende behoeften van ouderen met complexe chronische gezondheidsproblemen, zoals in de onderstaande casus wordt geïllustreerd.

## Casus - De huidige situatie - oudere ontvangt versnipperde zorg

Mevrouw M. is een 89-jarige thuiswonende vrouw die ondanks meerdere aandoeningen en polyfarmacie in staat is om frequente familie- en sociale contacten te onderhouden. Als zij hevige uitstralende pijn in haar been krijgt, raken al gauw zeven verschillende zorgprofessionals bij haar betrokken. Ze kunnen echter niet voorkomen dat haar zelfstandigheid fors afneemt. De pijn van mevrouw M. neemt haar leven over en ze weet niet welke zorgverlener haar verder kan helpen. Geen van deze zorgprofessionals bespreekt de doelen van mevrouw M. noch haar voorkeuren voor de behandeling met haarzelf of met elkaar.

Het is nog onvoldoende bekend wat de optimale manier is om zorg te leveren die toegespitst is op de complexiteit van het individu. Er is meer inzicht nodig in "wat er gedaan moet worden, door wie, voor wie en op welk moment" om ouderenzorg op maat te kunnen leveren.

Het proefschrift start vanuit de volgende assumptie:

"Zorg op maat door het stellen van doelen en verhoogde patiëntbetrokkenheid verbetert het welbevinden van kwetsbare ouderen."

Deze assumptie is getoetst door niet alleen de effecten, maar ook de mechanismen en context van het stellen van doelen te bestuderen. Deze zogenaamde realistische evaluatiebenadering pasten wij toe binnen verschillende bestaande zorgprojecten.

# De effecten van het stellen van doelen voor ouderen binnen proactieve zorg

Hoofdstuk 2 beschrijft de effecten van het stellen van doelen voor 453 kwetsbare ouderen (65+) op welbevinden bij Wijs Grijs. Dit was een proactief aangeboden geriatrisch assessment door een verpleegkundige of - voor de meest kwetsbaren - een specialist ouderengeneeskunde. Het assessment werd afgesloten met een conclusie en adviezen aan de oudere en de huisarts, die verstuurd werden naar de huisarts. Halverwege de duur van het programma is het oorspronkelijke programma (Wijs Grijs 1.0) aangepast met als doel de betrokkenheid van de ouderen te vergroten. Hiervoor werden individuele doelen gesteld met de deelnemers en de zorgverleners werden getraind in het gebruik van motiverende gespreksvoering (Wijs Grijs 2.0). Ouderen ontvingen daarbij ook een doelenkaart waarop hun doel en bijbehorende adviezen werden meegegeven. De ouderen die Wijs Grijs 2.0 volgenden hadden echter geen verschil in verandering in welbevinden vergeleken met de ouderen die het oorspronkelijke Wijs Grijs 1.0 programma doorliepen. Ook het deel van de Wijs Grijs 2.0-groep dat ook daadwerkelijk de doelenkaart ontving, ervaarde geen verandering in welbevinden.

In hoofdstuk 3 beschrijven we het proces van het stellen en behalen van doelen voor ouderen binnen SamenOud, een populatiemanagement programma. Door 233 ouderen (75+) werden samen met een casemanager doelen gesteld, om gezondheidsproblemen te verbeteren. Voor elk doel beoordeelden de ouderen de ernst van het huidige probleem en de beoogde ernst na een jaar, met een score variërend van 0 (geen probleem) tot 10 (extreem ernstig). Ze werden vervolgens begeleid door een casemanager om hun doelen te bereiken. Binnen een jaar gaven de ouderen een eindscore om deze doelen te evalueren. De ouderen stelden elk zo n drie doelen met een gemiddelde ernst van 6,0. De ouderen bereikten binnen een jaar bijna driekwart van deze doelen. De ouderen ervaarden gemiddeld 2,5 punten vooruitgang op een doel. Doelen voor lichamelijke gezondheid werden het meest frequent behaald en doelen voor mobiliteit en pijn het minst frequent.

# Mechanismen: Het perspectief van de oudere en de zorgprofessional Vervolgens onderzochten we mechanismen die het gebrek aan effect op het welbevinden binnen Wijs Grijs 2.0 kunnen verklaren (zoals beschreven in hoofdstuk 2). Hoofdstuk 4 bestudeert de ervaring van ouderen met Wijs Grijs 2.0. Tijdens diepte-interviews met 25 deelnemers aan het Wijs Grijs-programma vertelde de meerderheid tevreden te zijn over het programma. Deze tevredenheid leek echter alleen betrekking te hebben op de bejegening door de zorgprofessionals. Slechts

enkelen van hen vertelden ook profijt te hebben ervaren van deelname. De belangrijkste toegevoegde waarde van Wijs Grijs aan de bestaande zorg was het vervullen van de behoefte van de ouderen aan een holistische benadering, met het geriatrische (multidisciplinaire multi-domein) assessment. Knelpunten waren echter dat de betrokkenheid van ouderen en de juiste timing van het assessment werden belemmerd door de proactieve werving en dat het programma slechts beperkt geïntegreerd was met reeds betrokken zorgprofessionals.

In hoofdstuk 5 verklaren we de ervaring van zorgprofessionals met het stellen van doelen binnen Wijs Grijs 2.0. We evalueerden de toepassing van motiverende gespreksvoering met elf geluidsopnames van assessments. Slechts in één van de elf opnames werden alle normen voor redelijke motiverende gespreksvoering geobserveerd. Door 230 ouderen werden 280 doelen gesteld. De meeste van deze doelen misten echter kenmerken die belangrijk zijn voor daadwerkelijke gedragsverandering. Ze waren bijvoorbeeld niet concreet of niet geformuleerd op het niveau van gedrag. Uit interviews met de Wijs Grijs zorgprofessionals leerden we dat zij weinig tijd besteedden aan het uitwerken van plannen om de doelen te behalen en dat hen de vaardigheid ontbrak om motivatie te ontlokken. Het proactieve karakter van het programma bleek een belangrijke reden voor de beperkte implementatie van concrete doelen en de motiverende gespreksvoering. Uiteraard vermindert dit de kans op gedragsverandering dan wel het verbeteren van het welbevinden bij de deelnemende ouderen.

## Context: In hoeverre proactieve zorg en doelen stellen past bij de voorkeuren van ouderen

Vervolgens bestudeerden we een belangrijk onderdeel van de context waarin reorganisatie van zorg voor ouderen plaatsvindt, namelijk de voorkeuren van deze ouderen zelf. In hoofdstuk 6 worden de voorkeuren van ouderen (65+) beschreven. De voorkeur voor betrokkenheid bij gezondheidsbeslissingen en de voorkeur voor het uitvoeren van gezondheidsgedrag werden gemeten met twee Likert-schalen. Van 1408 ouderen geeft de helft aan de voorkeur te hebben om zowel gezondheidsbeslissingen zelf te nemen als om gezondheidsgedrag uit te voeren. De andere helft had op één of beide gebieden de voorkeur hier niet actief in betrokken te zijn. Een grotere betrokkenheid - zoals nagestreefd binnen Wijs Grijs 2.0 – sluit dus niet uniform aan bij de voorkeur van álle ouderen. We laten ook zien dat een lage voorkeur voor zowel beslissingsbetrokkenheid als gezondheidsgedrag significant gerelateerd was aan hogere leeftijd, alleenstaandziin, een niet-zelfstandige woonsituatie, laag opleidingsniveau, hogere kwetsbaarheid en lagere kwaliteit van leven. Deze demografische en klinische kenmerken voorspellen de voorkeuren voor een individu echter onvoldoende; geen enkel kenmerk is uniek voor een voorkeur. Daarom kan een zorgprofessional pas adequaat afstemmen op deze voorkeuren als de zorgprofessional ze bespreekt of verifieert.

# Aanpassing van de voorgestelde assumptie na het bestuderen van ouderenzorg op maat met de realistische evaluatiebenadering

In hoofdstuk 7 volgt een reflectie op alle resultaten. Het stellen van doelen lijkt voor zowel de praktijk als voor uitkomstmaten bij uitstek geschikt omdat doelen in staat zijn de heterogeniteit van de behoeften van ouderen te omvatten en veranderingen in de tijd te detecteren. Aangezien niet alle ouderen vertrouwen hebben in het proactief aanpakken van toekomstige problemen, of geen voorkeur geven aan gezondheidsgedrag, kost het tijd om hen te betrekken bij proactieve zorgbenaderingen. Met deze uitkomst dient rekening gehouden te worden bij het verder herontwerpen van de zorg voor ouderen. Tenslotte is bij veroudering en de zorgbehoeften van individuele ouderen overduidelijk sprake van niet-lineaire verbanden en complexe patronen. De impact hiervan op de zorginrichting en onderzoeksmethoden wordt besproken en alternatieve designs die rekening houden met deze complexiteit worden voorgesteld.

Concluderend hebben we door het bestuderen van het proactief stellen van doelen met kwetsbare ouderen een beter inzicht in de mate waarin de huidige zorgontwikkelingen aansluiten bij de behoeften, doelen en voorkeuren van ouderen. Daarom herformuleren we de assumptie die we aan het begin van het proefschrift opstelden als volgt:

"Zorg op maat voor kwetsbare ouderen met multimorbiditeit door het stellen van doelen en het aanpassen van hun betrokkenheid aan hun regie-voorkeuren, sluit aan bij hun behoefte aan holistische zorg, maar kan alleen impact hebben op individuele doelen wanneer deze zorg duurzaam contact met professionals omvat en in een netwerk van professionals wordt geboden die actief met elkaar afstemmen."

Natuurlijk vragen onze bevindingen om toekomstig onderzoek, evenals de inzet van beleidsmakers en zorgprofessionals. Desalniettemin is nu al een implicatie te schetsen voor de dagelijkse praktijk in het vervolg van de casus van mevrouw M.

## Casus - Rekening houden met de doelen en voorkeuren van mevrouw M.

De huisarts focust op de impact van de pijn op het leven van mevrouw M. en vraagt haar prioriteiten uit bij het zoeken naar een oplossing. Mevrouw M. geeft aan dat ze graag bewegingsoefeningen wil doen om het herstel te bevorderen. Daarna bespreekt de huisarts deze voorkeuren en doelen met de andere betrokken zorgprofessionals. Hierna kan een plan gemaakt worden voor een eenduidig pijnmanagement om zo haar welbevinden te verbeteren.

## LIST OF ABBREVIATIONS

(i)ADL (Instrumental) Activities of daily living

CEP Composite endpoint

CGA Comprehensive Geriatric Assessment

CI Confidence Interval

COPM Canadian Occupational Performance Measure

COREQ Consolidated criteria for Reporting Qualitative studies

GAS Goal Attainment Scaling
GeriatrICS The Geriatric ICF Core Set
GFI Groningen Frailty Indicator
GP General practitioner

HBP Health Behaviour Preference

HDEP Health Decision Engagement Preference

ICF International Classification of Functioning, Disability and

Health

INTERMED-E-SA INTERMED for the Elderly Self-Assessment

IQR Inter Quartile Range
MI Motivational Interviewing

MITI Motivational Interviewing Treatment Integrity (code)

NRS Numeric Rating Scale PCP Primary care practice

QoL Quality of Life

RCT Randomised controlled trial

SD Standard deviation

### **DANKWOORD**

A small step for mankind, a giant leap for this individual.

Voor het mede mogelijk maken van deze bescheiden stap voor de mensheid wil ik de volgende personen bedanken:

Allereerst alle ouderen die meededen aan de Werkplaatsen, SamenOud of Wijs Grijs. Bedankt voor het invullen van de (echt hele lange) vragenlijsten. Van de ouderen die meededen met de interviews leerden we dat een belangrijke motivator voor deelname aan Wijs Grijs het helpen van de wetenschap was. Bedankt voor het in ons gestelde vertrouwen. En zeker is het van waarde geweest! Daarnaast ook alle medewerkers en hulpverleners bij Wijs Grijs bedankt voor de openheid om jullie ervaringen te delen met mij als onderzoeker en jullie nieuwsgierigheid naar de mogelijkheden van het veranderen van de ouderenzorg, waardoor Sytse uitgenodigd werd om jullie handelen te evalueren en dit onderzoek mogelijk gemaakt werd.

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Roos, van, met en door jou leerde ik nog wel het allermeest.

### **CURRICULUM VITAE**

Wanda Rietkerk was born in Amersfoort, the Netherlands, on May 4<sup>th</sup>, 1985. She grew up in Leusden with two younger siblings. After completing primary Montessori school at 't Ronde in Leusden in 1998 and secondary school at 'de Amersfoortse Berg' in Amersfoort in 2003, she studied Medicine in Utrecht. At the geriatric department she finished her internships and obtained her medical degree in 2010. During her college years she joined the Utrecht sailing union Histos and for a full year acted as a board member.

Her scientific interest grew during her study and she finished three research projects at the Julius Centrum for General Practice research (Utrecht). Studying first medication adherence of COPD patients, thereafter business strategies of HIV-clinics in Lusaka, Zambia and lastly prediction factors for medication over-prescription in general practice.

In 2011, Wanda worked at the emergency department in the Sint Antonius Ziekenhuis, Oudenrijn in Utrecht. There her curiosity arose for the impact of diseases on people and their functioning. Therefore, she started working in a nursing home. She immediately liked the profession of the elderly care physician (ECP, in Dutch: *specialist ouderengeneeskunde, SO*), constantly working multi-disciplinary and paying much attention on advance care planning.

She decided to combine the 3-year elderly care physician vocational training with a PhD project (AlOTO) on tailoring care for community-dwelling frail older adults, resulting in this thesis. During this trajectory she also became chair of VASON – the national society for ECPs-in-training. At the end of her PhD she joined the University Network for Elderly Care (UNO-UMCG), an academic cooperation with care institutions in the north-eastern part of the Netherlands. By now, she started research on the different perspectives of care givers and professionals on crisis-events before nursing home admission.

She finished her ECP-training in 2019 in Heerenveen (at Meriant) and now works as elderly care physician in Meppel (at Noorderboog) where Wanda lives with her husband Karel and their daughter Roos (2016). As a clinician, she provides care for nursing home residents and consultations for community-dwelling frail patients. With her scientific and implementation experience she strives to bridge the knowledge-gap between academia and practice and enhance evidence-based practice in the daily nursing home routine.

Therefore, she is chair of the Noorderboog research commission and member of the Vilans commission "Erkende interventies". Wanda will continue to work for the UNO-UMCG to facilitate knowledge translation from academia to elderly care professionals.

## PRESENTATIONS AT INTERNATIONAL CONFERENCES

International Conference on Integrated Care (ICIC), Utrecht, the Netherlands			
Goal Planning in Person-Centred Care Supports Older Adults to Attain Their Health-Related Goals			
European Geriatric Medicine Society (EUGMS), Nice, France 2017 Goal planning in a person-centered care setting - are older adults able to attain their goals?			
European Geriatric Medicine Society (EUGMS), Oslo, Norway Into the black box of Geriatric Assessment – From assessment to outcomes			
Presentaties, nationaal Verenso (Vereniging voor Specialisten Ouderengeneeskunde) Doelen stellen en ermee aan de slag in een CGA – lukt dat?			
Thuiswonende kwetsbare ouderen stellen en behalen doelen met een case manager (Jan Stoop prijs)			
UKON – congres (Universitair Kennisnetwerk Ouderenzorg Nijmegen), en NHG – congres 2019 Proactieve integrale zorg voor ouderen, een haalbaar doel?			
UNO-UMCG – congres en Vilans, Zoek het Uit! – congres (workshop)  Als het thuis (even) niet meer gaat onderzoek naar de perspectieven op crisissituaties			
NHG – congres (wetenschapsvereniging voor huisartsen)  Het bespreekbaar maken van problemen in een geriatrisch assessment is geen sinecure  2018			
Verenso – congres (poster en presentatie) 2017 Kunnen thuiswonende ouderen hun gezondheids-gerelateerde doelen behalen?			
UNO-UMCG – congres 2016 Zorginnovatie in de 1e lijn – Wat Ieren we uit de wetenschappelijke evaluatie ervan?			
Verenso – congres (poster resp. presentatie) 2015 De black-box van een Comprehensive Geriatric Assessment – het proces van gesprek naar effecten			

Geriatrisch assessment in 1e lijn - patiënt tevreden maar geen effecten?

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**Rietkerk W**. Hora-Est: Zorg- en Welzijnsstandaard, integraal zorgprogramma voor kwetsbare ouderen. Ook laatste NPO-studie nu afgerond. Tijdschrift voor Ouderengeneeskunde, 2018, 6.

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