Shifting from “What is the matter?” to “What matters to you?”

Shared decision making for older adults with multiple chronic conditions and their informal caregivers
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Shifting from “What is the matter?” to “What matters to you?”
Shared decision making for older adults with multiple chronic conditions and their informal caregivers

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Prologue
An unsatisfactory conversation
On a Monday morning Mr. Hendriks visits the geriatrician at the outpatient clinic. Mr. Hendriks, aged 81, is married to Mrs. Hendriks (79), who accompanies him at this appointment. The geriatrician has read the medical history of Mr. Hendriks. He suffers from diabetes, cognitive impairment, a high blood pressure, arthrosis and he has stomach complaints. ‘What is the matter with you?’ the geriatrician asks. Mr. Hendriks complains about pain in his knees, which bothers him when he walks. After the physical examination the geriatrician also determines that the blood pressure has risen. ‘I will prescribe more painkillers for your knees and medication to lower your blood pressure.’ Then the geriatrician inquires about the memory problems. Mr. Hendriks states that it doesn’t bother him, but Mrs. Hendriks shakes her head while her husband speaks. ‘But he gets lost when I ask him to get a bread from the bakery!’ The geriatrician proposes to make an appointment for a memory test and Mr. Hendriks, reluctantly, agrees.

After the conversation:
Thoughts of Mr. Hendriks: ‘More medication and I already have so many! And I am so scared to do this memory test, they will find out about my forgetfulness and send me to a nursing home....’
Thoughts of Mrs. Hendriks: ‘Why doesn’t the doctor see how the situation really is? I cannot leave him alone anymore, he wanders off to I don’t know where.....I am so worried about the future, how long can I take care of him?’
Thoughts of the geriatrician: ‘I have treated the arthrosis and blood pressure according to the protocol and I suspect the memory test will show some deterioration. But I doubt whether he shall comply with the changes in the new medication regime, I hope his wife will assist him with that.’
General introduction
Introduction

Challenges in taking care of older adults with multiple chronic conditions

Mr. Hendriks is one of many older adults who have ‘Multiple Chronic Conditions’. Multiple Chronic Conditions (MCCs), also referred to as multimorbidity, is defined as the occurrence of two or more chronic conditions\(^1\)\(^-\)\(^3\). The prevalence of MCCs increases with age, estimations vary between 55-98% of the older adults (aged 65+ years) having MCCs, whereas lower prevalence rates are found in community dwelling older populations\(^1\),\(^4\) and higher prevalence rates are found in older populations already diagnosed with one chronic condition\(^5\)-\(^8\). Because of the worldwide ageing population, this number is increasing rapidly\(^9\). MCCs influence each other, their negative effects reinforce each other and ultimately may lead to geriatric syndromes, such as falls, functional disabilities, delirium, incontinence and pain\(^7\). There is a high level of agreement that MCCs have many negative consequences for older adults, such as functional impairment, a high treatment burden, a decline in health-related quality of life, a high need for care and a high risk on mortality\(^1\),\(^3\),\(^5\),\(^7\)-\(^12\). The more chronic conditions an older adult has, the lower his health-related quality of life will be\(^1\).

Healthcare is traditionally organised from a single disease-oriented perspective. Health professionals are encouraged to work according to evidence-based guidelines for diseases. However, most guidelines are based on research among single diseases in younger patients and provide little evidence for handling older patients with MCCs\(^6\),\(^7\),\(^9\),\(^12\),\(^13\). Treating diseases in isolation when people have MCCs can lead to burdensome and potentially inappropriate treatment\(^9\) and increases the risk of negative interaction with co-existing diseases\(^6\),\(^14\). Shifting from a disease-oriented approach to a patient goal-oriented approach could be more beneficial to an older adult’s wellbeing\(^15\),\(^16\). A patient goal-oriented approach aims to reach meaningful health outcomes as defined by the patient\(^17\). For many older adults with MCCs personal health outcomes as maintaining (functional) independence, reducing symptom burden, quality of life, social contacts and emotional wellbeing might become more important than disease specific outcomes, such as blood pressure or bone mass\(^13\). The best treatment for the disease might not be the same as the best treatment for the patient as a whole. As shown in the case of Mr. Hendriks, the question is whether prescribing more medication for Mr. Hendriks is really beneficial to his quality of life.

However, a patient goal-oriented approach requires another type of health care communication: instead of focusing on the treatment of each single disease, the conversation should start with exploring an older adult’s priorities regarding personal health outcomes, thus guiding the discussion of options and deciding about treatment or care. Since both the personal preferences of the older adult as well as the knowledge and experience of the health professional are needed to reach decisions that are in line with the preferred personal health outcomes, this type of health care communication is called ‘shared decision making’.
Chapter 1

Shared decision making

Definition of shared decision making
Shared decision making (SDM) can be defined as ‘a process in which decisions are made in a collaborative way, where trustworthy information is provided in accessible formats about a set of options, typically in situations where the concerns, personal circumstances, and contexts of patients and their families play a major role in decisions’. SDM is grounded on four ethical principles:
(1) respecting the autonomy of the patient by enabling individuals to make reasoned informed choices,
(2) the principle of beneficence
(3) the principle of non-maleficence
(4) the principle of reducing unwarranted practice variation (overuse or underuse) in light of justice and equity.

This implies not only that a patient is encouraged to share his priorities in personal health outcomes, but also that we consider the person as a whole, and not just focus on a single disease or symptom. Furthermore, the benefits of treatment must be balanced against the burden of treatment for each individual person. For older adults with MCCs these benefits of treatment gain more value if they contribute to their personal health outcome goals. In the care for older adults with MCCs these principles can be interpreted as follows: the key-question becomes ‘What matters most to you?’ instead of ‘What is the matter with you?’

The context of shared decision making, a paradigm shift in health care
Dutch society changed in the past decades from a welfare state to a participative society. In his first Throne speech (2013) the Dutch King Willem-Alexander described a vision on a participative society: ‘In this day and age, people want to make their own choices, organise their own lives and be able to take care of each other. It is in keeping with this development to organise care and social services close to people and in a cohesive manner.’ The aging population of the Netherlands urged a change in the healthcare system to keep the system affordable and staffed. Residential care homes were closed, older adults were encouraged to stay independent for as long as possible. Terms as ‘autonomy’ and ‘self-management’ became key words in health care for older adults. The older generation became better organized than ever, with senior organizations, media channels (Omroep Max) and in politics. The voice of the older adult matters, also in health care. In 2018 the Council of Older Persons was installed to advise the Dutch ministry of health, welfare and sports. In 2019 the Dutch committee ‘Future of care for home dwelling older adults’ advocated more autonomy to enable older adults to remain independent as long as possible.

These developments reflect that these days older adults are encouraged to take more ownership of their own health and thus are expected to participate more in health care conversations. In addition, the way in which our society defines ‘health’ shifted from ‘a state of complete wellbeing’ to ‘the ability to adapt and self-manage in the face of social, physical, and emotional challenges’. This new definition of health, also framed as ‘positive health’ resulted in the broad concept of health with six dimensions, including bodily functions, daily
functioning, mental functions, social participation, spirituality and quality of life. This facilitates the discussion of personal health outcomes for older adults in health care conversations.

**The history of shared decision making**

In the second part of the twentieth century the traditional paternalistic model of decision making, assuming a passive, dependent role for the patient in the treatment decision making process was gradually overtaken by an informed decision making model, in which the role of the health professional focused on informing the patient about treatment options and leaving the decision with the patients. However, whereas the paternalistic model left out the role of the patient, the informed model left out the role of the health professional. Both models did not acknowledge that both health professional and patient have valuable information that should be exchanged in order to make treatment decisions. The process in which both health professionals and patients share information and preferences in decision making, SDM, justifies the complexity of making health care decisions. In the day-to-day practice of health care, the concept of SDM was introduced in the early nineties of the last century and got slowly anchored in healthcare.

SDM models initially targeted medical decisions about equal treatment options, for example lumpectomy with radiotherapy versus mastectomy in breast cancer. However, these models were often not applicable to older adults with MCCs, since there are rarely two equal options, often due to the interaction of a treatment with other conditions. Also, in the care of older adults the option of 'watchful waiting' is often discussed, as opposed to starting a treatment.

In the last decade the boundaries of SDM started to change. First, the process of SDM was also applied to other type of decisions, e.g. care arrangements for people with dementia. Second, for older adults with MCCs, personal health outcomes became more determinative in choosing and weighing options than disease specific outcomes. This meant that within SDM there should be a shift towards exploring personal health outcomes rather than merely informing about disease specific outcomes and a person’s preferences in this respect. When health professionals involve older adults with MCCs in a SDM process, this should lead to decisions that are based on personal health preferences and which contribute to a person’s personal health outcomes, such as reduced treatment burden and unwanted healthcare. This new direction of shared decision making has so far been less developed and implemented than SDM for single diseases. New guiding principles and models are needed to guide a SDM process that meets the needs of older adults with MCCs. In conclusion, there is a movement towards SDM for older adults with MCC, however, the actual implementation of SDM in daily practice could be improved for older adults with MCCs.

**Models for shared decision making**

In order to guide the SDM process, collaborative models have been developed. Most models for SDM follow the following key steps.
Choice talk: creating choice awareness: the health professional informs the patient that a decision is to be made and that the patient’s opinion is important. The patient is being informed that more options are available and that the professional will form a partnership with the patient in this exploration of options.

Option talk: discussing the options: the health professional explains the options and the benefits and harms of each option.

Decision talk: eliciting preferences and making a decision: the professional and patient explore the patient’s preferences; the professional supports the patient in deliberation and a decision is being made.

These SDM models are important, but miss two steps that are crucial in the decision making process with older adults with MCCs. First, clarification of personal health outcomes should serve as a starting point for the SDM process. Second, for older adults the involvement of informal caregivers in the decision making process is often essential. SDM in this group is a triadic process, involving older adults with MCCs, their informal caregivers and health professionals.

The ‘Dynamic model of Shared Decision Making with frail older adults’
As an answer to the specific requirements needed for SDM with older adults with MCCs, an adapted model of SDM was developed by van de Pol et al. (2016): the ‘Dynamic model of SDM with frail older adults’ (see Figure 1). This model, validated by both health professionals and older adults with MCCs, states that adequate decisions are facilitated when they are based on the personal health outcomes goals as prioritised by patients. To this aim, this model introduces two preliminary steps, ‘Preparation’ and ‘Goal talk’, in addition to the generally known three steps of SDM models, i.e. ‘Choice talk’, ‘Option talk’ and ‘Decision talk’. Moreover, one additional last step, ‘Evaluation’, is added in the model. This model addresses specific issues as described above for SDM in older adults,
such as a broad ‘holistic’ assessment of the patient’s problems, an exploration of important health outcome goals and discussing the decision-making capacity and preferences of the patient and the informal caregiver. However, the feasibility and effectiveness of using this model in daily practice has not yet been studied.

**Knowledge gaps for SDM in older adults with MCCs**

The focus of this dissertation is on how SDM can facilitate health care conversations between health professionals, older adults with MCCs and their informal caregivers. To this end we have identified a number of knowledge gaps that are addressed in this dissertation. Research into these knowledge gaps will be guided by the Medical Research Council framework for complex interventions (MRC)\(^{41, 42}\). Working systematically through the framework improves the quality and evidence basis of interventions\(^ {41, 42}\). The MRC framework defines the following phases: (1) development phase (identifying existing evidence and gathering additional evidence), (2) feasibility phase (3) implementation phase and (4) evaluation phase (Figure 2).

**1. What are the experienced barriers to and facilitators of SDM with older adults?**

To facilitate the implementation of SDM for older adults with MCCs we need to explore existing barriers to and facilitators of SDM. Although several reviews reveal barriers to and facilitators of SDM in the general population, we expect that when facing decisions, older patients with MCCs may encounter additional barriers and facilitators, which should be identified to support the implementation of SDM\(^ {43, 44}\). For example, the influence of cognitive impairment, frailty and MCCs on SDM should be explored. Furthermore, as in the case of Mr. Hendriks, most of the care for older adults with MCCs is given by their relatives, the ‘informal caregivers’. Often they accompany the patient in the clinical consultation. They have an important role in the SDM process: as an information gatherer, coach, advisor, negotiator and/or caretaker\(^ {28, 38, 45}\). However, for many informal caregivers it is difficult to address their own concerns in the clinical encounter, for example when the patient has a lack of disease awareness due to cognitive decline\(^ {38, 46}\). Up to now, there has been little attention towards the role of informal caregivers in the SDM models\(^ {47, 48}\), while this is important in the context of older adults with MCCs. The barriers and facilitators informal caregivers experience in SDM need to be further explored.

Also health professionals experience particular challenges regarding SDM for older adults with MCCs. SDM requires a behavioural shift of health professionals. Most health professionals have learned to base their advice about treatment on their professional expertise. However, as mentioned before, in the case of older patients with MCCs, disease-specific guidelines are often not applicable\(^ {49-51}\). Thus, SDM becomes more challenging for health professionals when there is a lack of evidence on which option would be best for the patient. Discussing uncertainty and exploring what is important to the patient are challenging skills for health professionals working in tight time schedules\(^ {52}\). Fried (2016) wrote: ‘...finding the sweet spot for shared decision making will require clinicians to work against their natural impulses to tell the patient what to do when they’re certain of what’s best...’
and to leave the patient to decide when they’re not. (....) can be replaced with ‘This is a really hard decision because we aren’t sure what will happen if you choose option x; let me show you how I think about this, and you can tell me whether it fits with what’s important to you.’

More knowledge is needed about the barriers and facilitators health professionals perceive in SDM with older adults, thus guiding opportunities to support health professionals.

Research question 1: what are the experienced barriers to and facilitators of SDM for older adults with MCCs, from the perspective of older adults, informal caregivers and health professionals? (Chapter 2)

2. What are important personal health outcomes for older adults?
Research has shown that older adults are very well capable to prioritize their personal health outcomes54, 55. However, priorities on personal health outcomes may shift over time. There is an assumption that people who are already

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**Table 1. Overview of the phases of the Medical Research Council Framework that was used to answer the research questions.**

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<td>Delphi study (n= 57)</td>
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<tr>
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<td>DICO I Clinical video observational study Part 1 (n= 108)</td>
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Figure 2. Overview of the phases of the Medical Research Council Framework that was used to answer the research questions.
experiencing some decline in their daily activities, are more willing to accept further deterioration compared to people who don’t experience any decline in this area yet\textsuperscript{56}. For example, healthy people might think that a particular situation, such as being permanent bedridden or in permanent pain is unbearable, but people who are actually in such a situation, often still value their life and are willing to accept an even severe state\textsuperscript{56}. Furthermore, health professionals differ significantly from older adults and informal caregivers in what they think is important to older adults, for example regarding functional limitations, pain and social activities\textsuperscript{57}. More knowledge about views of older adults with MCCs regarding their personal health outcomes may facilitate health professionals to communicate with the older adult about his personal health outcomes.

Research question 2: what are views of older adults with MCCs on personal health outcomes? (Chapter 3)

3. How could personal reported outcome measurements (PROM’s) as the TOPICS-MDS be used to facilitate SDM?

Older adults with MCCs who want to participate in SDM need to be empowered to partake in this process. A better preparation, e.g. by a preparation intervention, followed by discussing this with the health professional, increases patient participating in decision making\textsuperscript{58}. Although several preparatory tools for patients have been developed in the recent years, most tools do not address the specific needs of older adults with MCCs\textsuperscript{59}. The TOPICS-MDS, a Patient Reported Outcome Measure (PROM) targeting older adults with MCCs, is currently implemented in Dutch Geriatric hospital care as a PROM for healthcare conversations\textsuperscript{60}. However, there is a lack of knowledge whether (1) this PROM contains all personal health outcomes older adults consider important and (2) this PROM is comprehensible for older adults with MCCs.

Research question 3: which patient reported health outcomes (PRO’s) should be discussed in health care conversations according to older adults with MCCs? (Chapter 4)

4. How can we measure SDM if personal health outcomes are discussed?

In this dissertation we focus on the actual SDM communication during the consultation. Existing measurement scales are constructed to measure the extent to which clinicians apply the SDM process, such as the validated observer OPTION-12 and OPTION-5 scales\textsuperscript{61-64}. However, the regular models and scales are not adapted to the SDM process in older adults with MCCs as described in the ‘Dynamic model for SDM in vulnerable older patients’\textsuperscript{31}. So far, adequate scales for measuring SDM for older adults are lacking. Existing SDM scales do not include health outcome goal clarification as an initial step in SDM, which is a very important element in the ‘Dynamic model for SDM in frail older patients’ (step 2). Furthermore, evaluation of the decision making process, the last step (step 6) in the ‘Dynamic model for SDM in vulnerable older patients’, is not included in existing scales\textsuperscript{65}. Since the clinician’s preparation for SDM (step 1 in the ‘Dynamic model for SDM in vulnerable older patients’) cannot be measured during the
actual consultation, this step was disregarded in view of measurement. Finally, since SDM for older adults with MCCs often has a triadic character, it is important to measure the participation of each party involved in the SDM: clinician, patient and informal caregiver. If all aspects of SDM with older adults are adequately measured, this provides information about which aspects of SDM are going well and what needs to be improved and with whom. This guides the development of interventions to solve the gaps.

Research question 4: how can we measure observed SDM during consultations with older adults, their informal caregivers and health professionals, based on the steps of the ‘Dynamic model of SDM with frail older adults’? (Chapter 5)

5. What is needed to improve SDM for older adults with MCCs and their informal caregivers?
The ‘Dynamic model for SDM in vulnerable older patients’ is a promising model to improve SDM. However, we need to know how to bridge the gap between this model and daily practice. What is needed for geriatricians, older adults with MCCs and informal caregivers to implement the ‘Dynamic model of SDM with frail older patients’ at geriatric outpatient clinics? The answers on the research questions formulated above (1-4) will guide the development of an intervention to facilitate the implementation of SDM for older adults. Such an intervention is considered a complex intervention because it contains several interacting components. For this reason the Medical Research Council framework for complex interventions (MRC) will be used41, 42.

Research question 5: which theory- and evidence-based intervention can be developed, pilot-tested and implemented to improve the implementation of the ‘Dynamic model of SDM with frail older adults’? (Chapter 6)

6. What may be expected after the implementation of the ‘Dynamic model of SDM with frail older adults’?
If an intervention is developed and implemented targeting an improved level of SDM in older patients with MCCs, the effect of such an intervention should be measured, this is the evaluation phase of the MRC framework. The main outcome for this is observed triadic SDM during consultations (research question 4), in which decisions are reached that are based on patients’ preferences for personal health outcome goals and in cooperation with the informal caregiver. In current SDM models, there is little attention for the discussion about an older person’s desired role regarding the decision making process13, 15, 39, 58, 66-70. But older adults vary in whether they want and can participate in SDM67, 71. Therefore it is important to explain what is meant by SDM and to explore the patient’s preferred role in SDM71. If a patient does not want or is not able to make the decision together, the health professional still needs to explain that there are more options and has to probe the patients priorities in health outcome goals71. Therefore, it is important to focus on the effectiveness of the intervention with regard to the preferences that older adults with MCCs have for the role and participation regarding SDM before the consultation and how they perceived this role and participation after the consultation. Finally, we would expect that an intervention leads to a decrease
General introduction

in decisional conflict and a raise in perceived SDM among older adults with MCCs. Perceived level of SDM refers to how the patients have experienced SDM. Decision conflict is defined as ‘personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values’ (73).

Research question 6: what are the effects of an evidence based intervention, based on the steps of the ‘Dynamic model of SDM with frail older adults’, to improve the implementation of SDM for older adults with MCCs? (Chapter 7)

7. How do personal characteristics of older adults influence the SDM process?
Characteristics as low health literacy, frailty and anxiety are highly prevalent among older adults with MCCs and are suspected to influence the SDM process (74-78). However, little is known about how these characteristics hamper or perhaps even facilitate SDM. More knowledge is needed about how personal characteristics of older adults influence the SDM process and SDM outcomes. This knowledge may facilitate health professionals tailor their information in the SDM process to the needs of the individual older person in front of them, enabling more older adults to participate in SDM (78).

Research question 7: which personal characteristics of older adults with MCCs influence the participation in SDM and the outcomes of SDM? (Chapter 8)

Outline of the thesis

All the studies covered in this thesis have been set up to answer the research questions as steps towards a better understanding and implementation of SDM, as a contribute to personal health outcomes that improve the lives of older adults with MCCs and their informal caregivers. Based on the knowledge gaps described above, I conducted seven studies which are briefly summarized below, to provide an outline of the thesis.

Following the MRC framework, in the development phase a theoretical basis for the SDM MCC intervention was identified in chapter 2, through a systematic literature review of barriers to and facilitators of SDM (RQ1). This was expanded in chapter 3 with empirical research on how MCCs influences personal views on the ageing process (RQ2). Furthermore, chapter 4 reports on recommendations of older adults on the use of the PROM TOPICS-MDS as input for health care conversations (RQ3). Chapter 5 outlines the development of the OPTION MCC scale through a video-observational study. This observation measurement scale aims to assess the extent that health professionals involve patients and informal caregivers in triadic decision-making tasks during videotaped consultations (RQ4). Chapter 6 describes the development of the evidence based SDM MCC intervention to improve SDM for older adults with MCCs and reports on the feasibility and implementation phase of the intervention (RQ5). The evaluation phase (chapter 7) consisted of a second clinical video observational study, in which SDM was measured by the newly constructed OPTION MCC and compared
to the ‘care as usual’ as measured in the first video-observational study (RQ6). Finally, by analysing the data of the two video observational studies, the influence of personal characteristics of older adults with MCCs on participation in SDM and outcomes of SDM was explored in chapter 8 (RQ7). The main research findings are summarized in chapter 9 and discussed in the light of the broader empirical literature. The implications of the findings are further discussed and perspectives are provided for future research, policy and practice in SDM for older adults with MCCs.
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General introduction


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Barriers and facilitators for shared decision making in older patients with multiple chronic conditions: a systematic review

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Submitted
Abstract

**Background:** The aim of this study was to describe barriers and facilitators for shared decision making (SDM) as experienced by older patients with multiple chronic conditions (MCC), informal caregivers and health professionals.

**Methods:** A structured literature search was conducted with 5 databases. Two reviewers independently assessed studies for eligibility and performed a quality assessment. The results from the included studies were summarized using a predefined taxonomy.

**Results:** Our search yielded 3838 articles. Twenty-eight studies, listing 149 perceived barriers and 67 perceived facilitators for SDM, were included. Due to poor health and cognitive and/or physical impairments, older patients with MCC participate less in SDM. Poor interpersonal skills of health professionals are perceived as hampering SDM, as do organizational barriers, such as pressure for time and high turnover of patients. However, among older patients with MCC, SDM could be facilitated when patients share information about personal values, priorities and preferences, as well as information about quality of life and functional status. Informal caregivers may facilitate SDM by assisting patients with decision support, although informal caregivers can also complicate the SDM process, for example, when they have different views on treatment or the patient’s capability to be involved. Coordination of care when multiple health professionals are involved is perceived as important.

**Conclusions:** Although poor health is perceived as a barrier to participate in SDM, the personal experience of living with MCC is considered valuable input in SDM. An explicit invitation to participate in SDM is important to older adults. Health professionals need a supporting organizational context and good communication skills to devise an individualized approach for patient care.
Background

There is much agreement that the prevalence of multiple chronic conditions (MCC) has many negative consequences for older adults, such as functional impairment, a high treatment burden, a decline in health-related quality of life, increased use of health care and a higher risk of mortality. Therefore, for many older adults with MCC, maintaining (functional) independence, reducing symptom burden and acquiring emotional health and safety might be more important health outcomes than disease-specific outcomes. The best treatment for the disease might not be the same as the best treatment for the patient as a whole. However, this requires another style of health care communication: instead of focusing on the treatment of each individual condition, the conversation should start with exploring an older adult’s priorities regarding preferred health outcomes, thus guiding the discussion of options and decisions about treatment or care. Since both the personal preferences of the older adult and the professional experience of the health professional are needed, this process is called ‘shared decision making’.

Shared decision making (SDM) facilitates the discussion between health professionals and older patients with multiple chronic conditions (MCC) when decisions have to be made about the desired care and treatment. Elwyn (2017) describes SDM as “a process in which decisions are made in a collaborative way, where trustworthy information is provided in accessible formats about a set of options, typically in situations where the concerns, personal circumstances, and contexts of patients and their families play a major role in decisions”. The outcomes of SDM mainly report on cognitive-affective outcomes of SDM, such as knowledge and decisional conflict, and the evidence points towards positive effects of SDM in this perspective. In particular the many studies about the use of patient decision aids provide evidence about better informed patients. There are fewer studies about behavioural outcomes such as compliance to treatment or adoption of health behaviors and about health outcomes such as quality of life. Also the evidence in those studies directs less clearly to positive effects of SDM.

SDM is not yet common practice; it is estimated that in only 10% of the situations in which health decisions have to be made, SDM is used. Both health professionals and patients experience barriers in making shared decisions. Most reviews focus on SDM in a general population. One review reveals barriers and facilitators of SDM in the daily life of people with dementia. However, we expect that when facing decisions, older patients with MCC and their informal caregivers may encounter additional barriers and facilitators, which should be identified to support the implementation of SDM. For example, characteristics such as anxiety, low health literacy and frailty are highly prevalent among older adults with MCC and may influence the SDM process. Anxiety is highly prevalent among older adults and associated with MCC. Anxiety in SDM may leave the patient wanting to surrender decision making to the clinician. Low HL is especially prevalent among older adults, with rates of low health literacy ranging from 30% - 68%. The prevalence of low HL increases when there are MCC. Low
HL among older adults is associated with poor shared decision making ability\textsuperscript{27}. Older adults with MCC who lack the ability to understand and communicate information may have trouble participating in parts of the SDM process, such as interpretation of test results and understanding the risks and benefits of procedures, leading to uncertainty and decisional conflict\textsuperscript{27, 28}. It is estimated that approximately 20-30\% of adults over 75 years are frail\textsuperscript{32}. For adults who are frail balancing benefits and harms of a treatment is important, since resilience capacity is often low. Furthermore, the presence of an informal caregiver, such as a family member or friend, at a medical consultation is common among older adults with MCC, for example, in our observational study we found that in 63\% of the geriatric consultations older adults were accompanied by informal caregivers\textsuperscript{33}. Informal caregivers are often involved in discussing the patients health situation and participate in decision making\textsuperscript{34}. Their role becomes more substantial when older patients are less able to participate in the consultation, for example in cases of cognitive decline\textsuperscript{35-37}. Therefore, SDM with older adults with MCC often has a triadic character, in which older patients with MCC, their informal caregivers and health professionals participate.

In a previous review about patient-reported barriers and facilitators to SDM a taxonomy of barriers and facilitators to SDM was developed\textsuperscript{19}. In this taxonomy (see Supplementary Table S2) barriers and facilitators were coded into the following categories: predisposing factors (patient and decision characteristics), interactional context factors (social factors regarding the relation between patients and health professionals), preparation for the SDM encounter (perceived need for preparation by patients and expectations about involvement) and preparation for the SDM process (providing information about options, decision support and terminology used). To gain more insight into the implementation of SDM, we enriched this taxonomy with organizational factors (health care organizations), social factors (health care settings, interdisciplinary team) and policy factors (health care system, health government) as reported by Grol et al\textsuperscript{38}. To explain the taxonomy, we developed Figure 1, which visualizes the adapted taxonomy. From all three perspectives (patient, informal caregiver and health care professional), barriers and facilitators could be reported for all types of factors.

The aim of this study is to conduct a systematic review to identify barriers and facilitators that older patients with MCC, their informal caregivers and health professionals experience in SDM.

**Methods**

This systematic review followed the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) statement\textsuperscript{39}.

**Search strategy**

We searched five electronic databases (Medline, EMBASE, PsycINFO, Cinahl, and Cochrane Central Register of Controlled Trials (Central)). Because the concept of SDM was not widely spread until the early 1990s, our search covers the period from 1980 to January 1, 2019. Based on a list of 20 key articles in the field of barriers and facilitators to SDM, the clinical librarian developed a search
strategy (Supplementary Table S1). We used both keywords and MeSH terms for ‘shared decision making’, ‘older patients’, ‘multiple chronic conditions’, ‘barriers’ and ‘facilitators’.

**Eligibility criteria**
A study was eligible for inclusion if 1) it was an original collection of data, 2) the design targeted older people (mean age > 65 years) with MCC (> 2 chronic conditions), 3) the results reported perceived barriers and/or facilitators for SDM, and 4) the study focused on either the perspective of patients and/or that of informal caregivers, health professionals or both. Conference/poster abstracts and articles that could not be retrieved were excluded.

**Study selection**
First, titles and abstracts, and second, full-text versions of potentially relevant articles were screened independently by two authors (RP, NT) on the basis of the eligibility criteria. Disagreements were resolved through discussion with a third reviewer (MS).

**Data extraction and quality assessment**
Information about the characteristics of the studies (type, setting) and perceived barriers and facilitators to SDM were extracted independently by two reviewers (RP, NT) using a data extraction sheet. Data synthesis was achieved using deductive content analysis. The reviewers identified each unit of text (a paragraph or sentence depicting one idea) relevant to the main outcomes (barriers or facilitators)
to SDM). Each unit of text was subsequently coded according to the taxonomy of barriers and facilitators to SDM. Two researchers (RP, NT) independently coded all retrieved units of text, and any discrepancies between the codes were resolved through discussions.

Similar to other reviews about facilitators and barriers for SDM, the quality of the included studies was assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (SQAC)\(^{19,21,40}\). The quality scores of the SQAC were used to define a minimum threshold for the inclusion of studies. Following the SQAC manual, the cut-point for exclusion was set at \(<0.55\) (range 0-1). All studies were independently assessed by two researchers (RP, NT), and disagreements were resolved through discussion with a third reviewer (MS).

Results

Study selection
The database searches generated 3838 unique abstracts. After screening titles and abstracts, 183 full texts were reviewed, of which 28 studies met the inclusion criteria (Fig. 2).

Study characteristics
The included studies (Table I) comprised 2990 older adults, 337 informal caregivers (IC) and 527 health professionals (HCPs). The studies originated from the U.S.A. (n=13), Canada (n=4), Sweden (n=4), Norway (n=2), the Netherlands (n=2), Australia (n=1), Germany (n=1) and the U.K. (n=1). Nineteen studies used a qualitative design\(^{41-59}\), five studies used a quantitative design\(^{60-64}\) and four studies used a mixed-method design\(^{65-68}\). Neither the quantitative nor the mixed-methods studies carried out statistical analysis regarding the barriers and facilitators, they all reported about perceived barriers and facilitators. The 28 studies reported perceived barriers and facilitators from different stakeholder perspectives: nine studies (32\%) reported on the patient perspective\(^{41,43,45,46,48,49,62-64}\), three studies (11\%) focused on the informal caregiver perspective\(^{42,57,60}\), eight studies (29\%) reported on the health professional perspective, and 7 studies (25\%) reported more than one perspective\(^{55,56,58,66-68}\). Decisions were about medical treatment\(^{44,45,47,48,53,61-65}\), medication\(^{41,53}\), goals of care\(^{50,52,54,58,66}\), daily life and lifestyle\(^{48,58,60,61}\), hospital admission or discharge\(^{42,43,51}\) and ethical or end-of-life dilemmas\(^{46,49}\).

Ten studies were based in a hospital setting\(^{42-45,50,51,53,58,64,67}\), six in a primary care setting\(^{41,47,55,59,62,65}\), four in a community care setting\(^{46,57,60,63,69}\), one in a long-term care setting\(^{48}\), one in a hospice\(^{49}\), one in a post-acute residential care setting\(^{61}\), one in a rehabilitation setting\(^{68}\), and one in a geropsychiatry inpatient unit\(^{52}\). Three studies were based in a combined setting, e.g., hospital and primary care\(^{54,56,66}\). The study patients’ age for each study is depicted in Table I. In all studies, patients had > 2 diagnoses, although in one study, a subgroup of patients had < 2 diagnoses\(^{63}\).
Review of barriers and facilitators for SDM in older adults

Records identified through database searching (n = 5407)

Duplicates removed (n = 1569)

Records screened (n = 3838)

Records excluded (n = 3655)
   Reasons: no original data collection, not about older people with MCC or not about barriers/facilitators of SDM

Full-text articles assessed for eligibility (n = 183)

Full-text articles excluded, with reasons (n = 155)
   • No original collection of data (31)
   • Not about older people with MCC (59)
   • Not about SDM (28)
   • Not about barriers/facilitators for SDM (28)
   • Conference/poster abstract (7)
   • Could not be retrieved (2)

Studies included in the review (n = 28)

Figure 2. PRISMA flow diagram of literature review process for studies on barriers of and facilitators to shared decision making in older patients with multiple chronic conditions

Quality assessment

Supplementary Table S3 shows the quality assessment scores of the included studies. All qualitative studies scored > .55 and thus met the quality standard. However, three qualitative studies\(^6, 50, 52\) were case studies and could not be assessed within the SQAC format. All the quantitative studies scored > .77. The mixed-method studies had a summarized score > 0.80 (see Supplementary Table S3).

Barriers and facilitators for SDM for older patients with MCC

A comprehensive overview of all barriers and facilitators found is presented in Table 2. From the twenty-eight included studies, we found 149 perceived barriers and 67 perceived facilitators for SDM in older patients with MCC. Most barriers were found in the following categories: predisposing factors (n=51, 34%), interactional context factors (n=32, 21%) and organizational context factors (n=22, 15%). Most
<table>
<thead>
<tr>
<th>First author</th>
<th>Setting</th>
<th>Country</th>
<th>Design study</th>
<th>Reporting focus: Barriers (B) and/or Facilitators (F)</th>
<th>Perspective</th>
<th>Participants (n)</th>
<th>% Female</th>
<th>Mean age of patients (years) (if not available: age range)</th>
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<td>B&amp;F</td>
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<td>72</td>
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<td>B</td>
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<td>100 patients</td>
<td>100</td>
<td>71</td>
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<td>B&amp;F</td>
<td>Patients</td>
<td>51 patients</td>
<td>63</td>
<td>77</td>
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<td>Quantitative</td>
<td>B</td>
<td>Patients</td>
<td>2017 patients</td>
<td>57</td>
<td>range 65 &gt;85</td>
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<td>Norway</td>
<td>Qualitative</td>
<td>B&amp;F</td>
<td>Patients</td>
<td>41 patients</td>
<td>46</td>
<td>86</td>
</tr>
<tr>
<td>Ekdahl</td>
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<td>Sweden</td>
<td>Quantitative</td>
<td>B&amp;F</td>
<td>Patients</td>
<td>15 patients</td>
<td>67</td>
<td>84</td>
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<td>Sweden</td>
<td>Quantitative</td>
<td>B</td>
<td>Patients</td>
<td>156 patients</td>
<td>49</td>
<td>83.1</td>
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<td>(case study)</td>
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<td>100</td>
<td>75</td>
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<td>U.S.A.</td>
<td>Qualitative</td>
<td>F</td>
<td>Patients and informal caregivers</td>
<td>38 patients</td>
<td>48 (total group)</td>
<td>78</td>
</tr>
<tr>
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<td>primary care</td>
<td>U.S.A.</td>
<td>Qualitative</td>
<td>B</td>
<td>Patients and informal caregivers</td>
<td>20 patients</td>
<td>61</td>
<td>82</td>
</tr>
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<td>Setting</td>
<td>Country</td>
<td>Methodology</td>
<td>Setting of Data Collection</td>
<td>Numbers</td>
<td>Setting of Data Collection</td>
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<tr>
<td>Kiselev, 2017</td>
<td>hospital &amp; community care</td>
<td>Germany</td>
<td>Mixed methods</td>
<td>B&amp;F</td>
<td>283 patients, 14 professionals (clinicians, nurses, therapists, psychologist, social worker)</td>
<td>66 unk*</td>
<td>74.4</td>
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<tr>
<td>Rose, 2018</td>
<td>rehabilitation</td>
<td>U.K.</td>
<td>Mixed methods</td>
<td>B</td>
<td>40 patients, 24 professionals (rehabilitation staff)</td>
<td>23 unk.</td>
<td>83</td>
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<tr>
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<td>U.S.A.</td>
<td>Qualitative</td>
<td>B&amp;F</td>
<td>6 patients or informal caregivers, 30 clinicians, health systems, and payers</td>
<td>unk. unk.</td>
<td>unk.</td>
<td></td>
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<td>Doekhie, 2015</td>
<td>primary care</td>
<td>Netherlands</td>
<td>Qualitative</td>
<td>B</td>
<td>19 patients, 10 informal caregivers, 38 professionals (clinicians, nurses, paramedics)</td>
<td>79 40 unk.</td>
<td>81.6</td>
<td></td>
</tr>
<tr>
<td>Puts, 2017</td>
<td>hospital</td>
<td>Canada</td>
<td>Mixed methods</td>
<td>B</td>
<td>29 patients, 24 informal caregivers, 28 professionals (oncologists and family physicians)</td>
<td>24 resp. 36</td>
<td>patients divided in 2 age groups: 63-79 &amp; &gt;80;</td>
<td></td>
</tr>
<tr>
<td>Bragstad, 2014</td>
<td>hospital</td>
<td>U.S.A.</td>
<td>Qualitative</td>
<td>B</td>
<td>Informal caregivers</td>
<td>19 informal caregivers</td>
<td>68 n.a.**</td>
<td></td>
</tr>
<tr>
<td>Peacock, 2017</td>
<td>community care</td>
<td>Canada</td>
<td>Qualitative</td>
<td>B</td>
<td>Informal caregivers</td>
<td>18 informal caregivers</td>
<td>44 n.a.</td>
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<td>Setting</td>
<td>Country</td>
<td>Design</td>
<td>Focus</td>
<td>Participants</td>
<td>Perceived Barriers/Facilitators</td>
<td></td>
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<tr>
<td>Ekdahl44, 2012</td>
<td>hospital</td>
<td>Sweden</td>
<td>Qualitative</td>
<td>B&amp;F</td>
<td>Health professionals</td>
<td>29 physicians</td>
<td>34</td>
<td>n.a.</td>
</tr>
<tr>
<td>Fried47, 2011</td>
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<td>U.S.A.</td>
<td>Qualitative</td>
<td>B</td>
<td>Health professionals</td>
<td>40 physicians</td>
<td>n.a.</td>
<td></td>
</tr>
<tr>
<td>Blaum54, 2018</td>
<td>primary care &amp; hospital</td>
<td>U.S.A.</td>
<td>Qualitative</td>
<td>B</td>
<td>Health professionals</td>
<td>9 general practitioners, 5 cardiologists</td>
<td>n.a.</td>
<td></td>
</tr>
<tr>
<td>Gopalraj50, 2012</td>
<td>hospital</td>
<td>U.S.A.</td>
<td>Qualitative (case study)</td>
<td>B&amp;F</td>
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<td>1 patient</td>
<td>100</td>
<td>94</td>
</tr>
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<td>Milte61, 2015</td>
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<td>Australia</td>
<td>Quantitative</td>
<td>B</td>
<td>Health professionals</td>
<td>2 geriatricians</td>
<td>59</td>
<td>n.a.</td>
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<tr>
<td>Schuling63, 2012</td>
<td>hospital</td>
<td>The Netherlands</td>
<td>Qualitative</td>
<td>B</td>
<td>Health professionals</td>
<td>13 physicians</td>
<td>15</td>
<td>n.a.</td>
</tr>
<tr>
<td>Molinari52, 2016</td>
<td>geropsychiatry inpatient unit</td>
<td>U.S.A.</td>
<td>Qualitative (case study)</td>
<td>F</td>
<td>Health professionals</td>
<td>1 patient</td>
<td>0</td>
<td>‘late 60s’</td>
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<td>Légaré65, 2013</td>
<td>primary care</td>
<td>Canada</td>
<td>Mixed methods</td>
<td>B&amp;F</td>
<td>Health professionals</td>
<td>Participants: a) 276 home care providers b) 7 members health care team c) 8 managers</td>
<td>Participants: a) 82 b) 100 c) 50</td>
<td>n.a.</td>
</tr>
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<td>Lindhardt51, 2008</td>
<td>hospital</td>
<td>Sweden</td>
<td>Qualitative</td>
<td>B&amp;F</td>
<td>Health professionals</td>
<td>8 nurses</td>
<td>100</td>
<td>n.a.</td>
</tr>
</tbody>
</table>

*a* ‘Reporting focus’ refers to whether the study reports about perceived barriers to and/or facilitators of SDM

*b* ‘Perspective’ refers to either the perspective of patients or informal caregivers or health professional from which the perceived barriers or facilitators are reported. Some studies describe perceived barriers or facilitators from more than one perspective

* unk.: unknown

**n.a.: not applicable
facilitators were found in the following categories: interactional context factors (n=23, 34%) and preparation for the SDM process (n=19, 28%). In Table 2 is also depicted how many studies reported about a specific barrier or facilitator, to provide insight into how often a factor was reported. In the next section the most frequently mentioned barriers and facilitators are described and explained from which perspective the barriers and facilitators were reported: patient perspective (PP), informal caregiver perspective (IP) or health professional perspective (HP).

Predisposing factors
Perceived barriers: When one is very ill, this affects one’s ability to understand information (HP/PP)\textsuperscript{43, 45, 64} and to participate in decision making (PP)\textsuperscript{49, 64}. Patients suffering from MCC are less likely to participate in SDM and worry about the burden of a treatment regime (PP/IP/HP)\textsuperscript{47, 56, 67}. Cognitive and physical impairments were considered barriers for SDM by patients, informal caregivers and health professionals. Cognitive impairment leads to difficulties in understanding information (PP/IP/HP)\textsuperscript{44, 45, 50, 60, 64}, not being able to express preferences (HP)\textsuperscript{44}, and not wanting (HP)\textsuperscript{61} or not being able (PP)\textsuperscript{45} to partake in decision making. Physical impairments can influence compliance (HP)\textsuperscript{47}, whereas severe illness (PP)\textsuperscript{49} can keep older patients with MCC from being able to partake in decision making. Health professionals often struggle with the uncertainties of applying disease-specific guidelines to older patients with MCC (PP/IP/HP)\textsuperscript{47, 53, 56}. For information about the exact numbers of articles reporting barriers, we refer to Table 2.

Perceived facilitators: Previous experience in dealing with conditions and decision making acts as a facilitator to SDM (PP)\textsuperscript{41, 43, 48}. Additionally, having personal values, such as religion, views on survival and suffering, and self-sufficiency facilitates the SDM process (PP/IP)\textsuperscript{58}. For information about the exact numbers of articles reporting facilitators, we refer to Table 2.

Interactional context factors
Perceived barriers: Both patients and health professionals reported poor communication techniques, poor language choice and lack of empathy as barriers for shared decision making (PP/IP/HP)\textsuperscript{41, 45, 50}. Older patients had little confidence that they could have a meaningful contribution to the shared decision-making process, or they felt that a lack of (medical) knowledge made them unable to participate (PP)\textsuperscript{41, 48}. On the other hand, some patients reported feeling that health professionals undervalue the expertise of patients (P)\textsuperscript{55}. Informal caregivers expressed dependency; they felt they were at the mercy of the individual health care personnel and that, in the end, the final decisions were made by the health professionals (IP/PP)\textsuperscript{42, 43}. Health professionals acknowledged that most of the time patients and informal caregivers are not seen as part of the health care team (IP/PP/HP)\textsuperscript{42, 43, 45, 55}.

Perceived facilitators: Health professionals report that clinicians who assessed a patient’s ability to understand information and to describe his or her symptoms, thoughts and feelings, particularly for patients with cognitive decline, facilitated SDM (HP)\textsuperscript{44, 50}. Patients reported that they did feel invited to partake in shared decision making when the doctor stimulated them to describe symptoms and ask questions and inquired what the patient’s main worries were (PP/IP)\textsuperscript{41, 43, 61}.
<table>
<thead>
<tr>
<th>Factor</th>
<th>Barriers (number of studies in which this factor was identified as a barrier)</th>
<th>Facilitators (number of studies in which this factor was identified as a facilitator)</th>
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<tr>
<td>Predisposing factors</td>
<td>Patient characteristics Being in poor health: 13</td>
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<td>Age: 4</td>
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<td></td>
<td>Poor articulation: 4</td>
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<td></td>
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</tr>
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<td></td>
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</tr>
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<td></td>
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<td>Prior exposure to illness/decision making point: 4</td>
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<tr>
<td></td>
<td>Personal values: 1</td>
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<td>Long term patient: None*</td>
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<td>Decision characteristics</td>
<td>Disease-based decision models (guidelines): 3</td>
<td>When decisions are allowed that are inconsistent with guidelines: 1</td>
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<td></td>
<td>Burden of treatment regimen: 2</td>
<td>Major decision: 1</td>
</tr>
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<td></td>
<td>Shock of receiving diagnosis: 2</td>
<td>Timing along the illness trajectory: None</td>
</tr>
<tr>
<td></td>
<td>Minor decision: 1</td>
<td>Minor decision: None</td>
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<td></td>
<td>Timing along the illness trajectory: None</td>
<td>Time to come to terms with diagnosis: None</td>
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<td>Major decision: None</td>
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<td>Embarrassing or sensitive topics: None</td>
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<td>Interactional context factors</td>
<td>Power (im)balance in the patient-clinician relationship Presumptions about the patient role</td>
<td>Presumptions about the patient role</td>
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<td>Not having explicit ‘permission’ to participate in SDM: 6</td>
<td>Having explicit ‘permission’ to participate in SDM: 4</td>
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<td>Expectation of the clinician making the decisions: 2</td>
<td>Perceived acceptability of asking the clinician questions: None</td>
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<td></td>
<td>Desire to act as a ‘good’ patient (driven by fear of consequences): 1</td>
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<tr>
<td></td>
<td>Belief that clinicians do not want patients involved: 1</td>
<td></td>
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<tr>
<td></td>
<td>Perceived acceptability of asking the clinician questions: 1</td>
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</tr>
<tr>
<td></td>
<td>Clinicians reinforces passivity by rewarding the behaviour: None</td>
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<tr>
<td>Table 2. Continued</td>
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</tr>
<tr>
<td>--------------------</td>
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</tr>
<tr>
<td><strong>Interpersonal characteristics of the clinician</strong></td>
<td><strong>Trust</strong></td>
<td></td>
</tr>
<tr>
<td>Patients undervalue their expertise relative to clinicians</td>
<td>Trust in clinician: None</td>
<td></td>
</tr>
<tr>
<td>‘Doctor knows best’ and patients have ‘inferior’ knowledge: 3</td>
<td>Lack of trust in clinician: None</td>
<td></td>
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<tr>
<td>Patients are not capable of understanding medical/technical information: 2</td>
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<td></td>
</tr>
<tr>
<td>Clinicians with poor interpersonal skills: 5</td>
<td><strong>Preparation for an SDM encounter</strong></td>
<td><strong>Perceived need for preparation</strong></td>
</tr>
<tr>
<td>Authoritarian HCPs: 4</td>
<td>Patient does not want or need to participate in SDM: 4</td>
<td></td>
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<tr>
<td>Clinician does not listen to patients concerns: 2</td>
<td>Patient is not entitled to a choice: 1</td>
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</tr>
<tr>
<td>Perceptions that clinicians are already doing SDM: 1</td>
<td>Patient is not explicitly offered a choice or it is presented in a biased way: 1</td>
<td></td>
</tr>
<tr>
<td>Lack of individualized approach and not asked about preferences: 1</td>
<td>‘Doing nothing’ is not an option: None</td>
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<tr>
<td>Clinician does not address patient directly: 1</td>
<td>Not knowing what to expect from the SDM consultation: None</td>
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<tr>
<td>Poor relationship with clinician: None</td>
<td><strong>Expectation of SDM outcomes</strong></td>
<td></td>
</tr>
<tr>
<td>Individualized approach where clinician seeks patient’s preferences: 4</td>
<td>Patient focus on treatment burden versus clinicians concerns about morbidity and mortality: 2</td>
<td></td>
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<tr>
<td>Clinicians with positive interpersonal skills: 2 Equal relationship: 1</td>
<td>Not wanting responsibility for wrong decision: 1</td>
<td></td>
</tr>
<tr>
<td>Clinician listens to patients concerns: 1</td>
<td>Fear of accepting reality of diagnosis: None</td>
<td></td>
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<tr>
<td>Good relationship with clinician: None</td>
<td><strong>Preparation for the SDM process</strong></td>
<td><strong>Providing information about options</strong></td>
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<td>Trust in clinician: 6</td>
<td>Insufficient information about condition, options and outcomes: 3</td>
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<tr>
<td>Lack of trust in clinician: None</td>
<td>Clinician does not explain the options and outcomes: 2</td>
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</tr>
<tr>
<td>Clinician knows patient’s and informal caregivers’</td>
<td>Clinician in repair-reflex mode (solutions without listening</td>
<td></td>
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<tr>
<td><strong>Table 2. Continued</strong></td>
<td><strong>Terminology used by HCPs</strong></td>
<td><strong>Decision support</strong></td>
</tr>
<tr>
<td>------------------------</td>
<td>----------------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td></td>
<td>Clinician uses medical terminology: 1</td>
<td>Decision support from informal caregivers: 4</td>
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<td>Clinician uses simple terminology: 1</td>
<td>Lack of written decision support: 1</td>
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<td></td>
<td>No flexibility of clinicians when patients want something different: 1</td>
<td>Purpose of decision support tool is unclear: None</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Social context</strong></th>
<th><strong>View of colleagues</strong></th>
<th><strong>Collaboration</strong></th>
<th><strong>Leadership and social learning</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Disagreement between colleagues: 3</td>
<td>Degree of cooperation and response between colleagues: 10</td>
<td>Lack of support from management (incentive, feedback, role models): 3</td>
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<td>Degree of contact between colleagues: 1</td>
<td>Hierarchical structure of professionals: 1</td>
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</tr>
<tr>
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<td>Social norms and values: None</td>
<td>Social norms and values: None</td>
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</tr>
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<td></td>
<td>Degree of cooperation and response between colleagues: 6</td>
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</tr>
<tr>
<td></td>
<td>Support from management (incentive, feedback, role models): None</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Organizational context</strong></th>
<th><strong>Organizational characteristics</strong></th>
<th><strong>Economic and political context</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Complexity of the organization: 4</td>
<td>Unattractiveness of innovation by means of financial arrangements: 2</td>
</tr>
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<td></td>
<td>Complexity of the organization: 1</td>
<td>Attractiveness of innovation by means of financial arrangements: 1</td>
</tr>
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<td>Continuous learning opportunities: None</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Lack of support services: None</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of resources (staff): None</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No arrangements for continuous learning: 1</td>
<td></td>
</tr>
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<td></td>
<td>Lack of resources (time): 11</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of support services: 2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of resources (staff): 4</td>
<td></td>
</tr>
</tbody>
</table>

| **Other** | 6 | None |

*None’ refers to the fact that no barrier or facilitator was found for this factor
Additionally, holding the belief that they are the ones with the most knowledge about their own body and particular conditions facilitated active involvement of older patients (PP)\textsuperscript{41}.

**Preparation for an SDM encounter**

**Perceived barriers:** Not all patients want or need to participate in SDM (HP/PP)\textsuperscript{44, 45, 48}. A segment of the older patients preferred a more passive role in SDM (HP/PP)\textsuperscript{44, 45, 48}. Health professionals, however, viewed a lack of participation as a barrier to SDM because they feel uncomfortable when they have to guess the patient’s preferences (HP/PP)\textsuperscript{44, 45}. Different views may complicate SDM, e.g., patients focus on treatment burden versus clinicians concerns about morbidity and mortality (HP)\textsuperscript{47, 54}.

**Perceived facilitators:** Patients feel they have an own responsibility in asking questions, learning about their disease and medications and inquiring on investigations and medical considerations (PP)\textsuperscript{41, 45}. Also, patients suggested that motivation, self-confidence, preparing themselves and family support could enable them to participate in SDM (PP/HP)\textsuperscript{68}.

**Preparation for the SDM process**

**Perceived barriers:** When health professionals did not adapt information to the personal needs and capacities of patients or used medical terminology, their behaviours were experienced as a barrier to SDM (PP)\textsuperscript{43, 64}. Decision support from informal caregivers can also be a burden to SDM. First, informal caregivers sometimes feel forced responsibility in decision making (IP)\textsuperscript{57}. Second, there can be different views between informal caregivers and health professionals, e.g., informal caregivers being overprotective or acting against professional advice (PP/IP/HP)\textsuperscript{55}. Third, there can be conflicting views between informal caregivers and patients about treatment or care but also about the ability of the patient to communicate adequately with the health professional (PP/IP/HP)\textsuperscript{55, 57, 59}. This might occur particularly in cases of cognitive decline. Finally, SDM can be complicated when there is not one but more than one informal caregiver involved, sometimes each with a different opinion (PP/IP/HP)\textsuperscript{55}.

**Perceived facilitators:** When patients had cognitive decline or were too ill, informal caregivers supported the decision-making process by providing information, asking questions and assisting in receiving and understanding information (PP/HP)\textsuperscript{41, 43, 44, 49, 51, 61}. In addition, supportive informal caregivers ensured that patient preferences were recognized\textsuperscript{59}. Furthermore, personal experiences of family and friends are important in balancing options (PP/IP/HP)\textsuperscript{58, 67}. Tailored information about conditions, options and outcomes was experienced as a facilitator to SDM (PP/HP)\textsuperscript{41, 61}. Health professionals state that information about the patients’ quality of life and functional status and knowledge about patient and informal caregivers’ priorities, goals and preferences facilitates SDM (PP/IP/HP)\textsuperscript{56}.

**Social context**

**Perceived barriers:** Care for older patients with MCC often involves many different types of health professionals often working in different health care settings. Poor or inefficient communication between them, leading to difficulty in prioritization and no one having the overview of a patient’s case, was experienced as a barrier
to SDM and to the need for integrated care in general (PP/IP/HP)\textsuperscript{44, 45, 47, 50, 55.} Differences in vision, for example, medical focus versus focus on wellbeing, or conflicting ideas about patient involvement hamper SDM (PP/IP/HP)\textsuperscript{51, 55, 65, 68.} 

**Perceived facilitators:** Conversely, good cooperation, communication and the use of the same vocabulary among the interdisciplinary team members facilitated SDM (HP)\textsuperscript{47, 50, 65.}

### Organizational context

**Perceived barriers:** Studies reporting organizational barriers were mostly situated in hospital settings (n=8) or in primary care settings (n=2). A high turnover in staff makes it difficult to get to know older patients and results in a lack of continuity of care and situations in which it is unclear who is responsible for the patient (HP)\textsuperscript{44, 51, 65.} Lack of a good electronic patient record results in the patient having to frequently repeat explanations (PP/IP/HP)\textsuperscript{56.} One study reported that patients sometimes felt urged to make room for new patients and that so-called ‘shared decisions’ about discharge were actually made solely by the professionals (PP)\textsuperscript{43.} Discussing the personal preferences of older patients requires a relationship between the patient and clinician, and time is necessary to establish such a relationship. One study reported that when patients felt that the staff was stressed, they experienced less ability to participate in decision making (PP)\textsuperscript{45.}

**Perceived facilitators:** When the workflow is genuinely organized around the patient, this facilitates SDM (PP/IP/HP)\textsuperscript{56.}

### Economic and political context

**Perceived barriers:** When there is a system of payment for productivity, this hampers the SDM process since choosing a treatment is rewarded above watchful waiting (PP/IP/HP)\textsuperscript{56.} Additionally, formal re-imbursement rules limit choices for patients (PP/HP)\textsuperscript{66.}

**Perceived facilitators:** On the other hand, a value-based payment system facilitates SDM (PP/IP/HP)\textsuperscript{56.}

### Other perceived barriers

Six barriers did not fit into the above framework. Patients mentioned having intense emotions, such as anger and frustration (PP)\textsuperscript{49.} and having a constantly changing medical condition, leading to difficulties in keeping up with information (PP)\textsuperscript{41.} as barriers for SDM.

### Differences in perspectives between patients, informal caregivers and health professionals

Figure 3 demonstrates how the main barriers and facilitators in this review were experienced from three different perspectives: patients, informal caregivers and health professionals. Almost all barriers and facilitators were reported from more than one perspective. For example, poor health is experienced as a barrier to SDM by patients, informal caregivers and health professionals. The main barriers from a patient’s perspective were found in predisposing factors (n=24, 20%) and interactional context factors (n=23, 19%). Informal caregivers experienced most barriers in predisposing factors (n=10, 50%), while
health professionals reported mainly barriers in predisposing factors (n=17, 22%) and in the organizational context (n=12, 15%).

**Discussion**

We identified 28 studies papers to report on perceived barriers and facilitators for SDM in older patients with MCC. The main barriers for SDM as experienced by older patients with MCC are ascribed to personal patient characteristics, such as poor health and/or cognitive or physical impairments. MCC might complicate SDM in several ways: patients with MCC experience less participation in SDM and health professionals experience difficulties with single disease-based guidelines. Furthermore, patients and health professionals experience that differences in views on treatment burden versus morbidity and mortality complicates SDM. Additionally, with MCC, there are often more health professionals involved, which may lead to conflicting views on treatment priorities, patient and caregiver involvement and no one having an overview of a patient’s case. Health professionals perceive poor interpersonal skills as a barrier to SDM as well as organizational barriers, such as pressure for time and high turnover of patients. Financial incentives, such as payments for productivity, are experienced as counterproductive to SDM, when
‘doing nothing’ is also an important option to discuss. However, older patients with MCC perceive that SDM is facilitated when patients share information about personal values, priorities and preferences, and information about quality of life and functional status. Decision support by informal caregivers is perceived as a facilitator to SDM, although informal caregivers can also complicate the SDM process, for example, when an informal caregiver has different views on treatment or about the patient’s capability to be involved. The main experienced facilitator for SDM is an individualized approach in which health professionals probe patient preferences. Coordination of care when multiple health professionals are involved seems important.

Most of the main perceived barriers and facilitators for SDM were reported from more than one perspective. There was great overlap between patients and health professionals in what they perceived as helping or hindering SDM. Commonly experienced, frequently reported barriers included patient characteristics (poor health, cognitive impairments), poor communication techniques by health professionals and organizational constraints (e.g., time pressure). Commonly experienced facilitators were acknowledgement of the complex conditions of patients by health professionals and the effect of this factor on participation in SDM.

These findings should be considered in relation to other reviews about the implementation of SDM. We found that poor health and cognitive impairment in older patients are perceived barriers to participation in SDM, whereas other reviews do not reveal these factors as important barriers. This observation suggests that the presence of MCC in old age requires more effort from health professionals to engage patients in SDM. The review of Joseph-Williams (2014) emphasizes the importance of knowledge to patients when participating in SDM; patients often feel insecure about their own medical knowledge and undervalue their knowledge about their personal situation and experiences. The current review confirms that patients often underestimate their own expertise, but, in contrast, reveals that due to their MCC, they feel more experienced in using health care facility systems than those with single health conditions and perceived that because of the chronic aspect of their conditions, they had greater knowledge about their particular condition and preferences. Feeling no permission to participate in SDM is also mentioned in the review by Joseph-Williams and is consistent with our findings. In a review about key components of SDM models was found that only approximately one third of the SDM models includes ‘discussing the preferred roles of patients’ and ‘communicating that the patients’ opinion is important’. Elwyn et al. (2017) transformed the first step of their SDM model ‘Choice talk’ to ‘Team talk’, emphasizing the importance of explaining the intention to collaborate and support deliberation. During the development of the ‘Dynamic model for SDM in frail older patients’, patients stressed the importance of being engaged in the dialogue.

Consistent with previous research, we found that professionals perceive a lack of agreement on the SDM process or SDM aids. In our study, this is ascribed to the involvement of multiple professionals in the case of patients with MCC. Although the aspect of time is also described in existing reviews about the implementation of SDM, the findings in this review stress that health professionals experience that more time is needed to establish a relationship with
older patients.

This review also addressed the informal caregivers’ perspective on SDM. Echoing previous research, we found that decision support from informal caregivers is experienced as a considerable facilitator to SDM\textsuperscript{35-37}, however, there are several ways in which decision support from informal caregivers may also pose a burden on SDM\textsuperscript{55, 57, 59}.

Our findings should also be interpreted in the broader context of SDM developments. This study highlights that for older adults with MCC an individualized approach is needed, taking into account the personal experience of patients that live with chronic conditions facilitate SDM. These personal experiences may direct the discussion about patients personal preferred health outcomes. This in line with the ‘Action Steps for decision making for older adults with MCC’, according to the MCC guiding principles, that emphasizes to start with identifying and communicating preferences and priorities\textsuperscript{74}. Although older adults vary in whether they want and are able to participate in SDM, considering preferences is relevant for all patients\textsuperscript{44, 45, 48, 74}. Tinetti (2019) found that working according to patients priorities led to less treatment burden and less unwanted healthcare\textsuperscript{75}. They also reported that initial fear among physicians that patients would formulate unrealistic goals was unjustified; if patients were guided through the SDM process, they formulated personal and realistic goals. This was confirmed by the study of Feder (2019) who also found that discussing personal goals led to a better relationship with physicians\textsuperscript{76}.

We conducted a broad and systematic search; however, although we searched for studies about SDM in other health disciplines, most studies targeted clinicians. Furthermore, using an existing taxonomy has advantages and disadvantages. This taxonomy used in this study to structure barriers and facilitators was developed and used in previous reviews, thus making a comparison of the results possible. However, we found additional barriers and facilitators; those barriers were directly related to the characteristic features of SDM for older patients with MCC, which was not a target population during the original development of the taxonomy. Barriers that were added to the taxonomy were ‘Disease-based decision models (guidelines)’, ‘Burden of treatment regimen’, ‘Patient focus on treatment burden versus clinicians concerns about morbidity and mortality’ and ‘Decision support from informal caregivers’. As facilitators were added: When decisions are allowed that are inconsistent with guidelines’ and ‘setting an agenda’.

**Conclusions**

Although poor health is experienced as a barrier to participate in SDM, the personal experience of living with MCC is perceived as valuable to SDM. Patients feel that an explicit invitation to participate in SDM is important. Informal caregivers would like to be respected as full partners in the SDM process; however, more research on their perspective is required. Health professionals expressed the need a supporting organizational context and good communication skills to work out an individualized approach for care. Finally, health professionals consider a value-based payment system as a facilitator to SDM unlike a payment-for-productivity system.
References


Review of barriers and facilitators for SDM in older adults


Review of barriers and facilitators for SDM in older adults


71. Bomhof-Roordink H and Gartner FR. Key components of shared decision making models: a systematic review. *BMJ*
**Supplementary Table S1: Medline via Ovid Search strategy search strategy**

MEDLINE (Ovid)
Database(s): Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1980 to 1-1-2019

**Search Strategy**

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<tr>
<th>#</th>
<th>Searches</th>
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<tr>
<td>1</td>
<td>decision making/ or Patient Participation/ or decision support techniques/ or (decision mak* or joint working or decision aid* or decision box*).ti,ab,kw. or (shar* adj3 decision*).ti,ab,kw. or (patient* adj (decision* or orientation* or involvement*)).ti,ab,kw. or (shar* adj (information* or care)).ti,ab,kw. or (decision support adj (technique* or system* or method* or intervention*)).ti,ab,kw.</td>
</tr>
<tr>
<td>2</td>
<td>aged/ or “aged, 80 and over”/ or frail older patients/ or exp Aging/ or Geriatrics/ or (elder* or older people* or older person* or older adult* or older patient* or old people* or old person* or old patient* or old adult* or frail* or geriatric* or ag?ing or senior*).ti,ab,kw.</td>
</tr>
<tr>
<td>3</td>
<td>Comorbidity/ or Chronic Disease/ or (comorbidit* or multimorbidit* or co-morbidit* or multi-morbidit*).ti,ab,kw. or (multiple adj (condition* or disease*)).ti,ab,kw. or frail elder*.ti,ab,kw. or (complex* adj3 (care or healthcare)).ti,ab,kw. or (chronic*.af. and (disease* or condition* or ill*).ti,ab,kw.</td>
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<tr>
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</tr>
<tr>
<td>5</td>
<td>1 and 2 and 3 and 4</td>
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<tr>
<td>6</td>
<td>comment/ or editorial/ or letter/ or news/ or (editorial* or comment* or letter* or systematic review*).ti,ab,kw.</td>
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<tr>
<td>7</td>
<td>5 not 6</td>
</tr>
<tr>
<td>8</td>
<td>limit 7 to ((dutch or english or german) and yr=&quot;1980 -Current&quot;)</td>
</tr>
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</table>

List of key articles used by the development of the search strategy:


4. Holmes-Rovner MV, Valade D, Orlowski C, Draus C, Nabozy-Valerio B,


an alternative health outcomes paradigm. New England Journal of Medicine, 366(9), 777-779.

Supplementary Table S2: Original taxonomy of barriers and facilitators

<table>
<thead>
<tr>
<th>Predisposing factors</th>
<th>Barriers</th>
<th>Facilitators</th>
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<tbody>
<tr>
<td>Patient characteristics</td>
<td>Being in poor health</td>
<td>Being in good health</td>
</tr>
<tr>
<td></td>
<td>Cognitive/physical impairments</td>
<td>Prior exposure to illness/decision making point</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>Long term patient</td>
</tr>
<tr>
<td></td>
<td>Ethnicity</td>
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<td>Poor articulation</td>
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<td>Difference in personal characteristics</td>
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**Organizational context**

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**Economic and political context**

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## Supplementary Table S3: Quality assessment of included studies (according to the Standard Quality Assessment Criteria (Kmet, Lee, & Cook, 2004))

### Qualitative studies (part 1)

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### Chapter 2

#### Qualitative studies (part 2)

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# Quantitative studies

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### Mixed Method Studies

#### Qualitative part

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## Mixed Method Studies

### Quantitative part

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<td>If interventional and blinding of investigators was possible, was it reported?</td>
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<td>If interventional and blinding of subjects was possible, was it reported?</td>
<td>n/a</td>
<td>n/a</td>
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<td>Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?</td>
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<td>Sample size appropriate?</td>
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<tr>
<td>Analytic methods described/justified and appropriate?</td>
<td>2</td>
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<tr>
<td>Some estimate of variance is reported for the main results?</td>
<td>2</td>
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<tr>
<td>Controlled for confounding?</td>
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<tr>
<td>Results reported in sufficient detail?</td>
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<tr>
<td>Conclusions supported by the results?</td>
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<tr>
<td>Total score /possible maximum score</td>
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<td>20/22</td>
<td>19/22</td>
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<td>Summary score (0-1)</td>
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<td>Summary score mixed methods</td>
<td>0.95</td>
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## Supplementary Table S4: PRISMA checklist

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<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist Item</th>
<th>Reported on page #</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Title</td>
<td>1</td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td>31</td>
</tr>
<tr>
<td><strong>ABSTRACT</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td>32</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>3</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td>33, 34</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).</td>
<td>34</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
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<tr>
<td>Protocol and registration</td>
<td>5</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td>-</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td>35</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td>34, 35</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
<td>Supp. table 1</td>
</tr>
<tr>
<td>Study selection</td>
<td>9</td>
<td>State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
<td>35</td>
</tr>
</tbody>
</table>
Review of barriers and facilitators for SDM in older adults

Data collection process
10 Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.

Data items
11 List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.

Risk of bias in individual studies
12 Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.

Summary measures
13 State the principal summary measures (e.g., risk ratio, difference in means).

Synthesis of results
14 Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I2) for each meta-analysis.

Risk of bias across studies
15 Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).

Additional analyses
16 Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.

RESULTS

Study selection
17 Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.

Study characteristics
18 For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.

Risk of bias within studies
19 Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).

Results of individual studies
20 For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.

Synthesis of results
21 Present results of each meta-analysis done, including confidence intervals and measures of consistency.

Risk of bias across studies
22 Present results of any assessment of risk of bias across studies (see Item 15).

Additional analysis
23 Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).

n.a. indicates not applicable.
Chapter 2

**DISCUSSION**

<table>
<thead>
<tr>
<th>Item</th>
<th>Details</th>
<th>Page</th>
</tr>
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<tbody>
<tr>
<td>Summary of evidence</td>
<td>Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).</td>
<td>47, 48</td>
</tr>
<tr>
<td>Limitations</td>
<td>Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).</td>
<td>49</td>
</tr>
<tr>
<td>Conclusions</td>
<td>Provide a general interpretation of the results in the context of other evidence, and implications for future research.</td>
<td>49</td>
</tr>
</tbody>
</table>

**FUNDING**

<table>
<thead>
<tr>
<th>Item</th>
<th>Details</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Funding</td>
<td>Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.</td>
<td>2</td>
</tr>
</tbody>
</table>


For more information, visit: www.prisma-statement.org.
Do multiple chronic conditions influence personal views on the ageing process? A qualitative analysis

Ruth E. Pel-Littel
Marjon van Rijn
Paulien W. Vermunt
Julia C.M. van Weert
Mirella M. Minkman
Gerben ter Riet
Wilma J. Scholte op Reimer
Bianca M. Buurman

Journal of Aging Research & Clinical Practice 2018; 7: 20-26
Abstract

Objectives: For older persons with two or more chronic diseases (multiple chronic conditions) insight into what they perceive as important in their lives is essential when discussing preferences in the shared decision making process. The aims of this study were to 1) investigate the personal views on the ageing process communicated by older persons and 2) compare the personal views of older persons with and without multiple chronic conditions.

Design: Using structured interviews participants were asked five questions about what they perceived as important in terms of ageing, worries, their future, healthy ageing and quality of life. Two independent researchers coded the data and performed content analyses. A stratified content analysis was performed to explore whether persons with and without multiple chronic conditions expressed different personal views with regard to the ageing process.

Participants & setting: 547 community dwelling older persons aged 70 years and above

Results: The mean (SD) age was 78.9 (5.9) years, and 60.3% were female. Multiple chronic conditions were present in 72% of the study sample. There were no significant differences in demographic characteristics between persons with and without multiple chronic conditions. However persons with multiple chronic conditions more often had polypharmacy (43% vs 24%; p<0.001), more difficulties with (instrumental) activities of daily living (mean number of impairments 2.4 vs 0.8; p < 0.001) and reported more falls (35% vs 23% p = 0.01) than those without multiple chronic conditions. The qualitative analysis identified the following main themes: ageing was associated with acceptance of ageing, (further) deterioration and worries about limitations and family. A healthy lifestyle, keeping busy, maintaining social contacts and a positive attitude were considered prerequisites to healthy ageing. In 24 out of 28 sub-themes no significant differences were found between participants with and without multiple chronic conditions. Persons with multiple chronic conditions more often expressed that ageing for them meant having to cope with deterioration and limitations, they had more worries and feared more deteriorations compared to those without multiple chronic conditions. Also persons with multiple chronic conditions less often considered a positive attitude to life a prerequisite to healthy ageing.

Conclusions: Acceptance of ageing, (further) deterioration and worries about limitations and family were important themes on the ageing process communicated by older persons. Overall, we found no major differences between persons with and without multiple chronic conditions. The results of this study may help raising awareness amongst health care professionals that eliciting and understanding an older persons’ views on the ageing process is an important first step in making health decisions that support older persons’ personal goals and expectations.
Introduction

Older persons with multiple chronic conditions (MCC) face many health-related decisions, including those related to diagnostic procedures, medication use and invasive treatments\(^1\). MCC is defined as having two or more chronic conditions\(^1\). For professionals caring for older persons with MCC is challenging due to the limitations of single-disease-focused guidelines, which do not take into account the complexity of MCC and are sometimes contradictory\(^2\). Moreover, having MCC often leads to problems in the functional, social or psychological domains\(^2\). The presence of MCC in older persons influences their goals and expectations of medical treatment; for older persons with MCC maintaining independence and quality of life becomes more important than survival\(^6\). The American Geriatrics Society stated that especially for older persons with MCC it is necessary to elicit their personal values and views before starting medical treatment\(^2\). These personal values and views might contribute to the agreement between diagnostic procedures and treatment and the outcomes that are important to an older person.

The dynamic model for shared decision-making in frail older patients\(^6\) presents this clarification of personal values and views as an important first step preceding the talk in which options are presented and preferences must be articulated about the various options. The best option always depends on the person’s individual preferences regarding the preferred outcome, such as quality of life or survival\(^6,8\). However, as stated in the literature identifying a person’s values, is not yet a regular component of health care conversations\(^8-10\). Health care professionals often lack routine practices in eliciting older persons’ preferences, and older persons often lack the confidence to express them\(^8,9,11,12\).

This study wants to contribute in exploring the personal views of older persons with and without MCC in order to raise awareness among health care professionals regarding the topics that are important to older persons. This supports the first step in making shared decisions, namely exploring an older persons personal goals and expectations. The aim of this study was to 1) investigate which personal views on the ageing process older persons hold and 2) compare the views of older persons with and without MCC.

Methods

Design and setting

Baseline data from a cluster randomized clinical trial (C-RCT) and a prospective cohort study were combined for this study. The aim of the C-RCT was to investigate whether functional decline in community-dwelling older persons can be delayed or prevented by a comprehensive geriatric assessment, multifactorial interventions and nurse-led care coordination\(^13,14\). The overall effects of this C-RCT yielded neutral findings\(^13\). For the present study, we included community-dwelling persons aged >70 years from two GPs in IJmuiden, the Netherlands, participating in the intervention arm of the C-RCT. Additionally, we performed a prospective cohort study in the region of Amsterdam among eight GPs in the Netherlands. Both studies were conducted between December 2010 and 2014. Details on the C-RCT have been published elsewhere\(^13,14\).
Participants and recruitment
All community dwelling persons who were 70 years and older and registered with one of the participating GPs were selected from the electronic medical records by their GP. Persons were excluded if they were terminally ill, suffered from dementia, did not understand Dutch, planned to move or spend a long time abroad or lived in a nursing home. Eligible persons received a letter with information on the study from their GP, together with a written informed consent form, a self-reporting questionnaire and a stamped envelope \(^\text{14}\). Because of the aim of the C-RCT, participants in the intervention arm of the C-RCT were at increased risk for functional decline, based on the Identification of Seniors At Risk Primary Care screening questionnaire (ISAR PC) \(^\text{15}\). In the prospective cohort study, we included participants with and without an increased risk of functional decline based on the ISAR PC. The study was approved by the Medical Ethics Committee of the Academic Medical Centre, University of Amsterdam (protocol ID MEC10/182).

Data collection and outcomes
The self-reported questionnaire was conducted at baseline to all participants and included questions on multimorbidity, polypharmacy, activities of (instrumental) daily living (KATZ Activities of Daily Living), cognition (Mini Mental State Examination), quality of life (EQ-6D), health care utilisation, psychological status (Rand 36) and falls \(^\text{16}\). MCC was defined as having two or more chronic conditions \(^\text{1}\) and based on a questionnaire to record MCC. This questionnaire consists of 17 pre-defined chronic conditions (e.g. diabetes, asthma, cancer) and is widely used in the Netherlands \(^\text{17}\). Participants were asked whether they experienced the pre-defined morbidities in the last twelve months. After filling out the self-reported questionnaire, all participants were visited at home by a Community Care Registered Nurse (CCRN), who performed a comprehensive geriatric assessment (CGA) \(^\text{14}\). In two out of twelve GPs in the intervention arm of the C-RCT and in all eight participating GP’s in the prospective cohort study, the CGA started with five open questions on personal views on the ageing process and included 1) What does it mean for you to get older? 2) Do you worry about things? 3) What do you think the future will be like? 4) What, in your opinion, is needed for healthy ageing? and 5) What does quality of life mean to you? The CCRN summarized the answer to each question. The answers were recorded concisely by the CCRN.

Statistical analyses
Two researchers (RP, PV) independently analysed all answers to the five questions by means of an inductive content analysis \(^\text{18}\). In the first step, the categories were derived from key words in the data in an inductive content analysis based on a random and representative sample of the answers of 200 participants (with and without MCC). Subsequently, each answer was classified into one of the defined categories. When persons addressed more than one category within one answer, the first two categories were noted. Only very few people addressed more than two categories. If the categories contained less than 5% of the total number of answers in both groups, they were included in the category ‘other’. Descriptive statistics were used to characterize the participants with and without MCC. Due to
the original qualitative nature of the data regarding the five questions, quantitative statistics have limited applicability. However, to compare the groups at baseline we used chi square tests and independent sample t-tests as appropriate. The same procedure was followed to compare the personal views on the ageing process in older persons with and without MCC. We used SPSS (version 21.0) for the statistical analyses.

Results

Participants
Data regarding the subject of this study were collected among 547 participants. A flowchart of the inclusion is shown in Figure 1. The characteristics of the 547 participants are presented in Table 1. In total, 396 participants (72%) had MCC. There were no statistically significant differences in the demographic characteristics between persons with and without MCC. However, persons with MCC compared to those without MCC more often had polypharmacy (43% vs 24%; p<0.001), experienced more difficulties with (instrumental) activities of daily living (mean number of impairments 2.4 vs 0.8; p< 0.001) and a lower health-related quality of life (20% vs 10%; p < 0.001). Furthermore, their psychological health status was lower (19% vs 16%; p = 0.01), and they reported to have had more falls (35% vs 23% p = 0.01).

Personal views on the ageing process
Table 2 shows the categories and themes that the participants addressed answering the five questions with regard to personal views on the ageing process. We described the emerging themes for each question and provided an example for each theme.

![Flowchart of the participants](image)
### Table 1. Baseline Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Persons with MCC*</th>
<th>Persons without MCC*</th>
<th>P-value</th>
<th>Total</th>
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<tbody>
<tr>
<td></td>
<td>N= 396 (72%)</td>
<td>N= 151 (28%)</td>
<td></td>
<td>N = 547 (100%)</td>
</tr>
<tr>
<td>Demographics</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Age, in years (mean, SD)</td>
<td>79.3 (5.9)</td>
<td>77.7 (5.7)</td>
<td>0.23</td>
<td>78.9 (5.9)</td>
</tr>
<tr>
<td>Female sex (n, %)</td>
<td>248 (62.6)</td>
<td>82 (54.3)</td>
<td>0.08</td>
<td>330 (60.3)</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school or less (n, %)</td>
<td>85 (21.5)</td>
<td>27 (17.9)</td>
<td></td>
<td>112 (20.5)</td>
</tr>
<tr>
<td>Secondary education (n, %)</td>
<td>269 (67.9)</td>
<td>104 (68.9)</td>
<td>0.65</td>
<td>373 (68.2)</td>
</tr>
<tr>
<td>College or university (n, %)</td>
<td>37 (9.3)</td>
<td>16 (10.6)</td>
<td></td>
<td>53 (9.7)</td>
</tr>
<tr>
<td>Socioeconomic status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low (%)</td>
<td>267 (67.4)</td>
<td>121 (80.1)</td>
<td></td>
<td>388 (70.9)</td>
</tr>
<tr>
<td>Intermediate (%)</td>
<td>97 (24.5)</td>
<td>26 (17.2)</td>
<td>0.01</td>
<td>123 (22.5)</td>
</tr>
<tr>
<td>High (%)</td>
<td>31 (7.8)</td>
<td>4 (2.6)</td>
<td></td>
<td>35 (6.4)</td>
</tr>
<tr>
<td>Married/living together (n, %)</td>
<td>168 (42.4)</td>
<td>81 (53.6)</td>
<td>0.06</td>
<td>249 (45.5)</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent, alone (n, %)</td>
<td>213 (53.8)</td>
<td>69 (45.7)</td>
<td>0.08</td>
<td>282 (51.6)</td>
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<td>Home for the elderly (n, %)</td>
<td>182 (45.0)</td>
<td>80 (53.0)</td>
<td></td>
<td>262 (47.9)</td>
</tr>
<tr>
<td>Clinical characteristics</td>
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<tr>
<td>Polypharmacy(^a) (≥5) (n, %)</td>
<td>216 (43.4)</td>
<td>36 (23.8)</td>
<td>&lt;0.001</td>
<td>252 (46.1)</td>
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<tr>
<td>Modified Katz-ADL index(^b) (mean, SD)</td>
<td>2.4 (2.3)</td>
<td>0.8 (1.3)</td>
<td>&lt;0.001</td>
<td>1.9 (2.2)</td>
</tr>
<tr>
<td>ADL impairment (mean, SD)</td>
<td>0.7 (0.9)</td>
<td>0.2 (0.4)</td>
<td>&lt;0.001</td>
<td>0.6 (0.8)</td>
</tr>
<tr>
<td>IADL impairment (7 items) (mean, SD)</td>
<td>1.3 (1.6)</td>
<td>0.4 (1.0)</td>
<td>&lt;0.001</td>
<td>1.1 (1.5)</td>
</tr>
<tr>
<td>Cognitive functioning(^c) (mean, SD)</td>
<td>27.9 (3.3)</td>
<td>28.0 (2.6)</td>
<td>0.09</td>
<td>27.9 (2.4)</td>
</tr>
<tr>
<td>Health-related quality of life(^d)</td>
<td>0.8 (0.2)</td>
<td>0.9 (0.1)</td>
<td>&lt;0.001</td>
<td>0.8 (0.2)</td>
</tr>
<tr>
<td>Psychological health status(^e)</td>
<td>70.2 (18.7)</td>
<td>79.2 (15.8)</td>
<td>0.01</td>
<td>72.7 (18.3)</td>
</tr>
<tr>
<td>Quality of Life(^f), (mean, SD)</td>
<td>7.5 (1.0)</td>
<td>7.8 (0.9)</td>
<td>0.03</td>
<td>7.5 (1.0)</td>
</tr>
<tr>
<td>Falls (≥1) in past 12 months(^g) (n, %)</td>
<td>139 (35.1)</td>
<td>34 (22.5)</td>
<td>0.01</td>
<td>173 (31.6)</td>
</tr>
</tbody>
</table>

\(^*\) MCC (multiple chronic conditions) is defined as having > 2 chronic conditions.
\(^a\) Polypharmacy: use of ≥5 different medications
\(^b\) Modified Katz-ADL, Katz-ADL and Katz IADL scale indicate ADL and IADL dependency; higher scores indicate more impairment (range 0-15)
\(^c\) Mini Mental State Examination: lower score indicates lower cognitive functioning (range 0-30)
\(^d\) EQ-5D: utility weights can be attached to the EQ-5D health state. Utility views range from 1 (best possible health) to -0.59 (worse than death)
\(^e\) Rand-36: higher score indicates better psychological and social functioning (range 0-100)
\(^f\) “Could you provide a rating for your quality of life (0: very bad – 10: very good)?”
\(^g\) “Have you experienced one or more falls in the past 12 months?”
Do multiple chronic conditions influence personal views on the ageing process?

What does it mean for you to get older?
"Getting older is not so bad; it’s the limitations that become a nuisance."

In answering the question ‘What does it mean for you to get older?’, the respondents addressed the following themes: ‘having to manage decline and limitations’ (17.6%), ‘a positive experience’ (14.2%), ‘a negative experience’ (14.4%), ‘acceptance’ (15.4%), ‘no difficulties’ (9.6%), ‘no specific meaning’ (7.8%) and ‘fine, if my condition remains as it is’ (8.5%).

Do you worry about things?
“I worry about my husband and that I can’t provide care for him anymore."

In response to the question ‘Do you worry about things?’, 24.2% of the persons expressed worries. Of those who expressed worries, the concerns were focused on ‘deterioration’ (37.0%) and ‘family’ (29.0%). The other respondents (34.0%) did not specify the nature of their worries.

What do you think the future will be like?
“If it continues the way it is going now, great.”

Persons addressed the following themes for the question ‘What do you think the future will be like?’: ‘hoping or expecting the situation to remain as is’ (19.0%), ‘having an overall negative view on the future’ (17.5%) and ‘don’t know’ (16.9%). Other themes that were addressed by the respondents were as follows: ‘it cannot be influenced, just have to wait and see’ (13.8%), ‘fearing more limitations’ (8.6%), ‘having an overall positive view on the future’ (9.2%) and ‘maybe a change in living conditions’ (6.0%).

What, in your opinion, is needed for healthy ageing?
“Go to bed on time, eat well and exercise.”

In answering the question ‘What, in your opinion, is needed for healthy ageing?’, the majority of the respondents answered ‘a healthy lifestyle, balance between activity and rest’ (52.4%). A smaller proportion of persons addressed the following themes: ‘keeping busy and interested’ (13.1%), maintaining social contacts, family’ (7.5%) and ‘having a positive attitude to life’ (7.5%).

What does quality of life mean to you?
“That I can wake up healthy every day.”

In response to the question ‘What does quality of life mean to you?’, the persons addressed the following themes: ‘health (both physical and mental)’ (18.1%), ‘being able to do what you want to do’ (17.6%), ‘having social contacts, family and friends around you’ (14.2%), ‘that you are able to enjoy things’ (11.2%) and ‘remaining independent’ (8.4%). Some persons did not define quality of life but expressed their feeling about it: ‘I am positive about my quality of life’ (15.8%).

Differences between older persons with and without MCC
For four of the 28 sub-themes statistically significant differences were found between participants with MCC compared to participants without MCC. With regard to the question ‘What does it mean for you to get older?’ persons with MCC more often mentioned ‘having to address deterioration and limitations’ compared to persons without MCC (19.4% vs 12.9%, p=0.03). Persons with
Table 2. Personal views on the ageing process

<table>
<thead>
<tr>
<th>Emerging themes</th>
<th>Example</th>
<th>Persons with MCC*</th>
<th>Persons without MCC*</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>N **= 477</td>
<td>N **= 171</td>
<td>N **= 648</td>
</tr>
<tr>
<td></td>
<td></td>
<td>% (n)</td>
<td>% (n)</td>
<td>% (n)</td>
</tr>
<tr>
<td>Question: What does it mean for you to get older?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Having to address decline and limitations</td>
<td>“Getting older is not so bad; it’s the limitations that are a nuisance”</td>
<td>19.3 (92)</td>
<td>12.9 (22)</td>
<td>17.6 (114)</td>
</tr>
<tr>
<td>A positive experience</td>
<td>“After a studying and working phase, I’m now in the phase of ‘enjoying life’”</td>
<td>14.9 (71)</td>
<td>12.2 (21)</td>
<td>14.2 (92)</td>
</tr>
<tr>
<td>A negative experience</td>
<td>“I don’t like it; I’m only going ‘down’”</td>
<td>14.9 (71)</td>
<td>12.9 (22)</td>
<td>14.4 (93)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>“Yes, one gets older; little can be changed about that”</td>
<td>14.1 (67)</td>
<td>19.3 (33)</td>
<td>15.4 (100)</td>
</tr>
<tr>
<td>No difficulties</td>
<td>“I’ve experienced no problems”</td>
<td>8.8 (42)</td>
<td>11.7 (20)</td>
<td>9.6 (62)</td>
</tr>
<tr>
<td>It has no specific meaning</td>
<td>“It just happens; it doesn’t bother me”</td>
<td>7.8 (37)</td>
<td>8.2 (14)</td>
<td>7.8 (51)</td>
</tr>
<tr>
<td>Fine, if my condition remains as it is</td>
<td>“I don’t mind getting older, as long as I don’t experience physical discomfort”</td>
<td>7.3 (35)</td>
<td>11.7 (20)</td>
<td>8.5 (55)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>13.0 (62)</td>
<td>11.1 (19)</td>
<td>12.5 (81)</td>
</tr>
<tr>
<td>Question: Do you worry about things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Worries</td>
<td>“No”</td>
<td>51.9 (237)</td>
<td>63.7 (109)</td>
<td>55.1 (346)</td>
</tr>
<tr>
<td>Worries</td>
<td>“Yes” (no further explanation)</td>
<td>21.9 (119)</td>
<td>19.3 (33)</td>
<td>24.2 (152)</td>
</tr>
<tr>
<td>Worries about deterioration</td>
<td>“Yes, I worry about having ailments that add up”</td>
<td>8.4 (38)</td>
<td>5.9 (10)</td>
<td>7.6 (48)</td>
</tr>
<tr>
<td>Worries about family</td>
<td>“Yes, I worry about my husband and that I won’t be able to provide care for him anymore”</td>
<td>6.1 (28)</td>
<td>5.9 (10)</td>
<td>6.1 (38)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>7.7 (35)</td>
<td>5.3 (9)</td>
<td>7.0 (44)</td>
</tr>
<tr>
<td>Question: What do you think the future will be like?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoping or expecting the situation to remains as is</td>
<td>“If it continues the way it is going now, great”</td>
<td>18.1 (75)</td>
<td>20.3 (31)</td>
<td>19.0 (106)</td>
</tr>
<tr>
<td>Having an overall negative vision of the future</td>
<td>“It will probably all get worse slowly; I feel pessimistic about it”</td>
<td>17.9 (74)</td>
<td>16.3 (25)</td>
<td>17.5 (99)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>“I cannot foresee the future”</td>
<td>16.2 (67)</td>
<td>19.0 (29)</td>
<td>16.9 (96)</td>
</tr>
</tbody>
</table>
Do multiple chronic conditions influence personal views on the ageing process?

### Table 2. Continued

<table>
<thead>
<tr>
<th>Emerging themes</th>
<th>Example</th>
<th>% (n)</th>
<th>% (n)</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It cannot be influenced, just have to wait and see</td>
<td>“The future will present itself”</td>
<td>13.5 (56)</td>
<td>14.4 (22)</td>
<td>13.8 (78)</td>
</tr>
<tr>
<td>Dreading more limitations</td>
<td>“I think it will get worse because of the discomfort”</td>
<td>10.6 (44)</td>
<td>3.3 (5   )</td>
<td>8.6 (49  )</td>
</tr>
<tr>
<td>Having an overall positive vision of the future</td>
<td>“If things continue like this, I’ll make it to 95”</td>
<td>7.7 (32)</td>
<td>13.1 (20)</td>
<td>9.2 (52  )</td>
</tr>
<tr>
<td>Maybe a change in living conditions</td>
<td>“I live in a house, but I want to move to a flat because there will be no stairs”.</td>
<td>6.0 (25)</td>
<td>5.9 (9   )</td>
<td>6.0 (34  )</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>9.9 (41)</td>
<td>7.9 (12)</td>
<td>9.4 (53  )</td>
</tr>
</tbody>
</table>

**Question: What, in your opinion, is needed for healthy ageing?**

| A healthy lifestyle, balance between activity and rest | “Go to bed on time, eat well and exercise”                          | 51.5 (225)| 54.4 (98)| 52.4 (323)|
| Keeping busy and interested                       | “To do a lot, have hobbies, leave the house a lot”                  | 12.4 (54)| 15.0 (27)| 13.1 (81  )|
| Social contacts, family                           | “To keep being among other people and to not grow lonely”           | 7.1 (31) | 8.3 (15)| 7.5 (46  )|
| Having a positive attitude toward life            | “Being cheerful is very important to me to be happy”               | 6.2 (27) | 10.6 (19)| 7.5 (46  )|
| Other                                              |                                                                        | 22.9 (100)| 11.7 (21)| 19.6 (121)|

**Question: What does quality of life mean to you?**

| Being able to do what you want to do               | “To have a normal life, to do what you are used to doing”            | 16.7 (74)| 20.0 (35)| 17.6 (109)|
| Health (both physical and mental)                  | “That I can wake up healthy every day”                                 | 16.7 (74)| 21.7 (38)| 18.1 (112)|
| I am positive about my quality of life             | “I still enjoy every day of life!”                                    | 16.4 (73)| 14.3 (25)| 15.8 (98  )|
| Social contacts, family and friends around you     | “As long as I can socialize, for example with my family”              | 15.8 (70)| 10.3 (18)| 14.2 (88  )|
| That you are able to enjoy things                  | “To live pleasurably, to have a broad interest in all things”         | 9.9 (44) | 14.3 (25)| 11.2 (69  )|
| Staying independent                               | “To stay independent as long as possible”                             | 8.3 (37) | 8.6 (15)| 8.4 (52  )|
| Other                                              |                                                                        | 16.2 (72) | 10.9 (19)| 14.7 (91  )|

* MCC is defined as having > 2 chronic conditions.
** n = As persons could address multiple themes in one question, N represents the number of answers and not the number of persons.
MCC less frequently reported for the question ‘Do you worry about things?’ that they had no worries compared to those without MCC (51.9% vs 63.7%, p=0.01). With regard to the question ‘What do you think the future will be like?’ persons with MCC expressed ‘dreading more limitations’ more often compared to persons without MCC (10.6% vs 3.3%, p=0.02). Finally, regarding the question ‘What, in your opinion, is needed for healthy ageing?’ persons with MCC said ‘having a positive attitude to life’ less often compared to persons without MCC (6.2% vs 10.6%, p=0.03).

Discussion

In this study, we explored which personal views older persons have regarding the ageing process and if there were differences in personal views between older persons with and without MCC. The personal views that were communicated most often were the association of ageing with (further) deterioration, acceptance of ageing and worries about limitations and family. Healthy lifestyles, staying active, keeping social contacts and a positive attitude were considered prerequisites to healthy ageing. The ability to do what one wants to do, good health and social contacts contributes to quality of life. Persons with MCC experienced more impairments in activities of daily living and had a lower health-related quality of life and a lower psychological health status compared to those without MCC. Older persons with and without MCC addressed many of the same topics regarding the ageing process but an important difference was that persons with MCC had more worries, had a more negative view on the future and especially feared further physical deteriorations and limitations.

The 28 sub-themes we identified regarding the personal views on the ageing process are consistent with studies that focus on successful ageing. In studies that focus on the factors that define successful ageing, participants highlighted that being able to do what you want to do, good health and social contacts are prerequisites for healthy ageing and quality of life and not solely the absence of physical limitations. Moreover, many participants in studies focussing on successful ageing mentioned the importance of a positive attitude to cope with the decline in health many of the participants experienced. This is a key feature of the resilience literature that is a further development of the successful ageing movement. Resilience focuses on a person’s lifelong search to find a balance between limitations and opportunities, also encompassing a social view on health. Many factors addressed by older persons in our study focused on this social view on health, such as maintaining social contacts and being able to do what they wanted to do.

In our study participants identified the preservation of physical function as an important factor contributing to quality of life. The importance of preservation of physical function has also been found in previous studies on outcomes that are important to older persons with MCC. For example, the study of Fried et al emphasises the importance of functional outcomes for patients when they consider a treatment. Although we did not find many differences between older persons with and without MCC, those with MCC had more worries and specifically about further deteriorations. At the start of the study they already had more impairment...
in ADLs. Therefore, this group is at higher risk to develop new disabilities because of their chronic conditions and more frequent hospitalizations\(^1\). It indicates that for older persons with MCC the prevention of functional decline becomes more important.

We expected to find more differences between persons with and without MCC but the differences in personal views were limited. A first explanation might be that the five questions were not asked in the context of a treatment decision. Maybe personal views change when facing an actual treatment decision and differences between patients with and without MCC might become visible. Another explanation could be that the nature and duration of the existing comorbidities influence personal views. According to Gijsen et al\(^1\) the consequences of specific disease combinations vary and depend on many factors. It is possible that specific combinations of coexisting morbidities do influence a person’s view on the ageing process, but we were not able to explore this in our study.

The strength of this study is that we were able to assess personal views in more than 500 older participants, and were able to confirm that many older persons have the same personal views on the ageing process and what is needed for healthy ageing and quality of life. However, this study has some limitations. First the inclusion of the five questions used to gain insight into aspects that matter to older persons was recommended by CCRN and has no theoretical basis. Furthermore, the answers were written interpretations recorded concisely by the CCRN, which may have caused some bias. Future in-depth interviews on the answers could provide more insight into the underlying views of persons and the influence of these views on health decisions.

In conclusion, the results of this study show that older persons with and without MCC perceive a broad range of personal views as important in their stage of life. Those views can influence the health-related decisions that need to be made regarding diagnostics, treatment and care. For older persons with MCC fear of deterioration is a relevant topic to discuss because of the impact on quality of life: interaction with family members, good physical and mental health and being able to do what you want to do. When eliciting a patients views in the context of a treatment decision, MCC must be taken into account because of their influence on functional outcomes and the impact of that on quality of life. The results of this study may help raise awareness amongst health care professionals that questioning and understanding individuals’ views can contribute to making health decisions that support an individual’s personal goals and expectations.
Chapter 3

References


Do multiple chronic conditions influence personal views on the ageing process?


Recommendations of older adults on how to use the PROM ‘TOPICS-MDS’ in healthcare conversations: a Delphi study

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Franca H. Leeuwis
Jeanet W. Blom
Bianca M. Buurman
Mirella M. Minkman

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Abstract

In shared decision making, the exploration of preferred personal health outcomes is important. Patient-reported outcome measures (PROMs) provide input for discussions between patients and healthcare professionals. The Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS) PROM is a multidimensional questionnaire on the physical and mental health and wellbeing of older adults. This study investigates how the TOPICS-MDS could be used in individual healthcare conversations. We explored views of older adults regarding 1) whether the health domains they want to discuss are included in the TOPICS-MDS and 2) the comprehensibility of the TOPICS-MDS for healthcare conversations with older adults. A three-round Delphi study was conducted. A total of 57 older adults participated in the study, the mean (SD) age was 71.5 (8.5) years, and 78.9% of the participants were female. The participants were divided into four panels based on educational level and cultural background. We used online questionnaires and focus groups. Consensus was pre-defined to be the point when >75% of the participants agreed that a domain was important or very important (scored on a 5-point Likert scale). The inter-expert agreement was computed for Round 1 and 3 with Kendall’s W. Round 2 was a focus-group. Qualitative data were analyzed by content analysis. Older adults considered ‘functional limitations’, ‘emotional wellbeing’, ‘social functioning’ and ‘quality of life’ to be important domains of the TOPICS-MDS to discuss in healthcare conversations. The participants added ‘coping with stress’, ‘dealing with health conditions and the effects on life’ as extra domains for healthcare conversations. Challenges regarding the comprehensibility of the TOPICS-MDS included difficult words and lengthy or sensitive questions. Questions that included multiple topics were difficult to understand. The TOPICS-MDS covers the domains of life that older adults value as important to discuss with healthcare professionals, and two additional domains were identified. For older adults with a low level of education or a culturally diverse background, the TOPICS-MDS needs to be adjusted for comprehensibility.
Introduction

Shared decision making (SDM) facilitates the communication between healthcare professionals and patients when decisions have to be made about diagnostic procedures, treatment options or care options. For older adults, SDM becomes much more complex when there are multiple chronic conditions (MCC) to take into account. MCC are highly prevalent in older adults\(^1\) and are defined as two or more concurrent chronic conditions that collectively might have an adverse effect on one’s health status, daily functioning or quality of life\(^3\)\(^-\)\(^7\). The presence of MCC in older adults influences the goals and expectations of care and treatment. For instance, the ability to maintain independence and a good quality of life often becomes more important than life expectancy\(^6\),\(^9\). Therefore, it is important to explore preferred health outcomes first, before focusing on the treatment options for one or more conditions. In other words, it is recommended to treat the patient rather than the disease.

Accordingly, the ‘dynamic model of SDM in frail older patients’ was developed for older adults with MCC. The model emphasizes the exploration of personal goals and preferred health outcomes as an initial step preceding the deliberation about concrete treatment options\(^10\). However, reflecting on one’s own health and formulating preferences for health outcomes in a discussion with a healthcare professional is not common practice for older adults\(^11\)\(^-\)\(^13\). Older adults often lack the confidence to express their personal views, and healthcare professionals often fail to elicit older adults’ preferences and goals\(^11\),\(^13\)\(^-\)\(^15\).

Patient-reported outcomes measures (PROMs) are used for quality improvement, research and benchmark purposes, but they can also be used as input for individual healthcare conversations between patients and healthcare professionals. Therefore, the use of a PROM could support SDM by providing a tool for older adults to reflect on their health and empower them to discuss topics and health outcomes that are important to them\(^16\). For this purpose, the Dutch Geriatric Society selected the ‘Older Persons and Informal Caregivers Survey Minimum DataSet’ (TOPICS-MDS) PROM\(^17\). The TOPICS-MDS comprises two multidimensional questionnaires: (1) one on the physical and mental health and wellbeing of older adults and (2) one on the caregiver burden and quality of life of informal caregivers. The creation of the TOPICS-MDS was a joint effort by eight Dutch universities participating in the National Care for the Elderly Program. The TOPICS-MDS has been compiled by a working group of experts and is based on validated and reliable questionnaires\(^18\). However, since the TOPICS-MDS was originally developed for research purposes, this PROM is not often used in individual healthcare conversations. The aim of this study was to explore whether the TOPICS-MDS, the questionnaire for older adults, could facilitate SDM conversations between professionals and older adults with MCC. Therefore, we (1) explored which health domains are important to discuss with healthcare professionals according to older adults in the Netherlands and (2) examined the comprehensibility of the current TOPICS-MDS items. We conducted a modified Delphi study with older adults.
Methods

Participants
The Delphi panel in this study comprised older adults living in the Netherlands. This study aimed explicitly to include a diversity of backgrounds (e.g., age, sex, education and cultural diversity) to reflect the mixed population of older adults in the Netherlands and support the external validity of this study. Participants were recruited through purposive sampling, which means they were recruited based on characteristics of the population and the purpose of the study. The inclusion criteria were persons 1) older than 50 years, 2) with sufficient Dutch language skills to understand the questionnaires in written or spoken form and 3) living in the Netherlands. We deliberately selected the age threshold of ‘> 50 years’ since research shows that persons with a low level of education or a culturally diverse background suffer from MCC at a relatively young age. Participants with a culturally diverse background or a low level of education were approached with the assistance of Pharos (Dutch Centre of Expertise on Health Disparities). In the Netherlands, there are over 200 different nationalities; therefore, it was impossible to involve all nationalities. Furthermore, it is difficult to recruit people with a low level of education to participate in research. Pharos has a broad network of ‘key figures’ in the populations that they approached to find eligible participants for the focus groups. The participants with a Hindu background originated mostly from the former Dutch colony of Suriname, and the participants with a Moroccan background were immigrant workers; thus, two different types of migrants in the Netherlands were represented. Highly educated (secondary education, college or university) participants were recruited by a website for older adults (Beteroud.nl) and social media (Facebook and Twitter).

Design of the Delphi study
The Delphi method is defined as ‘a group process involving an interaction between the researcher and a group of identified experts on a specific topic’. The Delphi method is widely used and accepted to reach a consensus. Delphi methodology combines quantitative and qualitative exploration of subjective assumptions surrounding a given topic and elicits opinions from experts to obtain a group response and consensus. A Delphi study is usually conducted in sequence rounds, which allows the experts to adapt their opinions and facilitates the yielding of consensus.

The Delphi procedure used in this study comprised three rounds that were completed over a three-month period in 2017. The first round of the Delphi study aimed to identify the important health domains to discuss in healthcare conversations according to older adults. The second round aimed to gain insights into the comprehensibility of the questions and response options of the TOPICS-MDS. The third round aimed to re-evaluate undecided health domains and reformulate TOPICS-MDS questions and response options.

Within the Delphi procedure, two methods were applied to obtain data within the rounds, namely, an online questionnaire and focus group sessions. These methods were chosen to allow a mixed composition of the panel and the ability.
Health domains older adults want to discuss in individual health care conversations

to support respondents in their understanding of the questions. Participants with a culturally diverse background or a low level of education were questioned in focus groups during Delphi Rounds 1 and 2. Focus groups allow more interaction between the panel experts and with support from the facilitators that guarantees attention for each participant, thus leading to a better understanding of the TOPICS-MDS when discussed with these specific groups. In Fig 1, an overview is presented of the study aims, methods and characteristics of participants.

<table>
<thead>
<tr>
<th>Round</th>
<th>Aim</th>
<th>Method</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Round 1</td>
<td>Assess health domains</td>
<td>Online questionnaire</td>
<td>N = 44</td>
</tr>
<tr>
<td></td>
<td>Focusgroups part 1</td>
<td></td>
<td>N = 6 Low educ.</td>
</tr>
<tr>
<td></td>
<td>F1: low education</td>
<td></td>
<td>N = 4 Moroccan</td>
</tr>
<tr>
<td></td>
<td>F2: cultural diverse background</td>
<td></td>
<td>N = 3 Hindu</td>
</tr>
<tr>
<td>Round 2</td>
<td>Discuss formulation of unclear questions</td>
<td>Focusgroup</td>
<td>N = 5</td>
</tr>
<tr>
<td></td>
<td>and response options</td>
<td></td>
<td>N = 6 Low educ.</td>
</tr>
<tr>
<td></td>
<td>Focusgroups part 2</td>
<td></td>
<td>N = 4 Moroccan</td>
</tr>
<tr>
<td></td>
<td>F1: low education</td>
<td></td>
<td>N = 3 Hindu</td>
</tr>
<tr>
<td>Round 3</td>
<td>Re-assess health domains &amp;</td>
<td>Online questionnaire</td>
<td>N = 24 (remaining</td>
</tr>
<tr>
<td></td>
<td>Assess reformulated questions and response</td>
<td></td>
<td>participants round 1)</td>
</tr>
<tr>
<td></td>
<td>options</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Figure 1.** Design of the Delphi study.

**Ethical considerations**

The requirement to obtain approval for this study was waived by the Institutional Review Board of the UMCU (19/355). For the online section of this study, participants provided their written informed consent, and the focus group discussion participants provided their verbal consent, which was audio recorded and transcribed verbatim.

**Design of the Delphi questionnaire**

The Delphi questionnaire was based on the original TOPICS-MDS (version before 2017) and presented to the participants in both the online questionnaire and the focus group. The TOPICS-MDS comprises 51 questions and collects data in seven domains: demographics, morbidity, quality of life, functional limitations,
mental health, social functioning and health service use. From these domains, four health domains from the TOPICS-MDS were evaluated in the Delphi: functional limitations, mental health, social functioning and quality of life. The other three domains, namely, demographics, morbidity and health service utilization, were not included in the Delphi study since those domains are core topics (case mix variables) in relation to health outcomes and thus do not need be evaluated in the Delphi. Since recent literature describes a more holistic scope on health domains, as expressed in the new definition of health from the World Health Organization and the literature about positive health, we added two more domains to the questionnaire: meaning in life and social and living environments.27-29

The questionnaire began with questions regarding the older adult’s demographic characteristics, followed by an open question about the current wellbeing of the older adult: ‘How would you rate your general wellbeing (range 0 - 10)’? This question was followed by questions about the importance of discussing each health domain with a healthcare professional in order to gain insight into the participant’s personal health outcomes. For each domain, the importance was assessed on a 5-point Likert scale (range: ‘not important’ to ‘very important’). The content of the Delphi questionnaire was similar in both the online questionnaire and the focus groups, although in the focus groups, the 5-point Likert scale was expressed in yellow paper stars that the participants could distribute to assess the importance.

First round
In Round 1, we aimed to determine the health domains that older adults consider important to discuss in healthcare conversations. Participants with a high level of education received the questionnaire (S1 File Round 1: online questionnaire) through a hyperlink, and participants with a low level of education or a culturally diverse background discussed the questions from the questionnaire during focus groups. For each domain, the importance was assessed on a 5-point Likert scale (range: ‘not important’ to ‘very important’). After assessing each health domain, participants were asked to provide a rationale regarding their answer. At the end, participants could add other health domains that they considered important to discuss with their healthcare professional and indicate the reason(s) for adding the domain(s). In the focus groups, all health domains were discussed plenarily, and participants were asked to assess the importance of the different health domains by means of a visual 5-point scale.

Second round
Round 2 was conducted exclusively in focus groups. There were four focus groups: one with participants with a high level of education (recruited from the participants that completed the online survey), one with participants with a low level of education and two with participants with culturally diverse participants. The aim of Round 2 was to gain insights into the comprehensibility of the TOPICS-MDS questions and response options when used in healthcare conversations. From the public TOPICS-MDS data repository, we derived the items from the questionnaire that had > 10% missing entries (n=12). We presumed that these twelve questions were difficult for people to answer, but the reason for the missing entries was unknown. These questions were discussed plenarily. Participants
were asked whether the formulations were understandable and clear and how the ambiguous questions needed to be revised.

**Third round**
Round 3 was conducted solely through an online questionnaire. This round aimed to assess the (modified) set of health domains and evaluate the reformulated questions and response options. The revised questionnaire was e-mailed to participants from the first round who had agreed to participate in the third round (S2 File. Round 3: online questionnaire). A summary of the comments on the health domains of the first round was shared with the participants. Using a Likert scale ranging from 1 (lowest) to 5 (highest) in levels of importance, the participants were required to assess each remaining health domain on the basis of the question, ‘How important is it to you that your healthcare professionals asks you about... (health domain)?’ In addition, the revised questions and response options from the focus group sessions were evaluated for comprehensibility.

**Data analysis**
Descriptive statistics were used to summarize the sociodemographic data of the participants and the quantitative data. The quantitative data were analyzed with ‘Statistical Package for the Social Sciences’ (SPSS, version 23) software. A consensus was reached when ≥ 75% of the participants assessed a health domain as important (4) or very important (5). When ≤ 50% of the participants assessed a domain as important (4) or very important (5), the domain was excluded. Items with an acceptance rate between 50% and 75% were re-evaluated in the next round. These consensus agreement scores were based on the methods of relevant, recently published Delphi studies. The inter-expert agreement was computed for Round 1 and 3 with Kendall’s W.

The qualitative data comprised the in-depth explanations of the motivations why participants ranked a domain as important to discuss in healthcare conversations. These data were collected with the purpose of enabling the participants of the following Delphi round to re-rank the health domains of the TOPICS-MDS with the group’s viewpoint in mind. The data included open text fragments (online questionnaire) and audio recordings (focus groups). The recordings of the focus groups were transcribed verbatim. First, the transcripts were read multiple times, so the reader was familiarized with the data. Subsequently, the transcripts were analyzed thematically by ‘open coding’ via the program ‘MAXQDA’. Following axial coding, the main themes were clustered and combined. Two researchers (RPL and LY) coded the first two transcripts independently and discussed them to reach a consensus. The remaining transcripts were coded by LY and subsequently discussed with RPL.

The remaining health domains and the restated questions and answer options, including the remarks made by participants in the previous rounds, were presented in Round 3 (S2 File. Round 3: online questionnaire). A consensus on the definitive list of important health domains was reached when ≥ 75% of the participants assessed a health domain as important (4) or very important (5). In addition, the restated questions and response options were presented. When ≥ 75% of the participants evaluated the restated question as better than the original question, it was recommended to carry out the adjustments.
Chapter 4

Results

Demographics of the participants
The demographic characteristics of the 57 participants are described in Table 1. The mean (SD) age was 71.5 (8.5) years, and 78.9% of the participants were female. Of the participants, 17 (29.8%) had a low level of education (primary school or less), and 13 (22.8%) had a culturally diverse background. These participants were Algerian (N=1), Belgian (N=1), Curaçaoan (N=1), German (N=1), Scottish (N=1), Surinamese (N=4) and Moroccan (N=4). All participants (N=57, 100%) lived independently or with relatives.

Table 1. Characteristics of the participants

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Participants in the online questionnaire with a high level of education n=44</th>
<th>Participants in the focus group with a low level of education n=6</th>
<th>Participants in the focus groups with a culturally diverse background n=7</th>
<th>Total N=57</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (n,%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>33 (75)</td>
<td>5 (83)</td>
<td>7 (100)</td>
<td>45 (78.9)</td>
</tr>
<tr>
<td>Age (mean, SD)</td>
<td>73.0 (7.5)</td>
<td>66.7 (11.3)</td>
<td>65.8 (9.5)</td>
<td>71.5 (8.5)</td>
</tr>
<tr>
<td>Level of education (n,%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>40 (90.9)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>40 (70.2)</td>
</tr>
<tr>
<td>Low</td>
<td>4 (9.1)</td>
<td>6 (100)</td>
<td>7 (100)</td>
<td>17 (29.8)</td>
</tr>
<tr>
<td>Ethnicity (n,%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>41 (93.2)</td>
<td>3 (50)</td>
<td>0 (0)</td>
<td>44 (77.2)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (6.8)</td>
<td>3 (50)</td>
<td>7 (100)</td>
<td>13 (22.8)</td>
</tr>
<tr>
<td>Marital status (n,%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/living together</td>
<td>21 (47.7)</td>
<td>0 (0)</td>
<td>4 (57.1)</td>
<td>25 (43.9)</td>
</tr>
<tr>
<td>Single</td>
<td>23 (52.3)</td>
<td>6 (100)</td>
<td>3 (42.9)</td>
<td>32 (56.1)</td>
</tr>
<tr>
<td>Living situation (n,%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent</td>
<td>44 (100)</td>
<td>6 (100)</td>
<td>7 (100)</td>
<td>57 (100)</td>
</tr>
</tbody>
</table>

Health domains to discuss in healthcare conversations: quantitative results
In Round 1 (n=57), we explored the importance of the six health domains to discuss in healthcare conversations according to older adults. As shown in Fig 2, none of the health domains were assessed as important (4) or very important (5) by more than 75% of the participants. Between 50 and 75% of the respondents assessed the original health domains, functional limitations, emotional wellbeing, social functioning and quality of life, as important (4) or very important (5) to discuss in healthcare conversations. Therefore, these domains were re-evaluated in the third round. Less than 50% of the participants assessed the added
Health domains older adults want to discuss in individual health care conversations

**Figure 2.** Round 1: overview of the assessments of the health domains. Frequency distribution (%) of the importance to discuss each domain with healthcare professionals. The bold black line represents the 50% threshold. The bold black dotted line represents the 75% threshold.

**Figure 3.** Round 3: overview of the remaining health domains. Frequency distribution (%) of the importance to discuss each domain with healthcare professionals. The bold black line represents the 50% threshold. The bold black dotted line represents the 75% threshold.
domains, meaning in life and living and social environments, as important (4) or very important (5) to discuss in healthcare conversations. Consequently, these domains were excluded.

Participants of Round 1 introduced three other domains that they felt were important to discuss with their healthcare professionals and are not domains in the current TOPICS-MDS. These domains were physical exercise (e.g., walking, cycling), coping with stress, and how to deal with the disease and its effects on daily life. These domains were included in Round 3, in which the health domains from Round 1 with an acceptance rate between 50% and 75% were re-evaluated.

As depicted in Fig 3, after Round 3 (n=24), the remaining health domains to discuss in healthcare conversations were functional limitations, emotional wellbeing, social functioning, quality of life, coping with stress and dealing with health conditions and the effects on daily life. The majority of the participants did not assess physical exercise as (very) important to discuss in healthcare conversations. The inter-expert agreement (Kendall’s W) was for Round 1 0.083 and for Round 3 0.058. Based on these low inter agreement scores we further used descriptive statistics.

Differences between the subgroups

There are differences between participants with a high level of education (n=44), participants with a low level of education (n=6) and participants with a culturally diverse background (n=7). An overview of how the health domains were rated in Round 1 by the different groups of participants can be found in Fig 4. More than 75% of the participants with a low level of education or a culturally diverse background assessed functional limitations, emotional wellbeing, social functioning and quality of life as important (4) or very important (5), while less than 75% of the participants with a high level of education assessed these domains as important (4) or very important (5).

Health domains to discuss in healthcare conversations: qualitative results

Participants in Round 1 were invited to substantiate their assessment of health domains, both in the online questionnaire and in the focus groups. The qualitative data are structured according to each health domain as described in the TOPICS-MDS: functional limitations, emotional wellbeing, social functioning and quality of life.

Functional limitations

The domain of functional limitations includes basic and instrumental activities of daily life and mobility, such as walking. Some participants wanted to discuss their limitations in daily life with healthcare professionals since they experience physical problems. The participants mentioned that it is important to discuss this topic with healthcare professionals since healthcare professionals can arrange adequate support:

‘I find it important to discuss functional limitations with my healthcare professional since he can arrange extra domestic help.’ (female participant, 81 years with a high level of education, online questionnaire).
Health domains older adults want to discuss in individual health care conversations

Figure 4. Overview of the assessments of the health domains by subgroups of participants
Frequency distribution (%) of the importance of discussing each domain with healthcare professionals. The light gray row represents the highly educated participants, the middle gray row represents the participants with a low level of education and the dark gray row represents participants from culturally diverse backgrounds.

Emotional wellbeing
The domain of emotional wellbeing concerns the mental state of a person, e.g. feeling nervous, calm, happy, depressed etc. Some participants found it important to discuss their emotional wellbeing with healthcare professionals because they tend to hide depressing thoughts from others:

'It is important that healthcare professionals ask about my emotional wellbeing because sometimes I feel depressed and if they ask me how I am doing emotionally, I can talk about it.' (female participant, 87 years, with a high level of education, online questionnaire).

Furthermore, some participants indicated that the relationship between the healthcare professional and the client is of importance:

'Yes, I would like to discuss this topic if I know the healthcare professional. If I have to stay one or two days in the hospital, I don’t want to tell them everything.'
The relationship with my GP (General Practitioner) is very important to me.’ (female participant, 71 years in a focus group with a culturally diverse background).

Social functioning
The domain of social functioning within the TOPICS-MDS reflects if a person feels impeded in entering into social contacts\(^\text{18}\). Participants found social functioning an important topic to discuss because many older adults live alone:

‘When you become older and when you live alone, loneliness plays a role.’ (female participant, 67 years with a high level of education, online questionnaire).

However, the participants thought that loneliness is a sensitive topic to discuss. Therefore, if healthcare professionals ask the correct questions, older adults may feel at ease when discussing these topics. Some participants found it important that this topic is discussed with healthcare professionals because the healthcare professionals can provide suggestions or solutions for this problem.

Quality of life
The domain of quality of life is composed of several attributes, such as mobility, self-care, usual activities, pain/discomfort, anxiety/depression and cognitive function\(^\text{18}\). Some participants indicated that the focus should not be on the different chronic conditions but on how these conditions can affect quality of life. It is important to discuss quality of life with healthcare professionals because the professionals may provide helpful recommendations and support:

‘First the GP and I talked about my situation. When we could not solve the problem, he referred me to a psychologist. I still talk to the psychologist. It was nice that he raised this topic because otherwise I might not have talked about it and I would not have a psychologist.’ (female participant, 69 years in a focus group with a low level of education).

Comprehensibility of TOPICS-MDS
Participants of Round 2 (n=18) introduced different comments and improvements regarding the questions and response options of the TOPICS-MDS. As shown in Table 2, participants indicated that the questions were sometimes difficult to understand and therefore hard to answer. The most frequently mentioned reasons were the use of difficult words, complex questions, sensitive questions (e.g., about urinary incontinence), lengthy questions and a multitude of TOPICS-MDS abbreviations within individual questions. In addition, participants mentioned that certain questions were difficult to answer due to the high number of response options (>5) or the lack of a specific answer (e.g., ‘sometimes’ instead of only ‘yes / no’). Based on the comments in Round 2, the twelve questions were reformulated and evaluated by participants in Round 3. Ten of the twelve restated questions were assessed as better than the original question. The restated questions were most positively rated when simple words were used. If difficult words were supplemented with examples for clarification, participants rated it also as ‘clearer’. Furthermore, the use of a visual scale as a response style was evaluated as ‘clearer’. Participants find a scale helpful since it clarifies the response options visually, which makes it easier to provide an answer.
**Table 2. Comprehensibility of the questions (Qualitative data from the focus groups, Round 2)**

<table>
<thead>
<tr>
<th>Barriers to the understanding of questions</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Language</strong></td>
<td></td>
</tr>
<tr>
<td>A frequently mentioned barrier was the use of difficult words. In particular, participants with a culturally diverse background experienced difficulties understanding specific questions.</td>
<td>‘What is ‘mood’ (in Dutch ‘stemming’)? I do not know. Is ‘stemming’ if you hear voices in your head? (participant in a focus group; question 3). ‘Yes, ‘brain function’ (in Dutch ‘hersenfuncties’), that is a difficult word’ (participant in a focus group; question 4).</td>
</tr>
<tr>
<td>Participants indicated that it would be helpful to provide examples when using a difficult word.</td>
<td>‘You may use the word ‘incontinence products’, but you can give examples like panty-liners, diapers or Tena Lady’ (participant in a focus group; question 6).</td>
</tr>
<tr>
<td>Moreover, participants indicated that the use of abbreviations makes the question difficult to understand.</td>
<td>‘And all the abbreviations, you just have to know what it all means’ (participant in a focus group; question 1).</td>
</tr>
<tr>
<td><strong>Formulation of the questions</strong></td>
<td></td>
</tr>
<tr>
<td>Some questions can be interpreted in various ways, making them hard to answer.</td>
<td>Question: Do you need help with taking your medicines? ‘There are actually two things. The first thing is which pills do I have to take in the morning and the second thing is how do I take the pills. Those are two different things. It is not clear what is meant by ‘help’’ (participant in a focus group; question 8).</td>
</tr>
<tr>
<td><strong>Nature of the questions</strong></td>
<td></td>
</tr>
<tr>
<td>Participants also indicated that certain questions were too direct or too sensitive. They prefer not to answer those questions.</td>
<td>‘People are embarrassed. Yes, especially if a man comes into a room and the woman must ask the man about incontinence problems. He will be embarrassed’ (participant in a focus group; question 6).</td>
</tr>
<tr>
<td>Participants have also mentioned that in several cultures the topic of ‘incontinence’ is taboo. Therefore, many persons do not talk about this topic. If they have to provide responses to this questionnaire, they would rather not answer this question.</td>
<td>‘Yes, (...) older people who get these questions need their children to help them to translate the questions. It may be that the children will skip these questions because of taboo or out of shame about asking their parents about this topic’ (participant in a focus group; question 6).</td>
</tr>
<tr>
<td><strong>Length of the questions</strong></td>
<td></td>
</tr>
<tr>
<td>Participants have indicated that some questions, especially the introduction of the question, were too extensive. Therefore, it was difficult to follow these questions.</td>
<td>‘You know that the last part of the sentence will be remembered. The information before the comma has already been forgotten. Therefore, it is important to make short sentences that are not divided into sections’ (participant in a focus group; question 4).</td>
</tr>
</tbody>
</table>
Table 2. Continued

<table>
<thead>
<tr>
<th>Barriers to the understanding of questions</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Multitude of topics</strong></td>
<td></td>
</tr>
<tr>
<td>Participants of this study also noticed that different topics were asked within individual questions.</td>
<td>Question: Please tick the box of the answer that best fits your situation. Brain functions such as memory, attention and thinking. ‘Ok, the first question. I have no problems with my memory, done. Do not ask the other things. That is too much in one question. You should not ask about all these topics at once’ (participant in a focus group; question 4).</td>
</tr>
<tr>
<td><strong>High number of response options</strong></td>
<td></td>
</tr>
<tr>
<td>Participants had difficulties answering specific questions due to a high number of response options. Participants proposed the use of a scale to visualize the response options.</td>
<td>‘Always, very often, quite often, sometimes, almost never, never. There are many different categories. I think that never and always are no good options, because everyone is nervous sometimes’ (participant in a focus group; question 9).</td>
</tr>
</tbody>
</table>

**Discussion**

The aim of this study was to explore whether the TOPICS-MDS could facilitate SDM conversations between healthcare professionals and older adults with MCC. The older adults who participated in this Delphi study evaluated the various health domains of the TOPICS-MDS in terms of importance to discuss the health domains when reflecting on one’s preferred health outcomes. The older adults assessed the following original health domains of the TOPICS-MDS as being important to maintain: functional limitations, emotional wellbeing, social functioning and quality of life. The following domains were also added: coping with stress and dealing with health conditions and the effects on daily life. We found differences between older adults with a low level of education or a culturally diverse background and older adults with a high level of education. Although we have to be cautious in our interpretations due to the size of the panels, the older adults in our groups with a low level of education or a culturally diverse background more heavily stressed the importance of discussing the health domains with healthcare professionals than did the older adults with a high level of education.

The identified domains are consistent with the findings of earlier studies. For example, the importance of discussing functional limitations in healthcare communication has also been described in other studies on outcomes that are important to older adults. For instance, Fried et al. (2002) emphasize the importance of functional outcomes for older adults when they consider a treatment.

In our study, older adults prefer to discuss emotional wellbeing with a healthcare professional. The older adults emphasized, however, the importance of a trustworthy relationship between the healthcare professional and the patient. These findings are in line with the results of the study by Ridd et al. (2009), who found that a long-lasting relationships and continuity of care are important when
Health domains older adults want to discuss in individual health care conversations

Discussing sensitive topics\textsuperscript{36}. Persons generally experience more superficial relationships with doctors and nurses in hospitals than with their general practitioner (GP), who they have known for a long time\textsuperscript{36}.

The results indicate that older adults find it important to discuss social functioning with their healthcare professionals. Participants indicated that they are likely to become lonely and discussing this topic with healthcare professionals can help them find solutions. These findings do not correspond with the findings of other studies; other studies have reported that lonely persons rarely discuss issues with their GP and that GPs typically ask persons about loneliness indirectly or not at all\textsuperscript{37-39}. An explanation for this inconsistency with previous literature may be that participants in the present study described a hypothetical situation (i.e., if I get lonely, I think I would like to talk to my GP); however, most studies about loneliness report about experiences from people who are lonely. Kharichi et al. (2017) emphasized that a good relationship between healthcare professionals and patients is necessary when discussing sensitive topics such as loneliness\textsuperscript{39}.

An additional domain introduced by the participants themselves was to talk with healthcare professionals about how to cope with stress. Stress can cause physical complaints and mental problems that can impair persons in conducting everyday activities in life and the feeling of happiness\textsuperscript{40}. However, we expect that similar to conversations on other sensitive topics, a trusting relationship between healthcare professionals and patients is a prerequisite for conversations on stress.

The last domain introduced by participants was dealing with a chronic condition and the effects on daily life. Dealing with the chronic condition and the effects on life has many relations with self-management and adaptation to changes. Barlow et al. (2002) define self-management as ‘a person’s ability to manage the symptoms and the consequences of living with a chronic condition, including treatment, physical, social and lifestyle changes’\textsuperscript{41}. A previous study about barriers to self-management identified poor communication with healthcare professionals as a barrier to active self-management\textsuperscript{42}. Other studies have shown that healthcare professionals can support persons' self-management by educating persons and providing information about chronic conditions and how to manage them\textsuperscript{43, 44}. Although participants identified self-management as a separate domain from quality of life, we think there is a close relationship between these two domains\textsuperscript{45}. Smith et al. (2008) introduced the Brief Resilience Scale to assess a person’s resilience, defined as ‘the ability to bounce back and recover from stress’\textsuperscript{45}. It is worth investigating whether this scale could be added to the TOPICS-MDS to address these two domains, coping with stress and dealing with the chronic condition and the effects on daily life.

There may be some explanations for the differences found between older adults with a high level of education and older adults with a low level of education or a culturally diverse background. The findings of earlier studies support our idea that in the Netherlands, older adults with a low level of education or a culturally diverse background make more frequent use of healthcare resources, especially GP services, and generally have more chronic conditions than older adults with a high level of education\textsuperscript{46, 47}. This concept might imply that due to frequent contact with their GP, individuals feel confident discussing a variety of health domains. However, within different cultures, a variety of beliefs and values determine views on health and the need for healthcare services, ranging from the use of only family
care to extensive use of professional care, indicating that there are many different circumstances that influence which topics older adults with a culturally diverse background wish to discuss with their doctor\textsuperscript{48}.

With regard to the comprehensibility of the TOPICS-MDS in conversations, the most frequent comments regarding the questions were the use of difficult words, the formulation and length of questions, the sensitive nature of the questions and the multitude of topics within individual questions. These barriers were identified by both older adults with a high education level and older adults with a low education level or a culturally diverse background.

Strengths and limitations
A strength of this study was the involvement of older adults themselves in assessing the comprehensibility of the TOPICS-MDS as a basis for conversations between older persons and healthcare professionals and the need to discuss topics with their healthcare professionals. Second, by the organization of both the focus group sessions and the online questionnaire, we ensured panel members with a low level of education and a culturally diverse background were included in groups who participated in online questionnaires infrequently\textsuperscript{49, 50}. However, the use of focus group sessions might have introduced slight bias since the opinions and ratings of others could have influenced the choices of participants, although the advantage of the sessions was that deep insights were gained. In addition, we did not involve participants with a culturally diverse background or a low level of education in Round 3 of the Delphi study, which influenced the credibility of the quantitative results. Another possible limitation of this Delphi study was the loss of participants in the third round (second internet questionnaire), which may have impacted the emerging consensus over time. Additionally, although panelists were committed to the study, a higher number of respondents and a better distribution of participants among the groups may improve the robustness of the results. Further research is needed to adapt and validate the TOPICS-MDS according to the discussed recommendations and to enhance the cultural sensitivity of the TOPICS-MDS.

Practice implications
The recommendations regarding the additional topics and the suggestions to improve the comprehensibility of the questions have been presented to the Dutch TOPICS Working Group. For the TOPICS-MDS to be used as input for individual healthcare conversations between older adults and healthcare professionals, the education of healthcare professionals is needed. Therefore, in the large scale SDM implementation program of the Dutch Care Institute (Zorg Instituut Nederland), a specific project has been designed to improve SDM with the PROM TOPICS-SF (Short Form), supported by the Dutch Geriatric Society. As a part of this project health professionals at geriatric hospital wards are supported in the use of the results of this PROM in individual health care conversations. For example, through e-learning, they learn how to use the PROM in healthcare conversations. In addition, the Dutch seniors’ organization KBO-PCOB and the Dutch migrant organization NOOM put a joint effort in the empowerment of older adults to prepare for a health care conversation with this PROM, with information
sessions for older adults and educational material.

**Conclusion**
This study yielded recommendations of older adults on how to use the TOPICS-MDS PROM in healthcare conversations. Older adults assessed the majority of the questions in the TOPICS-MDS as important for healthcare conversations and advised the inclusion of two more domains, namely, coping with stress and dealing with health conditions and the effects on life. Furthermore, the older adults identified barriers regarding the comprehensibility of the questions in the TOPICS-MDS. These recommendations benefit the discussion of preferred health outcomes for older adults.
References

Health domains older adults want to discuss in individual health care conversations

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Social relations and loneliness among older patients consulting their general practitioner. *Danish medical journal* 2017; 64: 2017/03/07.


Supplementary File 1: 
Round 1: online questionnaire

Introduction

Many older persons have an appointment with a general practitioner, a specialist in a hospital or is visited by a district nurse. At first your complaints will be discussed. But what else do you want to discuss?
The doctor or nurse (we call them ‘healthcare professionals’) will also ask you questions about other matters. For example, about your daily life or social situation. The healthcare professional will ask about these matters to get an idea about what is important to you, which can help to tailor treatments as best as possible to your personal situation.
But what should the healthcare professional exactly ask you about in order to get a good impression of your situation?
By completing this questionnaire, you help healthcare professionals (such as general practitioners, specialists and nurses) to ask the right questions.

By filling in the questionnaire, you give your permission for participation in the research. The data is processed anonymously and confidentially.

This research consists of three rounds:
Round 1: a questionnaire
Round 2: a group discussion with older persons and their family members
Round 3: a questionnaire

This is the first round. We will ask you at the end of the questionnaire if you want to participate in the second and third round. This is not mandatory.

This questionnaire consists of 23 questions and it takes about 10 minutes to complete this questionnaire.

We would like to thank you very much for your cooperation!
Chapter 4

**Personal information**

1. Date of birth
   --/--/--

2. Gender
   - Male
   - Female

3. Postal code

4. In which country were you born?
   - Netherlands
   - Another country:

5. In which country was your father born?
   - Netherlands
   - Another country:

6. In which country was your mother born?
   - Netherlands
   - Another country:

7. What is the highest level of education that you have completed?
   - Fewer than 6 years of primary school
   - 6 years of primary school, Iom school, mlk school (special education)
   - More than primary school / primary school without further completed education
   - Vocational school
   - Mulo / mms / mavo / secondary professional education
   - Hbs / gymnasium / atheneum (university entrance level)
   - University / tertiary education

8. What is your marital status?
   - Married
   - Divorced
   - Widow / widower / partner deceased
   - Unmarried
   - Long-term cohabitation, unmarried

9. What is your living situation?
   - Independent, alone
   - Independent, with others (partner, children, etc.)
   - Care home/residential care centre
   - Nursing home since
Overall wellbeing

10. Which report mark (1-10) would you give your overall wellbeing?

   Where is this report mark based on? (For example: because I can do many things independently, etc.)

11. To what extent do you consider it to be important that the healthcare professional asks you about your functional limitations in daily life? You can think of walking, eating and getting dressed.

   - Not important
   - Slightly important
   - Neutral
   - Important
   - Very important

   Why did you choose this answer?

12. To what extent do you consider it to be important that the healthcare professional asks you about your emotional wellbeing? You can think of nervousness, tranquillity and dreariness.

   - Not important
   - Slightly important
   - Neutral
   - Important
   - Very important

   Why did you choose this answer?

13. To what extent do you consider it to be important that the healthcare professional asks you about your social functioning? You can think of visits to family members and/or friends.

   - Not important
   - Slightly important
   - Neutral
   - Important
   - Very important

   Why did you choose this answer?
14. To what extent do you consider it to be important that the healthcare professional asks you about your quality of life?

- Not important
- Slightly important
- Neutral
- Important
- Very important

Why did you choose this answer?

15. To what extent do you consider it to be important that the healthcare professional asks you about your spirituality? You can think of zest of life, gratitude and the desire to achieve goals.

- Not important
- Slightly important
- Neutral
- Important
- Very important

Why did you choose this answer?

16. To what extent do you consider it to be important that the healthcare professional asks you about your environment? You can think of your living situation, safety, transport and support of friends and/or family.

- Not important
- Slightly important
- Neutral
- Important
- Very important

Why did you choose this answer?

17. Several topics were mentioned above, which can be discussed during a conversation with a healthcare professional. Would you like to indicate below which three topics are most important to you?

- Functioning in daily life
- Emotional wellbeing
- Social functioning
- Quality of life
- Spirituality
- Environment

18. Are there any other topics you would like to discuss with a healthcare professional?
Conclusion

19. Has someone helped you to complete this questionnaire?
   - No, I completed the list alone
   - Yes, somebody helped me to complete the list

20. If yes, what did the help consist of?
   - Someone else recorded the answers, but I selected the answers myself
   - I selected and recorded the answers together with someone else
   - Someone else selected and recorded the answers for me

21. Do you have any remarks/additions regarding the previously asked questions?

22. Between 29 May and 2 June, discussion group sessions will be organized with older persons and their families. The subject is: how to ask questions to older persons in a clear way. A discussion session will take one hour and a maximum of eight persons can participate. Simultaneously, the discussion session with (a maximum of eight) family members will be organized. The location will be chosen as centrally as possible depending on the residences of the participants. The travel costs will be reimbursed, and each participant receives a gift voucher of fifteen euros.

   Are you and your family member possibly be interested to participate in a discussion group session?
   
   Yes: Mail address: Residence: My family member will participate as well: Yes/No

23. On 19 June, the questionnaire will be sent for the third and final round of this research. May we also send you this questionnaire?
   
   NB. Everyone can participate in the third and final round, even if you do not want to participate in the discussion group session.
   
   Yes: Mail address
   No

Thank you very much for completing the questionnaire!

This research was set up and carried out by Vilans, a knowledge centre for long-term care, in collaboration with Radboud UMC, LUMC and Maastricht University. ZonMw finances this research. If you have any questions about this research, please contact Ruth Pel (r.pel@vilans.nl) or Cynthia Hofman (c.hofman@vilans.nl)
Supplementary File 2: 
Round 3: online questionnaire

Introduction

In the first questionnaire we have asked you which topics you find important to discuss with a general practitioner or a nurse (we call them ‘healthcare professionals’) if you need care or a treatment.

We have discussed the results of all questionnaires with different groups of older persons. This provided explanations of what older persons consider as important topics. In this questionnaire we will ask you to read the explanations and indicate once again to what extent a topic is important to you.

In addition, certain questions from a questionnaire that are often left unanswered were discussed with older persons. Examples for not answering the questions are unclearly written questions and the use of difficult words. We have reformulated these questions and we would like to know whether you think that the reformulated questions are better than the original questions.

By completing in the questionnaire, you give your permission for participation in the research. The data is processed anonymously and confidentially.

We would like to thank you very much for your cooperation!
Health domains older adults want to discuss in individual health care conversations

1. To what extent do you consider it to be important that the healthcare professional asks you about your functional limitations in daily life? You can think of walking, eating and getting dressed.

An explanation of the older persons about this question:
The participants indicated that this question makes clear whether help is needed. For example, the general practitioner can refer you towards other institutions for additional help. In addition, the participants mentioned that it is sometimes difficult for the older persons to start talking about this topic and therefore it is nice when healthcare professionals ask about it.

- Not important
- Slightly important
- Neutral
- Important
- Very important

The conversation about functional limitations in daily life includes the following questions:

Original question: Do you need help with combing your hair or shaving?
- Yes
- No

The participants noticed the following:
- Add the word ‘with’, most ladies don’t shave

New question: Do you need help with combing your hair or with shaving?
- Yes
- No

Do you perceive the restated question to be clearer than the original question?
- Yes
- No

Explanation:

Original question: Do you use incontinence products?
- Yes
- No

The participants noticed the following:
- Give examples, for example, diapers, panty liners or Tenalady
- The question is too direct. We prefer: do you ever have unwanted urine loss when you laugh or cough?
- We feel embarrassed to answer this question
Restated question:

a. Do you have undesirable urine loss?
   - Yes
   - No
   - Once in a while

b. Do you use something against the undesirable urine loss, for example, diapers, party liners or Tenalady?
   - Yes
   - No
   - Not applicable

Do you perceive the restated question to be clearer than the original question?
   - Yes
   - No
   - Explanation:

Original question: Do you need help to get up out of a chair?
   - Yes
   - No

The participants noticed to following:
   - Why getting up out of a chair? Can it also be a toilet, a bed or getting up from a couch?
   - We would like to add the option ‘sometimes’, because for some older persons, it depends on how long they have been sitting if they need help to get up out of a chair

Restated question:
Do you need help with getting up from for example a chair of a couch?
   - Yes
   - No
   - Sometimes

Do you perceive the restated question to be clearer than the original question?
   - Yes
   - No
   - Explanation:

Original question: Do you need help with taking your medicines?
   - Yes
   - No

The participants noticed to following:
   - The word ‘taking’ can encompass many things, such as purchase medicine, prepare medicine, give medication by putting it in the mouth
and make sure the patient swallows it.

Restated question: Do you need help with your medicines?
- Yes
- No

Do you perceive the restated question to be clearer than the original question?
- Yes
- No
- Explanation:

2. To what extent do you consider it to be important that the healthcare professional asks you about your emotional wellbeing? You can think of nervousness, tranquillity and dreariness.

An explanation of the older persons about this question:
The participants indicated that they will not quickly raise this topic themselves. In addition, they find it very important that they have a good relationship with the healthcare provider. Lastly, the older persons think that the reason why they go to the healthcare professional is of importance. Healthcare professionals do not always have to ask about their emotional wellbeing.

- Not important
- Slightly important
- Neutral
- Important
- Very important

The conversation about the emotional wellbeing includes the following questions:

Original question:
How often in the past months have you been very anxious?
- Always
- Very often
- Quite often
- Sometimes
- Almost never
- Never

The participants noticed to following:
- Rather “nervous” than anxious
- There are too many answer options

Restated question: How often have you been very nervous in the past month?
- Very often
- Sometimes
Chapter 4

- Almost never

Do you perceive the restated question to be clearer than the original question?
- Yes
- No
- Explanation:

Original question: How often in the past month have you felt sombre that nothing could cheer you up?
- Always
- Very often
- Quite often
- Sometimes
- Almost never
- Never

The participants noticed to following:
- We prefer other answer options, for examples with numbers
- Participants noticed that “nothing can cheer you up” is uncommon, there is always something that can cheer you up.

Restated question:
Mark with a cross on the ruler to indicate how often you felt sombre in the past month that almost nothing could cheer you up.

Never_________ Always

Do you perceive the restated question to be clearer than the original question?
- Yes
- No
- Explanation:

3. To what extent do you consider it to be important that the healthcare professional asks you about your social functioning? You can think of visits to family members and/or friends.

An explanation of the older persons about this question:
The participants brought forward that topics, such as loneliness can be discussed, and solutions can be provided. In addition, the participants feel more comfortable to talk about this topic with a healthcare professional they trust.

- Not important
- Slightly important
- Neutral
- Important
Health domains older adults want to discuss in individual health care conversations

4. To what extent do you consider it to be important that the healthcare professional asks you about your quality of life?

An explanation of the older persons about this question:
Participants mentioned that discussing quality of life only makes sense if the healthcare professional has enough time. By discussing quality of life, health professionals can look into whether older persons need help and who can possibly provide it.

- Not important
- Slightly important
- Neutral
- Important
- Very important

The conversation about the quality of life includes the following questions:

Original question: Tick the box next to the sentence that best describes your health right now.
Pain/symptoms:
- I have no pain or other symptoms
- I have moderate pain or other symptoms
- I have very severe pain or other symptoms

The participants noticed:
- Two different things are asked for
- The participants find the wording ‘very severe’ doubled.

Restated question:
Tick the box next to the sentence that best describes your health right now.
Pain:
- I have no pain
- I have moderate pain
- I have severe pain

Do you perceive the restated question to be clearer than the original question?
- Yes
- No

Explanation:

Original question: Tick the box next to the sentence that best describes your health right now.

Mood:
Chapter 4

- I am not anxious or despondent
- I am moderately anxious or despondent
- I am very anxious or despondent

The participants noticed the following:
- We would rather indicate how often this occurred. Therefore, we prefer the word ‘sometimes’ instead of the word ‘moderate’
- The question is too direct
- We would rather use the word ‘scared’ instead of the word ‘anxious’

Restated question:
Tick the box next to the sentence that best describes your health right now
Mood:
- I am not scared or despondent
- I am sometimes scared or despondent
- I am often scared or despondent

Do you perceive the restated question to be clearer than the original question?
- Yes
- No

Explanation:

Original question: Tick the box next to the sentence that best describes your health right now.
Brain functions such as memory, attention and thinking:
- I have no problems with my memory, attention and thinking
- I have some problems with my memory, attention and thinking
- I have severe problems with my memory, attention and thinking

The participants noticed the following:
- Participants find it difficult that three different things were asked within one question.
- Not everyone feels that forgetfulness is a problem. Therefore, it is important to not problematize the question.
- We would rather want to indicate how often we were bothered with something. Therefore, we would like to prefer the wording ‘sometimes’ instead of ‘some’.

Restated question: Tick the box next to the sentence that best describes your health right now.
Brain functions such as memory, attention and thinking:

How is your memory?
- Good
- Moderate
- Bad
How is your attention?
- Good
- Moderate
- Bad

How is your thinking?
- Good
- Moderate
- Bad

Do you perceive the restated question to be clearer than the original question?
- Yes
- No
Explanation:

Original question:
How is your quality of life in general?
- Excellent
- Very good
- Good
- Reasonable
- Poor

The participants noticed to following:
- We prefer to use ‘how do you perceive’ or ‘how satisfied are you’ instead of ‘how is’
- The participants indicated that quality of life is a vague concept. Providing examples would make it clearer.

Restated question: How do you perceive your quality of life? (For example, are you happy with your life as it is now, or how are you doing).
- Excellent
- Very good
- Good
- Reasonable
- Poor

Do you perceive the restated question to be clearer than the original question?
- Yes
- No
Explanation:

Original question:
Which report mark would you give your life at this moment?
Report mark: … Enter a figure between 0 and 10 here
The participants noticed the following:
- The participants preferred the wording ‘mark’ instead of ‘report mark’
- Using a yardstick would make it clearer

Restated question:
Which mark would you give your life at this moment?

0 __________________ 10

Do you perceive the restated question to be clearer than the original question?
- Yes
- No

Explanation:

Original question:
How is your quality of life in general, in comparison to one year ago?
- Much better
- Slightly better
- About the same
- Slightly worse
- Much worse

The participants noticed the following:
- We would prefer to use the wording ‘how do you perceive’ instead of ‘how is’.
- It was not clear what was meant by one year ago. Do you mean a calendar year ago or 12 months ago?

Restated question:
How do you perceive your quality of life, in comparison to one year ago?
- Much better
- Slightly better
- About the same
- Slightly worse
- Much worse

Do you perceive the restated question to be clearer than the original question?
- Yes
- No

Explanation:

New topics came forward from the interviews and group discussion sessions with the older persons.

To what extent do you consider it to be important that the healthcare professional asks you whether you exercise frequently?
Health domains older adults want to discuss in individual health care conversations

- Not important
- Slightly important
- Neutral
- Important
- Very important

To what extent do you consider it to be important that the healthcare professional asks you how you cope with stress?
- Not important
- Slightly important
- Neutral
- Important
- Very important

To what extent do you consider it to be important that the healthcare professional asks you how you deal with the health conditions and the effects on life?
- Not important
- Slightly important
- Neutral
- Important
- Very important
Conclusion

5. Has someone helped you to complete this questionnaire?
   - No, I completed the list alone
   - Yes, somebody helped me to complete the list

6. If yes, what did the help consist of?
   - Someone else recorded the answers, but I selected the answers myself
   - I selected and recorded the answers together with someone else
   - Someone else selected and recorded the answers for me

7. Do you have any remarks/additions regarding the previously asked questions?

Thank you very much for completing the questionnaire!

Please tick below:
   - I would like to receive my VVV gift voucher by post
   - I would like to receive my bol.com gift voucher by e-mail
   - I do not want a gift certificate

This research was set up and carried out by Vilans, a knowledge centre for long-term care, in collaboration with Radboud UMC, LUMC and Maastricht University. ZonMw finances this research.

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Measuring triadic decision making in older patients with multiple chronic conditions: Observer OPTIONMCC

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Patient Education and Counseling
Abstract

Objective: To develop a valid and reliable tool to measure triadic decision making between older adults with multiple chronic conditions (MCC), their informal caregivers and geriatricians.

Methods: Video observational study with cross-sectional assessment of interaction during medical consultations between geriatricians (n=10), patients (n=108) and informal caregivers (68) by three calibrated raters at the geriatric outpatient department of two Dutch hospitals. The Observer OPTION\textsuperscript{MCC} instrument was developed, based on the ‘Dynamic model of SDM in frail older patients’ and the ‘Observing Patient Involvement in Decision Making - 5 item scale’ (Observer OPTION-5).

Results: Factor analysis confirms that it is acceptable to regard the new scale as a single construct. The 7-item single factor solution explained 62.76% of the variability for geriatricians, 61.60% of the variability for patients and 54.32% of the variability for informal caregivers. The inter-rater ICC for the total Observer OPTION\textsuperscript{MCC} score was .96, .96 , and .95 (resp. geriatricians, patients, informal caregivers), with values ranging from .60 to .95 for individual items, showing good levels of agreement.

Conclusion and Practice Implications: We conclude that Observer OPTION\textsuperscript{MCC} is sufficiently valid and reliable to be used for the assessment of triadic SDM in populations of older patients with MCC.
Introduction

Despite proven benefits of shared decision making (SDM) among older adults, such as a better understanding, risk perception and less decisional conflict\(^1\),\(^2\), the implementation of SDM is not yet common practice\(^3\),\(^4\). Literature about SDM in older adults with multiple chronic conditions (MCC) reveals several facilitators to SDM. Discussing an older person’s desired role regarding decision making and clarification of personal values, goals and preferences are important enablers of the SDM process\(^5\)-\(^13\). Furthermore, a personalized approach regarding the distribution of information and tailored communication is an essential condition to the SDM process in older adults\(^6\),\(^14\)-\(^16\). In addition, informal caregivers (IC) play an important role in the SDM process: as an information gatherer, coach, advisor, negotiator and/or caregiver\(^17\)-\(^19\). The term ‘triadic decision making’ refers to decision making consultations in which three parties are involved: the physician, the adult patient and the adult companion (informal caregiver)\(^20\).

To facilitate the implementation of SDM in older adults with MCC and to comply with the particular demands for older patients, the ‘Dynamic model for SDM in frail older patients’ was developed\(^21\). This model states that adequate and informed decisions in older patients with MCC are facilitated when they are based on the goals and preferences as expressed by patients. To this purpose, the ‘Dynamic model for SDM in frail older patients’ introduces two preliminary steps: ‘Preparation’ and ‘Goal talk’, in addition to the generally known three steps of SDM-models, i.e. ‘Choice talk’; ‘Option talk’ and ‘Decision talk’\(^22\). Moreover, one additional last step, ‘Evaluation’, is added in the ‘Dynamic model for SDM in frail older patients’\(^21\).

Existing measurement scales have been constructed to measure the extent to which clinicians involve their patients in SDM, such as the validated observer OPTION-12 and OPTION-5 scales\(^23\)-\(^26\). However, the regular models and measurement scales are not adapted to the specific SDM process in older adults as described in the ‘Dynamic model for SDM in frail older patients’. Until now, adequate measurement scales to measure SDM in older adults are lacking. Existing SDM measurement scales do not incorporate the initial step of goal clarification, which is the most important element in the ‘Dynamic model for SDM in frail older patients’. Moreover, they do not take the role and participation of the patient and informal caregiver into account, though the latter often play a major role in the decision-making process\(^17\),\(^19\). Informal caregivers support the decision making process through providing information, asking questions and assisting in receiving and understanding information, in particular when older adults suffer from cognitive decline, are too ill or experience too much discomfort to participate in decision making\(^6\),\(^7\),\(^10\),\(^19\),\(^27\),\(^28\). The aim of this study was to develop a valid and reliable tool to measure triadic decision making in older populations with MCC based on the OPTION-5, including the participation of older adults and their informal caregivers: the Observer OPTION\(^{MCC}\).

Methods

Design

This video observational study was carried out at the geriatric outpatient...
departments of two Dutch hospitals: 1) the department of Geriatric Medicine of the Academic Medical Center (AMC) and 2) the outpatient clinic of Geriatric Medicine of the Medical Center Slotervaart, a non-academic teaching hospital (MC SLV). The study protocol was approved by the institutional Review Board of the AMC (W16_107#16.125), local approval was provided by the MC SLV (P1641).

Participants
The participants of this study were 108 (55 in AMC and 53 in MC SLV) older patients and their 68 informal caregivers who visited the geriatric outpatient clinic of one of the participating hospitals. A geriatric patient is not merely defined by age, but more by decreased functional reserves leading to frailty and the prevalence of more than one chronic condition. Inclusion criteria for this study were: 1) having an appointment at the geriatric outpatient clinic and 2) sufficient mastery of Dutch language. Exclusion criteria were: 1) being in terminal phase of life and 2) having a moderate to severe state of dementia (MMSE < 15) according to the medical file. Eligible geriatricians had to meet the following criteria: 1) specialized in geriatrics, 2) working at the outpatient clinic of the geriatric department. Temporary staff was not eligible.

Data collection
One week before the clinical consultation – in this study defined as ‘the consultation(s) during which the patients’ problems, diagnostic procedures, or treatment options are discussed’ – eligible patients were called and informed about the study. Interested patients received an information letter with informed consent form by mail. One day before the consultation, the patient was called again to remind the patient of the study and to give the opportunity to ask questions. Participating patients completed a pre-consultation questionnaire at home or just before consultation. After written informed consent from patient and informal caregiver was obtained, the consultation was video recorded. A research assistant was present to operate the recorder but left the room during the consultation itself. The geriatricians gave written informed consent, were informed about participation of their patients and answered a post-consultation survey.

Development of the Observer OPTIONMCC
The observer OPTION scale has been developed to assess the extent to which clinicians involve patients in decision making processes. The scale has been validated in different studies and is widely used by researchers to measure SDM. The original version consisted of 12 items (OPTION-12). Later a modified version was published with 5 items (OPTION-5). The OPTION comprises of a list of observable competences constructed to measure the skills of clinicians in team-, option- and decision talk. The OPTION-5 measures most, but not all, competences described in the ‘Dynamic model for SDM in frail older patients’. To construct the revised scale all competences described in the ‘Dynamic model for SDM in frail older patients’ were compared to the competences measured in the OPTION-5, and an adapted version, the Observer OPTIONMCC was composed (Supplementary Table S1). The OPTION-5 measures the competences regarding team-, option- and decision-
talk. Since the ‘Dynamic model for SDM in frail older patients’ introduces three additional steps: ‘Preparation’, ‘Goal talk’ and ‘Evaluation’, we had to develop extra items for the Observer OPTIONMCC scale. The first step of the ‘Dynamic model for SDM in frail older patients’, ‘Preparation’, is not incorporated in the Observer OPTIONMCC scale, since this step usually takes place before the clinical consultation and is therefore not observable.

The Observer OPTIONMCC follows the OPTION-5 scoring guidance. The score ‘0’ is allocated to the situation where the competency described is not observed, other scores (1 to 4) are allocated to increasing levels of achievement for the described competence. Furthermore, an additional set of observer items was constructed to measure the participation of patients and their informal caregivers during the SDM process. We developed for all Observer OPTIONMCC items a score to rate the level of participation of patients and informal caregivers on three levels: (0) no participation, (1) responsive participation and (2) active participation. The revised scale scoring guidance is depicted in Table 1.

Table 1. The OPTIONMCC scale scoring guidance

<table>
<thead>
<tr>
<th>Scale score</th>
<th>Geriatricians</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>The behaviour* is not observed</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>A minimal attempt is made to exhibit the behaviour</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>The geriatrician asks the patient about their preferred way of receiving information to assist decision</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>The behaviour is exhibited to a good standard</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>The behaviour is observed and executed to a high standard</td>
<td></td>
</tr>
</tbody>
</table>

*Observer items OPTIONMCC as described in Table 1

<table>
<thead>
<tr>
<th>Scale score</th>
<th>Patients</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No or minimal participation, e.g. only yes or no.</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Responsive participation, answers on questions but does not asks or actively contributes in the conversation</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Active participation, answers questions and asks questions, brings in own ideas and shares perceptions</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scale score</th>
<th>Informal Caregivers</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No or minimal participation, e.g. only yes or no.</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Responsive participation, answers on questions but does not asks or contributes in the conversation</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Active participation, answers questions and asks questions, brings in own ideas and shares perceptions</td>
<td></td>
</tr>
</tbody>
</table>
Other Measurements

Demographics
Patients’ and informal caregivers’ baseline characteristics included: age, gender, education (low, middle, high), and living situation.

Clinical characteristics
The level of patients’ frailty was measured with the Groningen Frailty Indicator (GFI)\(^{33}\), consisting of 15 self-reported items, with a total score ranging from 0 to 15\(^{34}\). A score of four or higher is considered as the cut-off point for frailty\(^{34}\). Higher scores on GFI indicated higher frailty levels. Polypharmacy was defined as ‘the use of >4 different medications\(^{33}\). The Charlson Comorbidity Index (CCI) was used as an indication for the number and severity of MCC\(^{35}\). The scores on the CCI range from 0 to 31, with a higher score indicating a greater number of comorbidities and/or more severe comorbidities\(^{36}\).

Characteristics of the consultations
Geriatricians reported for each consultation the most important problem presented by the patient, whether a decision was taken and the type of the decision. They indicated whether according to the geriatrician there were more options available and if so, if all options were equal; meaning subject to preference-sensitive decisions\(^{37}\).

Analysis

Inter-rater reliability
The video assessment was done by three independent observers using the Observer OPTION\(^{MCC}\). Training consisted of explaining the use of the scale, rating the same ten consultations, and discussing discrepancies. The original OPTION-5 guidelines were followed to minimize observer bias and reactivity\(^{38}\). The observers watched the video once before scoring. After ten training consultations, the observers rated another sample of ten consultations in order to establish ICC. The remaining consultations (n = 88) were rated independently, whilst every tenth consultation was discussed by all observers after rating to ensure a stable inter-rater-reliability. The data were analysed by studying the responses to each item, the scale reliability was assessed with inter-item and item-total correlations, summarized by Cronbach’s \(\alpha\). Inter-rater agreement was assessed using intraclass correlation coefficient (ICC). ICC scores above .40, .60 and .80 were interpreted as fair, moderate and substantial agreement respectively.

Factor analysis
The triadic Observer OPTION\(^{MCC}\) consists of a part for geriatricians, patients and informal caregivers. Exploratory factor analysis (varimax rotation taking eigenvalues of 1.1) was used to determine factor loadings.

Item response
The data were analysed by studying the responses to each item, both for geriatricians, patients and informal caregivers. The item response for geriatricians was presented both in percentages to show the distribution between the scoring
categories (0=min, 4=max) as well as in a mean score per item and in a total mean score. Conform OPTION-5 guidelines the scores were also transformed to a 0-100 score (0=min, 100=max). The item response for patients and informal caregivers was measured on a three-point scale (0=min, 2=max) and presented in percentages and a mean score per item and a total mean score.

**Results**

**Response**

In the study period 515 older adults visited one of the two hospitals for a geriatric consultation with a geriatrician of which 108 participated in the study. Figure 1 presents the flow chart of the study. We found no significant differences on age and gender between the participating patients (n=108) and the non-responding patients (n=407) (age p=.142, gender p=.066).

---

**Figure 1. Flowchart of the inclusion**

![Flowchart of the inclusion](image-url)
Table 2. Characteristics of participating patients (n = 108) and (most important) informal caregivers (n = 68)

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>Patients</th>
<th>Informal caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics</td>
<td>Total</td>
<td>Total</td>
</tr>
<tr>
<td>Na = 108 (100%)</td>
<td>Na = 68</td>
<td></td>
</tr>
<tr>
<td>AMC 55</td>
<td>AMC 32</td>
<td></td>
</tr>
<tr>
<td>MC SLV 53</td>
<td>MC SLV 35</td>
<td></td>
</tr>
</tbody>
</table>

**Demographics**

| Age, in years (mean, SD) | 78.0(8.2) | 66.6 (13.1) |
| Female sex (n, %)        | 55 (52.4) | 44 (64.7%)   |

**Level of education**

| Low (n, %) | 19 (18.8) |
| Middle (n, %) | 58 (57.5) |
| High (n, %)  | 23 (22.8)  |

| Independent, alone (n, %) | 41 (40.6) |
| Independent, with others (n, %) | 58 (57.5) |
| Home for the elderly (n, %) | 2 (2.0) |

**Relation to the patient**

| Husband/wife | n.a. |
| Daughter/Son | 38 (55.9%) |
| Other relative | 22 (32.4%) |
| Friend, neighbour, etc | 3 (4.4%) |

**Clinical characteristics**

| Polypharmacy b (≥4) (n, %) | 65 (69.1) | n.a. |
| Frailty c mean, SD | 4.4 (2.6) | n.a. |
| Comorbidity d | 2.09 (1.8) | n.a. |

<table>
<thead>
<tr>
<th>Main problems (n, %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cognition/dementia</td>
</tr>
<tr>
<td>falls/mobility</td>
</tr>
<tr>
<td>osteoporosis</td>
</tr>
<tr>
<td>anemia</td>
</tr>
<tr>
<td>thyroid problems</td>
</tr>
<tr>
<td>orthostasis</td>
</tr>
<tr>
<td>dizziness</td>
</tr>
<tr>
<td>abdominal complaints</td>
</tr>
<tr>
<td>depression</td>
</tr>
<tr>
<td>polypharmacy</td>
</tr>
<tr>
<td>hypertension</td>
</tr>
<tr>
<td>dyspnea</td>
</tr>
<tr>
<td>backpain</td>
</tr>
<tr>
<td>other</td>
</tr>
</tbody>
</table>

---

b: Polypharmacy: use of ≥4 different medications  
c: Frailty: GFI (score 0 - 15; > 4 indicates frailty)  
d: Comorbidity: CCI. A higher CCI-score (CCI-score > 5) is associated with higher morbidity and mortality  
sd=standard deviation

---

a: n varies slightly due to missing data
Baseline characteristics
Table 2 summarizes the socio-demographic and clinical characteristics for patients and informal caregivers. About half of the participating patients was female (52.4%) and lived with a partner (57.5%). The mean age was 78.0 years (SD = 8.2) and 19 (18.8%) of the respondents had a low education level. Polypharmacy was present in 65 patients (69.1%). The mean frailty score was 4.4 (SD = 2.6), the mean CCI score was 2.09 (SD 1.8). The most frequent problems presented were cognitive impairment, falls and osteoporosis. From 108 (100%) participating patients, 68 (63.0%) had an informal caregiver present at the consultation. Most participating informal caregivers were female (64.7%) and the mean age was 66.6 years (SD = 13.1). The majority of informal caregivers were middle or high educated (60%). The relation to the patient was mainly spouse (n=38, 56%) or child (n=22, 32%).

Consultation characteristics
The characteristics of the consultations are depicted in Table 3. According to the geriatricians, in 94 (87.9%) of the consultations a decision was made. In 88% of the decisions, more options were available. Of these, 43% were considered equal, meaning subject to a preference sensitive decision37.

<table>
<thead>
<tr>
<th>Table 3. Characteristics of consultations and decisions</th>
<th>N³ = 108 (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration (in min) mean (SD)</td>
<td>40.27 (26.7)</td>
</tr>
<tr>
<td>Consultations in which a decision was made (according to geriatrician)</td>
<td>94 (87.9%)</td>
</tr>
<tr>
<td>Most frequently discussed decisions (N= 128):</td>
<td></td>
</tr>
<tr>
<td>additional diagnostics</td>
<td>31 (24.2%)</td>
</tr>
<tr>
<td>medication</td>
<td>28 (21.8%)</td>
</tr>
<tr>
<td>follow-up</td>
<td>27 (21.1%)</td>
</tr>
<tr>
<td>referral to primary care (casemanager, General Practitioner, physiotherapist, psychologist)</td>
<td>19 (14.8%)</td>
</tr>
<tr>
<td>lifestyle (diet, exercise, alcohol)</td>
<td>12 (9.4%)</td>
</tr>
<tr>
<td>consultation other hospital specialist</td>
<td>8 (6.2%)</td>
</tr>
<tr>
<td>other</td>
<td>3 (2.3%)</td>
</tr>
<tr>
<td>More options were available (according to geriatrician)</td>
<td>85 (87.6%)</td>
</tr>
<tr>
<td>If so, options were considered equal (according to geriatrician)</td>
<td>36 (42.9%)</td>
</tr>
<tr>
<td>Comorbidities were discussed (according to observer)</td>
<td>89 (87.3%)</td>
</tr>
<tr>
<td>If so, comorbidities were considered in relation to decision (according to observer)</td>
<td>62 (72.9%)</td>
</tr>
</tbody>
</table>

a: n varies slightly due to missing data

Inter-rater reliability
The inter-rater ICC, summarized by Cronbach’s α, for the total Observer OPTIONMCC score was .96, .96, .95 (resp. geriatricians, patients, informal caregivers), with values ranging from .60 to .95 for individual items (see Supplementary Table S2), which showed good levels of agreement.
### Table 4. OPTIONMCC item response geriatricians (n = 10), patients (n=108) and informal caregivers (n = 68)

<table>
<thead>
<tr>
<th>OPTIONMCC Item</th>
<th>Item score (0 - 4) (%)</th>
<th>Mean OPTIONMCC score (0-4)</th>
<th>Mean transformed OPTIONMCC score (0 = min, 100 = max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Goal talk: - Identify discussion partner - Identify patient values and goals of care</td>
<td>12.6 37.9 30.1 13.6 5.8 100%</td>
<td>1.62 1.06</td>
<td>40.5 26.5</td>
</tr>
<tr>
<td>2 Option Talk: - Explaining there are more options</td>
<td>8.7 25.2 45.6 17.5 2.9 100%</td>
<td>1.81 .93</td>
<td>45.1 23.2</td>
</tr>
<tr>
<td>3 Team Talk: - Support deliberation / forming a partnership</td>
<td>39.8 26.2 17.5 10.7 5.8 100%</td>
<td>1.17 1.23</td>
<td>29.1 30.7</td>
</tr>
<tr>
<td>4 Option Talk: - Information about options</td>
<td>11.7 35.9 33.0 18.4 1.0 100%</td>
<td>1.61 .95</td>
<td>40.3 23.8</td>
</tr>
<tr>
<td>5 Decision Talk: - Eliciting preferences</td>
<td>17.5 27.2 28.2 13.6 13.6 100%</td>
<td>1.79 1.27</td>
<td>44.7 31.8</td>
</tr>
<tr>
<td>6 Decision Talk: - Integrating preferences</td>
<td>20.4 28.2 25.2 20.4 5.8 100%</td>
<td>1.63 1.19</td>
<td>40.8 29.7</td>
</tr>
<tr>
<td>7 Evaluation talk - Evaluating the SDM process - Preparing treatment plan</td>
<td>18.4 44.7 19.4 16.5 1.0 100%</td>
<td>1.37 1.00</td>
<td>34.2 24.9</td>
</tr>
<tr>
<td>Total OPTIONMCC</td>
<td></td>
<td>1.57 .86</td>
<td>39.3 21.4 (range 3.6-82.1)</td>
</tr>
</tbody>
</table>
### Table 4. Continued

<table>
<thead>
<tr>
<th>OPTION MCC item response patients and informal caregivers</th>
<th>Item score (0 - 2) (%)</th>
<th>Mean OPTION MCC score (0-2)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0  1  2</td>
<td>mean  Sd</td>
</tr>
<tr>
<td></td>
<td>Patients</td>
<td>Informal caregivers</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 Team Talk: - Support deliberation / forming a partnership</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13.6 53.4 33.0</td>
<td>1.19 .7</td>
</tr>
<tr>
<td></td>
<td>14.6 59.2 26.2</td>
<td>1.12 .6</td>
</tr>
<tr>
<td>1 Option Talk: - Information about options</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20.4 53.4 26.2</td>
<td>1.06 .68</td>
</tr>
<tr>
<td></td>
<td>21.4 42.7 35.9</td>
<td>1.15 .75</td>
</tr>
<tr>
<td>2 Decision Talk: - Eliciting preferences</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>21.4 48.5 30.1</td>
<td>1.09 .72</td>
</tr>
<tr>
<td>3 Evaluation talk: - Evaluating the SDM proces - Preparing treatment plan</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>27.2 53.4 19.4</td>
<td>.92 .68</td>
</tr>
<tr>
<td>Total OPTION MCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1.05 .54</td>
<td></td>
</tr>
</tbody>
</table>
Factor analysis
The scree plot showed the presence of one factor, the distribution of questions to this factor revealed a Cronbach’s $\alpha$ of .893 (geriatricians), Cronbach’s $\alpha$ of .890 (patients) and Cronbach’s $\alpha$ of .851 (informal caregivers) respectively. The 7-item single factor solution explained 62.76% of the variability for geriatricians, 61.60% of the variability for patients and 54.32% of the variability for informal caregivers.

The Observer OPTIONMCC item response
The Observer OPTIONMCC item response is depicted in Table 4. The overall mean Observer OPTIONMCC score (0 = min, 4 = max) for the geriatricians was 1.57 (SD .86), the mean transformed Observer OPTIONMCC score (0= min, 100 = max) was 39.3 (SD 21.4, range 3.6 - 82.1). The overall mean score (0= min, 2= max) for the patients was 1.05 (SD .54). The overall mean score (0= min, 2= max) for the informal caregivers was 1.04 (SD .50). There were no significant differences between consultations with and without informal caregivers on the OPTIONMCC score for geriatricians ($p=.194$ resp. patients ($p=.372$).

Discussion and Conclusion
Principal findings
Factor analysis confirms that it is acceptable to regard the scale as a single construct. We conclude that the Observer OPTIONMCC is sufficiently valid and reliable to be used in populations of older adults with MCC. Since the scale showed to be one dimensional through the factor analysis, the internal consistency could be assessed by Cronbach’s alpha. The Cronbach’s alpha was in all cases > .8 indicating a good internal consistency of the scale. The reliability of the Observer OPTIONMCC was established by calculating the ICC, which turned out to be very high (> .95), although the ICC on some individual items was lower, however still moderate (range .60 - .95). The face and content validity of the Observer OPTIONMCC was established by building on the proven valid and reliable OPTION-scale, and the concept of the ‘Dynamic model for SDM in frail older patients’. This study shows that with the Observer OPTIONMCC the constructs of the ‘Dynamic model for SDM in frail older patients’ are measured and can be used in further research on this model in other empirical studies.

The overall observed OPTIONMCC score for geriatricians (39.3, range 0 - 100) is high compared to the mean observed OPTION scores found in other studies: the mean OPTION score of 33 studies in the review of Couet et al. (2015) was 23 (range 0-100)\(^4\). However, the average duration of the consultations in this study was much longer (40.3 min) compared to other studies; Couet et al. (2015) reported a median length of consultation from 13 minutes. Several other studies confirm that there is more patient participation in longer visits\(^39\). Also, most studies in the review of Couet et al. reported on other disciplines, mostly general practitioners, and involved a younger population.

We observed a responsive participation of both patients and informal caregivers in SDM (resp. 1.05 and 1.04, range 0 - 2). To our knowledge, this is the first study that systematically integrates observed participation of older patients and informal caregivers during clinical consultations with an OPTION scale.
Phillipe et al. (2016) state in a systematic review that there are few reliable and valid observer-completed tool for patient participation related to SDM; all still in pilot stage and/or measuring patients’ perspective but not actual participation in SDM, which makes it not possible to compare our findings to other measures. Although we found no quantitative data on the observed participation of informal caregivers, the literature subscribes the importance of involving informal caregivers in SDM. Many studies describe that informal caregivers often play an important role in SDM, either because they represent the patient by providing information or because they have their own interests in the decision due to extensive frailty and increasing dependence of their relatives. Other studies report that the presence of an informal caregiver at the medical consultation is more common among older adults with MCC compared to a general population, and their role becomes more substantial when the older adult is less able to participate in the consultation. For example, when patients become more cognitively impaired, the caregiver plays a more active role in the decision-making process. Since (mild) cognitive impairment was reported as the main diagnosis in the study population, it seems very relevant that we observed the participation of informal caregivers. We found very similar scores for patient and informal caregiver participation, which is not in line with findings in the literature describing that when patients are accompanied by a third person, their share in the conversation decreases. An explanation for this could be that geriatricians are trained in triadic conversations; e.g. it is very common that an informal caregiver is present at the consultation.

The observer OPTIONMCC includes two new items compared to the observer OPTION-5: Goal talk (item 1) and Evaluation talk (item 7). The scores indicated that the patients participated most in the Goal talk, although geriatricians and informal caregivers scored only moderate participation on Goal talk. Evaluation talk scored of all items for all three parties the lowest. These results indicate that in training (geriatricians) and empowerment (patients and informal caregivers) more attention is needed towards forming a partnership and reflecting on the decision making process.

**Strengths and weaknesses**

The major strength in this study was the chosen methodology of observation based on videotaping real life consultations; which gave us an unique insight in the daily communication processes between geriatricians, older adults and their informal caregivers. An advantage of videotapes compared to audiotapes is that the researchers were able to distinguish between the contributions of older adults and their informal caregivers. Furthermore, the researchers were not present during the consultation, thus minimizing the influence on the behaviour of the participants. However, we cannot discount there could have been some influence of the presence of a video camera on geriatricians, patients and informal caregivers. The continuous calibrating between the raters was beneficial to the inter-rater-reliability of this study, and suggests that in order to get such a high ICC, continuous calibrating is necessary. Finally, in contrast to existing Observer OPTION instruments, the OPTIONMCC measures the discussion of patients’ personal goals as a first step in the SDM process, thus guiding the options that are relevant to those goals. In other versions of the OPTION ‘goal talking’
Chapter 5

deals with issues from the clinicians’ perspective, but doesn’t explore patients’ or informal caregivers’ reasons to consult the clinician and their personal goals. According to the ‘Dynamic model for SDM in frail older patients’ those personal goals should be the starting point in decision making, which we accommodated by adding ‘goal talk’ as an explicit step in the beginning of the consultation and assessing the contributions of all three parties.

This study has also some limitations. The participants were informed about the purpose to study communication during consultation, although SDM was not mentioned, which might have influenced their behaviour. The subscales for patients and informal caregivers are ranked on a three-point scale (no/minimal, responsive and active participation)\textsuperscript{4}4. Although this was based on the literature and reflected much of the levels of participation we observed in daily practice, this impedes a comparison with the subscale for the geriatricians, which is a five-point scale. Finally, only 63% of the patients were accompanied by an informal caregiver, 37% of the older adults came alone to the consultation. A sub-group analysis on differences between consultations with and without an informal caregiver revealed no significant differences on the Observer OPTION\textsuperscript{MCC} items of geriatricians and patients nor on the total mean score. Thus, in cases where the patients visits the geriatrician alone, the Observer OPTION\textsuperscript{MCC} can be used as a dyadic instrument, taking the perspectives of the geriatricians and patients into account.

**Conclusion**

We conclude that Observer OPTION\textsuperscript{MCC} is sufficiently valid and reliable to be used for the assessment of triadic SDM in populations of older patients with MCC. Since decisions about diagnosis, treatment and care should be made in close cooperation with older adults and their informal caregivers, the Observer OPTION\textsuperscript{MCC} adds value to former Observer OPTION’s by also measuring the patients’ and informal caregivers’ participation in SDM.

**Practice Implications**

The Observer OPTION\textsuperscript{MCC} can be used to measure triadic SDM in daily practice. Furthermore, it provides insight in how the different steps in SDM can be operationalised based on a dynamic model. Results from the current study indicate that improved SDM skills are needed for professionals, focusing on discussing personal goals and preferences, forming partnerships and reflecting on the decision making process. Since the instrument shows how and in which parts of the SDM process the participation of patient and informal caregivers manifests, the Observer OPTION\textsuperscript{MCC} can be used to tailor trainings interventions to professionals and to develop empowerment interventions for patients and informal caregivers.
References


35. Carlson ME, Pompei P and Ales KL. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation J Chronic Dis
Measuring SDM in older adults: the OPTIONMCC


Supplementary Table S1 Original and adapted OPTION, based on SDM OLD model

<table>
<thead>
<tr>
<th>Competences 'Dynamic model for SDM in frail older patients'</th>
<th>Observer Items OPTION( \text{OPTION}^5 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Preparation</td>
<td>Proposed Observer Items OPTION( \text{OPTION}^{\text{MCC}} )</td>
</tr>
<tr>
<td>History: did the patient previously discuss or document anything with regard to treatment in general or on specific issues e.g. resuscitation, advance care planning? (As a starting point for the conversation or as indicator in situations where the patient is incompetent)</td>
<td>(Preparation is not included in this observational instrument, since this usually takes place before the actual conversation between geriatricians and patients)</td>
</tr>
<tr>
<td>Problem analysis: functional assessment of all current problems. (Extensiveness of the analysis depends on the situation. Other caregivers can contribute. The comprehensive geriatric assessment (CGA) is a useful tool. Prioritise problems in consultation with the patient)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2 Goal talk</th>
<th>1 Goal talk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explain to the patient that a new (or exacerbation of a current) problem/disease has occurred and state that choices need to be made. Explain that every patient is unique and has his own preferences and priorities. Engage the patient in a dialogue to clarify several important general topics that require clarification before choices can be made regarding the current problem. Identify discussion partner: Has this patient sufficient decision-making capacity (cognitive, emotional)? If not, who is (by law) assigned to take the decisions? Does the patient want to take decisions? If not, who does the patient designate</td>
<td>The clinician: -explains to the patient that a new (or exacerbation of a current) problem/disease has occurred and state that choices need to be made. Explains that every patient is unique and has his own preferences and priorities. -engages the patient in a dialogue to clarify several important general topics that require clarification before choices can be made regarding the current problem. -identifies discussion partner: Has this patient sufficient decision-making capacity (cognitive, emotional)? If not, who is (by law) assigned to take the decisions? Does the patient want to take</td>
</tr>
</tbody>
</table>
Measuring SDM in older adults: the OPTION MCC

Identify patient values and goals of care (what is the role of his/her important values regarding decisions)? What are important values in the patients’ life? (Roles of outlook on life, perceptions, spirituality/religion, culture?)
Elicits goals of care. (Prolongation of life, functional autonomy, visit grandchildren, comfort, etc.)

3 Choice talk
Summarise the preceding steps (the actual problem and the identified values and goals of care) and verify if your recapitulation is correct. Explain that there are several treatment possibilities and offer choice. Invite the patient (or proxy decision maker) to formulate their treatment aims and support the patient: Convey that whilst the health professional is the medical expert, only the patient can be the expert on treatment aims, priorities and preferences. (Cure, quality of life, no treatment, no pain, comfort, etc.) Check if the patient (or proxy decision maker) has understood everything and summarise again if necessary. Continue to engage the patient in a dialogue.

1 Option talk: alternate Options
For the health issue being discussed, the clinician draws attention to or confirms that alternate treatment or management options exist or that the need for a decision exists. If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need decisions? If not, who does the patient designate (proxy decision maker)?
-Identifies patient values and goals of care (what is the role of his/her important values regarding decisions)? What are important values in the patients’ life? (Roles of outlook on life, perceptions, spirituality/religion, culture?)
- Elicits goals of care. (Prolongation of life, functional autonomy, visit grandchildren, comfort, etc.)

Participation of patient:
Participation of informal caregiver

2 Option talk: alternate Options
For the health issue being discussed, the clinician draws attention to or confirms that alternate treatment or management options exist or that the need for a decision exists. If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need.

Participation of patient
Participation of informal caregiver

2 Team Talk: support deliberation / forming a partnership
The clinician reassures the patient or re-affirms that the clinician will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained

3 Team Talk: support deliberation / forming a partnership
The clinician reassures the patient or re-affirms that the clinician will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained
information prior to the encounter, the clinician supports such a deliberation process.

Participation of patient: not / responsive / active
Participation of informal caregiver: not / responsive / active

4 Option Talk
List personalized treatment options (according to the identified values, goals of care and treatment aims). Discuss risks, benefits and side effects of every treatment option. Check which risks and side effects the patient is willing to take (opportunity/cost). Observe how the patient reacts and continue to engage the patient (and/or representative). If possible use decision aids. (visual support options can be helpful)

3 Option Talk: information about options
The clinician gives information or checks understanding about the options that are considered reasonable (this can include taking no action), to support the patient in comparing alternatives. If the patient requests clarification, the clinician supports the process.

Participation of patient: not / responsive / active
Participation of informal caregiver: not / responsive / active

4 Decision Talk: eliciting preferences
The clinician makes an effort to elicit the patient’s preferences in response to the options that have been described. If the patient declares their preference(s), the clinician is supportive.

5 Decision Talk: integrating preferences
The clinician makes an effort to integrate the patient’s elicited preferences as decisions are made. If the patient indicates how best to integrate their preferences as decisions are made, the clinician makes an effort to do so.
6 Evaluation talk
Discuss the decision-making process. Is everybody satisfied with the decision?
If not, enquire about the dissatisfaction and go back to a preceding step.
If yes: prepare a treatment plan based on the decision.

7 Evaluation talk
The clinician discusses the decision-making process. Is everybody satisfied with the decision?
If not, enquires about the dissatisfaction and go back to a preceding step.
If yes: prepares a treatment plan based on the decision.

Participation of patient: not / responsive / active
Participation of informal caregiver: not / responsive / active
### Supplementary Table S2 Intraclass Correlation Coefficient scores

<table>
<thead>
<tr>
<th>OPTION^{MCC} item</th>
<th>Clinician</th>
<th>Patient</th>
<th>Informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.60</td>
<td>.74</td>
<td>.72</td>
</tr>
<tr>
<td>2</td>
<td>.90</td>
<td>.81</td>
<td>.52</td>
</tr>
<tr>
<td>3</td>
<td>.93</td>
<td>.86</td>
<td>.77</td>
</tr>
<tr>
<td>4</td>
<td>.95</td>
<td>.86</td>
<td>.73</td>
</tr>
<tr>
<td>5</td>
<td>.93</td>
<td>.76</td>
<td>.75</td>
</tr>
<tr>
<td>6</td>
<td>.90</td>
<td>.77</td>
<td>.76</td>
</tr>
<tr>
<td>7</td>
<td>.79</td>
<td>.60</td>
<td>.94</td>
</tr>
<tr>
<td>total</td>
<td>.96</td>
<td>.96</td>
<td>.95</td>
</tr>
</tbody>
</table>
Supplementary File S3 Observer Optionmcc Score Sheet

Observer optionmcc

This score sheet is based on:

Measuring triadic decision making in older patients with multiple chronic conditions: Observer OPTIONmcc.


Clinicians

0 The behavior* is not observed
1 A minimal attempt is made to exhibit the behavior
2 The behavior is observed and a minimum skill achieved
3 The behavior is exhibited to a good standard
4 The behavior is executed to a very high standard

Patients

0 No or minimal participation, e.g. only yes or no
1 Responsive participation, answers on questions but does not ask or actively contribute in the conversation
2 Active participation, answers questions and asks questions, brings in own ideas and shares perceptions

Informal Caregivers

0 No or minimal participation, e.g. only yes or no
1 Responsive participation, answers on questions but does not ask or contribute in the conversation
2 Active participation, answers questions and asks questions, brings in own ideas and shares perceptions
1 Goal talk

<table>
<thead>
<tr>
<th>Clinician:</th>
<th>Patient</th>
<th>Informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**Clinician:**
- **The clinician explains to the patient that** a new (or exacerbation of a current) problem/disease has occurred and states **that choices need to be made**. Explains that every patient is unique and has his own preferences and priorities.
- **The clinician engages the patient in a dialogue to clarify several important general topics** that require clarification before choices can be made regarding the current problem:
  - **The clinician identifies discussion partner:** Does this patient have sufficient decision-making capacity (cognitive, emotional)? If not, who is (by law) assigned to make the decisions? Does the patient want to make decisions? If not, who does the patient designate? (proxy decision maker)
  - **The clinician identifies patient values** (what is the role of his/her important values regarding decisions): What are important values in the patients’ life? (Roles of outlook on life, perceptions, spirituality/religion, culture?)
  - **The clinician elicits goals of care** (Prolongation of life, functional autonomy, visit grandchildren, comfort, etc.)

2 Option talk: alternate options

<table>
<thead>
<tr>
<th>Clinician:</th>
<th>Patient</th>
<th>Informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**Clinician:**
- **For the health issue being discussed,** the **clinician draws attention to or confirms that alternate treatment or management options exist or that the need for a decision exists.** If the patient rather than the clinician draws attention to the availability of options, the clinician responds by agreeing that the options need deliberation.
### 3 Team talk: support deliberation/forming a partnership

<table>
<thead>
<tr>
<th>Clinician:</th>
<th>Patient</th>
<th>Informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4</td>
<td>0 1 2 0</td>
<td>0 1 2 0</td>
</tr>
</tbody>
</table>

- **Clinician:** The clinician reassures the patient or re-affirms that the clinician will support the patient to become informed or deliberate about the options. If the patient states that they have sought or obtained information prior to the encounter, the clinician supports such a deliberation process.

### 4 Option talk: information about options

<table>
<thead>
<tr>
<th>Clinician:</th>
<th>Patient</th>
<th>Informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4</td>
<td>0 1 2 0</td>
<td>0 1 2 0</td>
</tr>
</tbody>
</table>

- **Clinician:** The clinician gives information or checks understanding about the options that are considered reasonable (this can include taking no action), to support the patient in comparing alternatives. If the patient requests clarification, the clinician supports the process.

### 5 Decision talk: eliciting preferences

<table>
<thead>
<tr>
<th>Clinician:</th>
<th>Patient</th>
<th>Informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4</td>
<td>0 1 2 0</td>
<td>0 1 2 0</td>
</tr>
</tbody>
</table>

- **Clinician:** The clinician gives information or checks understanding about the options that are considered reasonable (this can include taking no action), to support the patient in comparing alternatives. If the patient requests clarification, the clinician supports the process.
6 Decision Talk: integrating preferences

Clinician: 0 1 2 3 4
Patient: 0 1 2
Informal caregiver: 0 1 2

Clinician: The clinician makes an effort to integrate the patient’s elicited preferences as decisions are made. If the patient indicates how best to integrate their preferences as decisions are made, the clinician makes an effort to do so.

7 Evaluation talk

Clinician: 0 1 2 3 4
Patient: 0 1 2
Informal caregiver: 0 1 2

Clinician: The clinician discusses the decision-making process: Is everybody satisfied with the decision? If not, enquires about the dissatisfaction and goes back to a preceding step. If yes: prepares a treatment plan based on the decision.

Calculation of score

- Clinician score: Sum of all items, divide by 7 [range 0-4]. For the transformed OPTION score (range 0-100): multiply by 25
- Patient and informal caregivers score: Sum of all items, divide by 7 [range 0-2]
Measuring SDM in older adults: the OPTIONMCC

Additional information

For rater manuals see:

Observer OPTION 5 Manual 2018

- OPTION Rater Manual
- Measuring shared decision making by assessing recordings or transcripts of encounters from clinical settings
- Glyn Elwyn, Stuart W Grande, Paul Barr
- The Dartmouth Institute for Health Policy and Clinical Practice
- http://www.glynelwyn.com/collaborate.html

Observer OPTION 12 Manual 2005

- OPTION Rater Manual 2005
- Observing patient involvement Evaluating the extent that clinicians involve patients in decisions
- Glyn Elwyn, Adrian Edwards, Michel Wensing and Richard Grol
- http://www.glynelwyn.com/collaborate.html
The development of the evidence-based SDM\textsuperscript{MCC} intervention to improve shared decision making in geriatric outpatients: the DICO study

Ruth E. Pel-Littel
Julia C.M. van Weert
Mirella M. Minkman
Wilma J.M. Scholte op Reimer
Marjolein H. van de Pol
Bianca M. Buurman

BMC Medical Informatics and Decision Making (2020) 20:35
Abstract

**Background:** Shared decision making (SDM) contributes to personalized decisions that fit the personal preferences of patients when choosing a treatment for a condition. However, older adults frequently face multiple chronic conditions (MCC). Therefore, implementing SDM requires special features. The aim of this paper is to describe the development of an intervention to improve SDM in older adults with MCC.

**Methods:** Following the Medical Research Council framework for developing complex interventions, the SDM^MCC^ intervention was developed step-wise. Based on a literature review and empirical research in a co-creation process with end users, we developed training for geriatricians and a preparatory tool for older patients with MCC and informal caregivers. After assessing feasibility, the intervention was implemented in a pilot study (N=108) in two outpatient geriatric clinics of an academic and a non-academic teaching hospital in Amsterdam, the Netherlands.

**Results:** Key elements of the training for geriatricians include developing skills to involve older adults with MCC and informal caregivers in SDM and following the six-step ‘Dynamic model for SDM with frail older patients’, as well as learning how to explore personal goals related to quality of life and how to form a partnership with the patient and the informal caregiver. Key elements of the preparatory tool for patients include an explicit invitation to participate in SDM, nomination that the patient’s own knowledge is valuable, invitation to form a partnership with the geriatrician, encouragement to share information about daily and social functioning and exploration of possible goals. Furthermore, the invitation of informal caregivers to share their concerns was also a key element.

**Conclusions:** Through a process of co-creation, both training for geriatricians and a preparatory tool for older adults and their informal caregivers were developed, tailored to the needs of the end users and based on the ‘Dynamic model of SDM with frail older patients’.
Shared decision making (SDM) reaches out towards decisions about treatment and care that are tailored to a patient’s personal preferences. The benefits of SDM among older adults are a better understanding of harms and benefits, risk perception and less decisional conflict. However, SDM in older adults with MCC, faces several barriers. Decisions about treatment choices for one disease are more difficult, as the co-existing conditions have to be taken into account. The best treatment for a single disease might not be the same as the best treatment for a patient with MCC. Instead of disease-specific outcomes, for many older adults with MCC, maintaining (functional) independence, decreasing specific symptoms or functional challenges (such as being able to walk the dog) and quality of life are considered important goals and priorities. This requires an approach of SDM in which, prior to discussing the benefits and harms of treatment options, personal goals are explored. Furthermore, older adults vary in whether they want to and can participate in SDM, and this also depends on the type of decision that has to be made. Factors that influence the low participation of older adults with MCC in SDM include a perceived lack of knowledge, low self-efficacy, fear, cognitive decline and the belief that there are no options. Older adults with MCC who want to participate in SDM need to be empowered to participate in this process. Moreover, SDM with older people with MCC is often characterized by ‘triadic decision making’, which refers to a decision-making process in which three parties are involved: the health professionals, an adult patient and an adult companion (informal caregiver). Informal caregivers, such as family members or friends who have caring relationships with the older patients often play an important role in SDM, either because they represent the patient by providing information or because they have their own interests in the decision due to extensive frailty, caring feelings and increasing dependence of their relative.

To address these needs, van der Pol et al. (2016) developed the ‘Dynamic model of SDM with frail older patients’. This model builds on existing models for SDM in the general population but adds several dynamic steps to address important issues for SDM with older patients with MCC, such as discussing personal goals related to quality of life and MCC, discussing roles in decision making and evaluating the decision process. A schematic version of this model is depicted in Figure 1. To bridge the gap between a theoretic model and the daily practice we should explore what is needed for both health professionals as well as older adults to implement the principles of SDM for older adults with MCC in healthcare conversations.

The aim of this research is to develop, pilot test and implement an intervention, called SDM, with the primary objective of an increased level of SDM for geriatricians, older adults with MCC and their informal caregivers visiting geriatric outpatient clinics. To this aim, we will explore what is needed for geriatricians, older adults with MCC and informal caregivers to implement the ‘Dynamic model of SDM with frail older patients’ at geriatric outpatient clinics. As part of this aim,
we will also examine whether and how existing patient tools could be used to help older adults with MCC and their informal caregivers prepare for a consultation at the geriatric outpatient clinic.

**Figure 1. Dynamic model for SDM in frail older patients**

Step 1:
Did the patient previously discuss or document anything with regard to treatment in general or on specific issues e.g. resuscitation, advance care planning? Functional assessment of all current problems. Prioritize problems in consultation with the patient.

Step 2:
Explain to the patient that a that choices need to be made. Explain that every patient is unique and has his own preferences and priorities. Engage the patient in a dialogue to clarify important general topics that require clarification before choices can be made regarding the current problem. Identify discussion partner: Has this patient sufficient decision-making capacity (cognitive, emotional)? If not, who is (by law) assigned to make the decisions? Does the patient want to make decisions? If not, who does the patient designate (proxy decision maker)? Identify patient values and goals of care (what is the role of his/her important values regarding decisions): What are important values in the patients’ life? (Roles of outlook on life, perceptions, spirituality/religion, culture?) Elicit goals of care. (Prolongation of life, functional autonomy, comfort, etc.)

Step 3:
Summarise the preceding steps (the actual problem and the identified values and goals of care) and verify if your recapitulation is correct. Explain that there are several treatment possibilities and offer choice. Invite the patient (or proxy decision maker) to formulate their treatment aims and support the patient: Convey that whilst the health professional is the medical expert, only the patient can be the expert on treatment aims, priorities and preferences. (Cure, quality of life, no treatment, no pain, comfort, etc.) Check if the patient (or proxy decision maker) has understood everything and summarize again if necessary. Continue to engage the patient in a dialogue.
Step 4:
List personalized treatment options (according to the identified values, goals of care and treatment aims). Discuss risks, benefits and side effects of every treatment option. Check which risks and side effects the patient is willing to take (opportunity/cost). Observe how the patient reacts and continue to engage the patient (and/or representative). If possible, use decision aids (visual support options can be helpful).

Step 5:
Inquire if the patient (or proxy decision maker) is ready to make a decision. If not, go back to the preceding steps. Focus on engaging a dialogue. Focus on the preferences of the patient and make a decision with the patient (and/or proxy decision maker). If the patient wants the doctor to decide: discuss this explicitly and connect to the identified patient values, goals of care and treatment aims.

Step 6:
Discuss the decision-making process. Is everybody satisfied with the decision? If not, enquire about the dissatisfaction and go back to a preceding step. If yes: prepare a treatment plan based on the decision.

Figure 1. Continued

Methods

To develop the SDM\textsuperscript{MCC} intervention, the Medical Research Council (MRC) framework was used\textsuperscript{16}. This framework provides guidance on the development, pilot testing, implementation and evaluation of complex health interventions\textsuperscript{16}. The phases of the MRC framework are (I) development of an intervention, (II) studying feasibility/pilot testing, (III) implementation, (IV) evaluation, (V) reporting and (VI) upscaling of the intervention. In this article, we report (V) about phases I - III (Figure 2).

Phase I | Development
The aim of the development phase is to identify a coherent theoretical basis guiding the systematic development of the SDM\textsuperscript{MCC} intervention. For this, we conducted a systematic literature review of barriers and facilitators to SDM as experienced by health professionals, older adults with MCC and their informal caregivers. This was expanded with empirical research by means of a qualitative content analysis of structured interviews, a Delphi study and the DICO I study: Decision making In Complex Old populations). This was a video observational study with cross-sectional assessment of interaction during (usual care) medical consultations between geriatricians (n=10), patients (n=108) and informal caregivers (n=68) by three calibrated raters at the geriatric outpatient department of two Dutch hospitals (after the implementation of the SDM\textsuperscript{MCC} intervention we are currently conducting the DICO II study with a similar design and a comparable patient group to study the effect of the SDM\textsuperscript{MCC} intervention). The results of these studies are summarized in this article and reported in detail elsewhere\textsuperscript{17-19}. The analysis of the results guided the development of the first prototype of the SDM\textsuperscript{MCC} intervention, which consisted of SDM\textsuperscript{MCC} training for geriatricians and a preparatory tool for older adults and their informal caregivers, based on the principles of the ‘Dynamic model of SDM with frail older patients’.
Phase II | Feasibility/pilot testing

In this phase, the prototypes of the SDM\textsuperscript{MCC} training for geriatricians and the preparatory tool for older adults and informal caregivers were pilot tested with end users: geriatricians (n=11), older adults and their informal caregivers (n=10).

The concept of training for geriatricians was discussed in two rounds of semi-structured interviews with geriatricians (n=11). All interview participants were recruited from the professional network of the principal investigator (RPL) and were based in Utrecht, Amsterdam and Hilversum (the Netherlands). The participants had not been previously involved in SDM implementation activities. The inclusion criteria for these geriatricians were that 1) they worked with patients with MCC on a daily basis and 2) geriatrics or internal medicine was their main specialization. After each interview, the concept training was adapted based on the results of the interviews. The semi-structured interviews were recorded and transcribed verbatim afterwards.

The preparatory tool was discussed in three interview rounds. In round 1, older adults (n=3) and informal caregivers (n=2) participated who had visited a geriatric outpatient clinic in the past month. In round 2, older adults (n=5) participated from the professional network of the principal investigator (RPL), who had experience both as a patient and as an informal caregiver, and geriatricians (n=2) from an academic hospital (AMC). In round 3, only the two geriatricians...
The development of the SDMMCC intervention

from the AMC participated. The purpose of the tool was explained by the researcher, and participants were invited to react to relevance, user-friendliness and understandability. Additionally, they were asked to react to the pictures that were meant to support the text. After each round, adaptations were made based on the results of the feasibility tests. This resulted in the final SDM\textsuperscript{MCC} training and preparatory tool.

**Phase III | Implementation**

The training was given to the nine geriatricians of the geriatric outpatient departments of two Dutch hospitals: 1) the Academic Medical Center (AMC) (n=4) and 2) the Medical Center Slotervaart, a non-academic teaching hospital (MC SLV) (n=5). These geriatricians met the following criteria: (1) specialized in geriatrics, (2) working at the outpatient clinic of the geriatric department. Temporary staff was not eligible. The purpose of the training was explained in a staff meeting at each hospital and each geriatrician got a formal invitation to attend the training. At the end of the training session, all participants were asked to evaluate the training by answering four questions: (What are you going to do differently tomorrow? What are your learning points? What grade do you give the training? Do you have any tips or comments?).

Eligible patients who were scheduled for visits at the geriatric outpatient clinics of these hospitals between September 2017 and June 2018 were approached by telephone and informed about the study. If they were willing to receive information about the study, an information letter and the preparatory tool was sent by mail. In the information letter about the study, the purpose of the preparatory tool was explained and patients were requested to fill in the preparatory tool, if possible with their informal caregiver and bring it to the consultation. Of all eligible patients (n=514), 108 consented to participate in the study (21% of all scheduled patients) (see Additional file 1: Flowchart of inclusion). To be eligible for the study patients had to meet the following criteria: 1) sufficient mastery of the Dutch language, 2) a life expectancy of more than 3 months, 3) not having a severe stage of dementia (MMSE < 15) according to the medical file, 4) being a geriatric patient visiting the geriatric outpatient department. A geriatric patient is not merely defined by age, but by decreased functional reserves leading to frailty and the prevalence of more than one chronic condition\textsuperscript{20}. In the Netherlands older adults are usually referred to a geriatrician by their General Practitioner when there are MCC often combined with various geriatric syndromes such as falls, cognitive impairment and functional decline. In an information letter about the study, the purpose of the preparatory tool was explained and patients were requested to fill in the preparatory tool, if possible with their informal caregiver and bring it to the consultation. Immediately after the consultation with the geriatrician, the patients were asked if they had received the tool, if they had completed it and what their opinion was about the tool. Furthermore, they were asked if they had discussed the tool with someone else, for example, a family member and if the researchers could receive the completed tool or take a picture of it. Additionally, informal caregivers were asked if they had read the tool, if they had completed the part for informal caregivers and how they appreciated the tool. Written informed consent was obtained from all older adults and informal caregivers.
**Patient involvement**
Both patients and their informal caregivers were involved in the development and testing of the intervention (Additional file 2: GRIPP2 reporting checklist).

**Results**
The participant included in the different phases of the study are presented in a flowchart.

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**PHASE I**
Development of the SDM\textsuperscript{MCC} intervention

**Theoretical basis**
- Literature review (n= 28 studies)

**Empirical basis**
- Qualitative content analysis of structured interviews (n= 547)
- Delphi study (n= 57)
- DICO I Clinical video observational study Part 1 (n= 108)

---

**PHASE II**
Feasibility/Pilot testing of the SDM\textsuperscript{MCC} intervention

**SDM\textsuperscript{MCC} training for geriatricians**
- Interview round A (n= 6 geriatricians)
- Interview round B (n= 5 geriatricians)

**Preparatory tool for patients**
- Version 1: (n= 3 geriatric patients & n= 2 informal caregivers)
- Version 2: (n= 5 older adults/informal caregivers)
- Final version (n= 2 geriatricians)

---

**PHASE III**
Implementation of the SDM\textsuperscript{MCC} intervention

**SDM\textsuperscript{MCC} 4-hour training for geriatricians**
- Hospital AMC (n= 4 geriatricians)
- Hospital SLV(n= 5 geriatricians)

**Follow-up on training (feedback loop)**
- Hospital AMC (n= 4 geriatricians)
- Hospital SLV(n= 2 geriatricians)

**Preparatory tool for patients**
- Sent (n= 108 geriatric patients)
- Completed (n= 56 geriatric patients & 20 informal caregivers)

---

**Figure 3. Flowchart of participants in different phases of the study**

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**Phase I | Development**
**Insights from existing literature and empirical evidence**
Table 1 depicts the analysis of the systematic literature review of barriers and facilitators to SDM, the qualitative content analysis of structured interviews, the Delphi study and the DICO I video observational study, all used for the development of the intervention. The results of Phase I guided the development of the SDM\textsuperscript{MCC} intervention.
The development of the SDMMCC intervention

Table 1. Results of Phase I

<table>
<thead>
<tr>
<th>Step</th>
<th>Aim</th>
<th>Results</th>
<th>Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>To identify barriers and facilitators to SDM with older adults with MCC</td>
<td>Main barriers: 1. Personal patient characteristics such as being in poor health and/or having cognitive or physical impairments. 2. Feeling no permission to participate in SDM</td>
<td>1. Tailor information to capacity of patient, discuss decision capacity/needs (A)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Health professionals with poor interpersonal skills, organizational barriers as time pressure and high turnover of patients.</td>
<td>2. Explicit invitation to participate in SDM: The doctor has medical knowledge - you have knowledge of your personal situation - together, we can decide what is best for you! (AB)</td>
</tr>
<tr>
<td></td>
<td>Main facilitators: 1. The patient's experiences of living with chronic health conditions 2. The assistance of informal caregivers in decision support.</td>
<td>3. Good patient preparation before consultation enables moving more quickly to the important points of discussion (A)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. An individualized approach where health professionals seek patient's preferences.</td>
<td>1. Appraisal of personal experiences of patients (A) 2. Involvement of informal caregiver in SDM by recognizing their contribution in care and inquiring about their concerns (AB) 3. Take personal goals into account by asking them what must happen to improve their quality of life (AB)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Step</th>
<th>Aim</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ia</td>
<td>Identifying existing evidence</td>
<td>Literature review (n= 28 reviewed studies)</td>
</tr>
<tr>
<td>Ib</td>
<td>Gathering additional empirical evidence</td>
<td>Qualitative content analysis of structured interviews (n = 547)</td>
</tr>
</tbody>
</table>

To investigate the personal views on the ageing process communicated by older persons

1. Acceptance of ageing, (further) deterioration and worries about limitations and family were important themes on the ageing process communicated by older persons.

1.1 Facilitation of discussion about ‘what matters to you’ by asking them what must happen to improve their quality of life (AB)

1.2 Discuss personal goals that contribute to quality of life (A)
Chapter 6

Table 1. Continued

| Delphi study (n = 57) | 1. The domains older adults gained consensus on were:  
|                      | - functional limitations  
|                      | - emotional wellbeing  
|                      | - social functioning  
|                      | - quality of life  
|                      | - coping with stress  
|                      | - dealing with chronic health conditions and the effects of them on daily life  
| 1.1 Address in goal talk these topics (AB)  
| 1.2 Explore impact of MCC on daily life (A) |

| DICO I Clinical video observational study Part 1 (n = 108) | 1. Main decisions are  
| 1. Which decisions face older adults with MCC and their informal caregivers during geriatric visits to the hospital?  
| - Additional diagnostics  
| - Medication  
| - Follow-up  
| - Referral to primary care (case manager, GP, physiotherapist, psychologist) |

| 2. Main roles in decision making were for patients: ‘triadic decision making’ 41%< >33% (preferred < > perceived), and for informal caregivers: ‘triadic decision making’ 71%< >55% (preferred < > perceived). Preferred and perceived participation was for patients 6.6< >5.1, for informal caregivers 7< >5.  
| 2. Discuss how older adults with MCC and informal caregivers want to be involved in decision making. Involve them according to their preferences. (A) |

| 3. The OPTIONMCC score was 42.5 (0-100), items about ‘team talk’ and ‘evaluation’ scored the lowest (resp. 31 & 36.5).  
| 3. Train geriatricians in team talk and evaluation phase in the process of SDM. (A) |

Development of the prototypes

Development of the prototype training for geriatricians

An expert panel was composed that consisted of the developer of the ‘Dynamic model of SDM with frail older patients’ (MvdP), a professor of Health Communication, specializing in older adults (JvW), the researcher/project leader, specializing in SDM and older adults (RPL), and a master student in management, policy analysis and entrepreneurship (ABP). As a basis for the training, they used an initial basic training that was previously developed to train General Practitioners in the ‘Dynamic model of SDM with frail older patients’. This training for General Practitioners was based on a teaching framework and proposed key competencies for SDM with older adults as composed by the original developer of the model. The insights gained in Phase 1 (see Table 1)
were plotted in a so-called ‘heat map’ to obtain insight into which current training components should be maintained, which components should be omitted and which elements were lacking and should be added to the training (Additional file 3). In the next step, the training for General Practitioners was modified according to these recommendations, which led to ‘Prototype SDM\textsuperscript{MCC} training geriatricians 1.0’.

In the development of the training, the principles of the Miller learning pyramid were applied\textsuperscript{21}. Within this classification, in the form of a pyramid that was developed to determine the competence level of doctors, four levels of competence are distinguished: 1: knowing (knowledge), 2: knowing how (knowledge can be used), 3: showing how (acting in a simulated environment) and 4: doing (acting in everyday practice). Table 2 depicts how the training was structured:

Table 2. Structure and learning objectives of the SDM\textsuperscript{MCC} training (final prototype)

<table>
<thead>
<tr>
<th>Structure of the SDM\textsuperscript{MCC} training</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Knows</strong></td>
</tr>
<tr>
<td>- What does the geriatrician already know, do and feel about SDM? (background, prejudices, pseudo-participation, how you feel about the subject).</td>
</tr>
<tr>
<td>- Introduction to SDM (general model, complexity of older adults with MCC, legal capacity/cognition/decision capacity, views of life and expectations/goals, role of informal caregivers)</td>
</tr>
<tr>
<td><strong>Knows how</strong></td>
</tr>
<tr>
<td>- Introduction steps of ‘Dynamic model of SDM with frail older patients’. (discuss for each step how to handle it, examples, discuss decision aids that patients or geriatricians have used)</td>
</tr>
<tr>
<td>- Introduction of preparatory tool for patients and informal caregivers</td>
</tr>
<tr>
<td>- Discussion of cases (CVA, Parkinson’s, falls)</td>
</tr>
<tr>
<td><strong>Shows how</strong></td>
</tr>
<tr>
<td>- Role-play is used to apply the learned skills with a professional training actor: introducing and practising own case studies of geriatricians</td>
</tr>
<tr>
<td><strong>Does</strong></td>
</tr>
<tr>
<td>- ‘Coaching on the job’: geriatricians got feedback from the trainer on a videotaped consultation of their daily routine practice.</td>
</tr>
</tbody>
</table>

**Learning objectives after following the training:**

| Knowledge | The participants have insight into the concept of SDM with older adults with MCC and informal caregivers. The participants have knowledge of the ‘Dynamic model of SDM with frail older patients’. |
| Skills | The participants gained practical skills to apply the model by practicing it with each other and with a professional training actor |
| Attitude | The participants have insight into their own behaviors and attitudes towards this subject. |

The development of the SDM\textsuperscript{MCC} intervention
Development of the prototype preparatory tool for older adults with MCC and informal caregivers

The patient tools were examined to evaluate how they met the formulated recommendations from Phase I (Table 3). All tools contain valuable components, but none of the tools met all recommendations as formulated in Phase I. Additionally, none of the tools focuses on the role of informal caregivers. The prototype of the preparatory tool for older adults with MCC and informal caregivers was therefore developed as a new tool, although we used some aspects of the existing tools22-24. Furthermore, we included elements we found in the international literature about empowering patients in SDM, such as the underlying principles of Question Prompt Lists and the ‘Ask 3 Questions’ campaign in the U.K. Magic program25-27.

Table 3. Description of existing tools for empowerment of patients

<table>
<thead>
<tr>
<th>Description</th>
<th>Valuable components that were used in the preparatory tool</th>
<th>Components not feasible for older population with MCC in geriatric consultations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toolbox Person-centred care22</td>
<td>Agenda setting</td>
<td>Aim at primary care</td>
</tr>
<tr>
<td></td>
<td>Goal setting</td>
<td>Invitation to SDM</td>
</tr>
<tr>
<td></td>
<td>Emphasize teamwork</td>
<td>Focus on disease management and lifestyle changes</td>
</tr>
<tr>
<td>This toolbox aims at supporting people with chronic diseases in primary care consultations. It addresses agenda setting, discusses goals and actions and follow-up. It consists of a part for general practitioners and a part for patients. In the part for patients, patients are explicitly invited to participate in SDM. It stimulates patients to think about what they want to discuss in the consultation. Topics raised by ‘fellow patients’ are given as an example. It emphasizes the teamwork between patient and health professional during the consultation when discussing different options, pros and cons and personal preferences. The tool also comprises space for a follow-up plan. The tool refers more to self-management and lifestyle changes and seems less suitable when facing medical decisions at the outpatient geriatric clinic.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><a href="http://www.watertoedoet.nl23">www.watertoedoet.nl23</a></td>
<td>Goal setting</td>
<td>Requiring digital health literacy</td>
</tr>
<tr>
<td>This is an extensive website aiming at awareness of what is important for patients and helps thinking about personal goals. It provides patients with a final print that they can bring to the clinical encounter.</td>
<td>Thinking about quality of life</td>
<td></td>
</tr>
</tbody>
</table>
### Table 3. Continued

<table>
<thead>
<tr>
<th><strong>Patient’s Action</strong></th>
<th><strong>Communication Card</strong></th>
<th><strong>PAC-card</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Encouragement</strong></td>
<td><strong>No preparation</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td><strong>PAC-card</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Communication</strong></td>
<td><strong>No preparation</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Card</strong></td>
<td><strong>Paper version</strong></td>
<td></td>
</tr>
<tr>
<td><strong>PAC-card</strong></td>
<td><strong>easy to use</strong></td>
<td></td>
</tr>
</tbody>
</table>

A PAC-card can be used by patients during a clinical encounter as a checklist to help them ask questions about their problem and treatment. It has an informative character and focuses on the problem of that actual moment. It does not address the discussion of personal goals or forming a trustful relationship between patient and health professional. The PAC-Card does not focus on the possibility of different options. It was developed to be used as a paper version.

<table>
<thead>
<tr>
<th><strong>Ask 3 Questions</strong></th>
<th><strong>(Magic Program)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Encouragement</strong></td>
<td><strong>Focus</strong></td>
</tr>
<tr>
<td><strong>Ask 3 Questions</strong></td>
<td><strong>on single</strong></td>
</tr>
<tr>
<td><strong>(Magic Program)</strong></td>
<td><strong>diseases</strong></td>
</tr>
</tbody>
</table>

The Ask 3 Questions campaign, part of the U.K. Magic program, is designed to encourage patients to ask questions and play a more active role in decisions about their treatment and care. This audit tool provides a simple checklist to help services assess how well they are promoting materials that encourage people to Ask 3 Questions:

- What are my options?
- What are the benefits and possible risks?
- How likely are these risks and benefits?

<table>
<thead>
<tr>
<th><strong>Question Prompt</strong></th>
<th><strong>Lists</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Encourage the</strong></td>
<td><strong>Focus</strong></td>
</tr>
<tr>
<td><strong>patient to</strong></td>
<td><strong>on</strong></td>
</tr>
<tr>
<td><strong>think</strong></td>
<td><strong>single</strong></td>
</tr>
<tr>
<td><strong>in advance</strong></td>
<td><strong>diseases</strong></td>
</tr>
<tr>
<td><strong>about questions</strong></td>
<td></td>
</tr>
<tr>
<td><strong>to discuss</strong></td>
<td></td>
</tr>
<tr>
<td><strong>during the</strong></td>
<td></td>
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<tr>
<td><strong>consultation</strong></td>
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</table>

A QPL is an inexpensive communication tool consisting of a structured list of questions designed to encourage information gathering. Patients can use these questions as examples which they can choose to discuss during the consultation. By using a QPL, patients are expected to participate more actively during their consultation, for instance by asking more and broader-ranging questions.
The tool (final version is depicted in Figure 4) consists of 4 pages. Page 1 is an explicit invitation to participate in SDM and an appraisal of the older adult’s personal expertise. Page 2 (1) encourages older adults to describe their daily activities and social contacts (focus on functional limitations and social functioning), (2) asks them to grade their quality of life and (3) inquires about what would be necessary to increase this grade by one point (personal goals). Page 3 helps the older adult prepare for the conversation with the doctor by means of an open question ‘what would you like to discuss with the doctor’ as well as by providing ‘example questions’ that help the older adult inquire about options, harms and benefits and implications for daily life. Page 4 is addressed to the informal caregiver. First, it explains why the geriatrician is also interested in the informal caregiver (recognizing partnership and recognizing the potential burden of informal care). Second, an outcome indicator about informal caregiver burden in dementia care used in the Netherlands was added to the tool\textsuperscript{28}. This indicator inquires about how the informal caregiver was feeling in the past month, through indicating their mood according to the rungs of a ladder drawing; furthermore, it asks the informal caregiver to write down three words about the best day in the past month and three words about the worst day in the past month.

**Phase II | Feasibility/pilot testing**

The aim of this phase was to pilot test the SDM\textsuperscript{MCC} training for geriatricians and the preparatory tool for older adults and informal caregivers and to co-create the final versions with the end users (i.e. geriatricians, geriatric patients and informal caregivers).

**Training for geriatricians**

In the first interview round (A), the components of the prototype training for geriatricians were presented to six geriatricians. Semi-structured interviews showed that the majority of the participants had a positive attitude towards the training. However, they thought the training should focus more on the problems they encounter in daily practice, such as conflicting visions between geriatricians and patients and how to explore the goals and preferences of patients. These problems were also perceived as most difficult to learn during the training because of the complexity of older people with MCC. Based on these results, the training was adapted to better match daily practice. For example, more practical exercise was organized with a professional training actor. In the second round (B), the adapted training was presented to five other geriatricians. In this round, some components remained the same, but some were added, altered or removed completely. For example, the training focused much more on ‘exploration of goals’, but learning ‘mapping the patients’ history’ was removed, since geriatricians do this already in each new consultation, which might differ from general practitioners. This process led to the final prototype for the training (Table 2).

**Preparatory tool for older adults and informal caregivers**

The first version of the preparatory tool was presented to three older adults with MCC and two informal caregivers. The interviewed older adults thought the first version contained ‘good questions’. However, all the informal caregivers had difficulty with the question addressed to them (the outcome indicator for informal
The development of the SDM$^{MCC}$ intervention

**Figure 4.** Final preparatory tool for older adults and informal caregivers.
caregivers in dementia care). They did not understand the meaning of ‘ticking a rung of the drawn ladder’ as an indicator about their feeling in the past month and had difficulty writing down three words about the best day in the past month and three words about the worst day in the past month. The informal caregivers proposed a simpler version of the question: ‘As an informal caregiver, I feel........’. Their input was used to develop a second version of the tool. The older adults, informal caregivers and geriatricians in the second round mainly recommended simplifying the language, and the participants gave many suggestions on how to make the text shorter and easier to interpret. They also gave suggestions regarding how to distinguish more clearly between the questions meant for older adults and those for informal caregivers. The drawn pictures in the tool, representing older patients, informal caregivers and geriatricians, were perceived as childish. This feedback guided the third version, and the only comment on the third version was to use a different photo for the front page, which was done in the final version of the preparatory tool.

Phase III | Implementation

**Implementation of the training for geriatricians**

The geriatricians (n = 9) of the two outpatient geriatric clinics of the AMC and MC SLV were invited to follow the training. In each hospital, one 4-hour training session was organized. In addition, a placemat with the steps of SDM with older adults with MCC was distributed, and the preparatory tool was shown and explained. The training was given by a teacher/researcher/general practitioner specialized in SDM with older adults with MCC from Radboud University in Nijmegen. A professional training actor attended the meeting to provide training opportunities. The principal researcher (RPL) was present to guide the process. In the AMC, two geriatricians followed the 4-hour training session, but two other geriatricians were not able to attend that day due to logistic reasons (1) and illness (1). These two geriatricians received an adapted training that consisted of two informative videos made by the trainer, about SDM in general and about the SDM/MCC model. This was followed by a meeting with the principal researcher to discuss SDM in older adults with MCC. In the MC SLV, all five geriatricians followed the training. All geriatricians were offered a feedback session with the trainer to discuss the SDM process, using a videotape of one of their daily clinical consultations with the target group. Six geriatricians (4 AMC, 2 MC SLV) were able to participate in this individual feedback session.

The geriatricians who followed the 4-hour training session graded the training with an 8 (0-10). They stated that they learned the most about communication strategies and the ‘Dynamic model of SDM with frail older patients’. When asked what they would do differently tomorrow; most of them said ‘Having a real goal talk with my patients.’ They appreciated the safe atmosphere during the training, the handouts and working with the training actor. For following training sessions, they advised using more real-life cases to practice with.

**Implementation of the preparatory tool for older adults and informal caregivers**

As depicted in Table 4, 74 (69%) older adults confirmed that they received the preparatory tool. The tool was filled out by 56 older adults (52%) and 20 (37%) informal caregivers. Of them, 26 older adults (35%) discussed the tool with their
informal caregiver. Of the older adults who had filled out the tool, 64% found the tool ‘good, clear or informative’, 8% thought the tool was ‘confusing, difficult’, 7% found the tool ‘limited, too short’, 5% considered the tool not applicable to their situation, 5% had no opinion and 11% had other remarks, mainly about logistics. Of the informal caregivers who had used the tool, 63% rated the tool as ‘good, clear or informative’, 19% considered the tool not applicable to their situation, 7% thought the tool was difficult, 4% found the tool ‘limited, too short’ and 7% had no opinion.

Table 4. Implementation of the preparatory tool for older adults and informal caregivers

<table>
<thead>
<tr>
<th>Patients: Did you receive the preparatory tool?</th>
<th>Yes (n,%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>74 (68.5)</td>
<td></td>
</tr>
<tr>
<td>Patients: Did you complete the preparatory tool?</td>
<td>56 (51.9)</td>
</tr>
<tr>
<td>Patients: Did you discuss the preparatory tool with your relatives?</td>
<td>26 (24.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What did you think of the preparatory tool?</th>
<th>Patients that used the tool (n= 56)</th>
<th>Informal caregivers that used the tool (n= 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>good, clear or informative</td>
<td>64%</td>
<td>7%</td>
</tr>
<tr>
<td>confusing, difficult</td>
<td>8%</td>
<td>4%</td>
</tr>
<tr>
<td>limited, too short</td>
<td>7%</td>
<td>19%</td>
</tr>
<tr>
<td>not applicable to their situation</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>no opinion</td>
<td>5%</td>
<td>11%</td>
</tr>
<tr>
<td>other remarks (mainly logistic)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Discussion

Our study shows that the SDM\textsuperscript{MCC} implementation intervention has been systematically designed based on both scientific and empirical evidence. The SDM\textsuperscript{MCC} intervention includes SDM training for geriatricians and a preparatory tool for older adults and informal caregivers. Through the process of co-creating with the end users, both products were tailored to the specific needs of older adults and geriatricians.

Key elements of the training for geriatricians in SDM\textsuperscript{MCC} include exploration of the current attitude towards and knowledge and use of SDM among participating geriatricians and a discussion about pseudo-participation and prejudice. This is followed by theory about SDM: general model of SDM, complexity in older adults with MCC, assessing legal capacity of older adults, cognition problems, life expectancy, personal goals, and the role of informal caregivers. The 6-step SDM\textsuperscript{MCC} model should be explained, discussing how to do each step and giving examples. Practical exercise, preferably with real-life cases and a training actor, fosters behavioural change.

Key elements of the preparatory tool for older adults include an explicit invitation to participate in SDM, appreciation of older adults’ own knowledge,
forming a team, sharing information about daily and social functioning and exploring possible goals. Furthermore, older adults are empowered to prepare what they want to discuss in the encounter, e.g., by example questions for older adults to inquire about options, benefits and harms of each option and potential consequences for other conditions (MCC). Finally, the concerns of informal caregivers are addressed by recognizing partnership and inquiring about the potential burden of informal care. Since the preparatory tool was evaluated positively by more than 60% of both patients and informal caregivers; there seemed to be sufficient ground to proceed with the implementation of the preparatory tool. However, this also shows that there still is room for improvement of the preparatory tool. Therefore, we recommend a continuous evaluation of the use of the preparatory tool in daily practice to generate further improvements, for example through interviewing patients more extensively about the preparatory tool.

To evaluate the SDM\textsuperscript{MCC} intervention, we will evaluate in the DICO II study the effect of SDM training for geriatricians on the level of SDM compared to the level of SDM in the clinical video observation study Part 1 (DICO I) and the effect of the SDM tool for older adults and informal caregivers by comparing the preferred and perceived participation and decision roles and decisional conflict with the findings of the DICO I study.

We expect that the use of the SDM\textsuperscript{MCC} intervention to implement the ‘Dynamic model of SDM with frail older patients’, tailored to the geriatric outpatient setting, will contribute to decisions that comply with personal goals and preferences. Also in recent literature about SDM, we see an increasing awareness of the need to explore personal goals and context in SDM and to support the older adult more through the SDM process\textsuperscript{15, 29}. Our findings are in line with Vermunt et al. (2017, 2018), who strongly advocate goal setting as a key element of a person-centred approach when caring for older adults with MCC\textsuperscript{5, 30}. The SDM\textsuperscript{MCC} intervention focuses on triadic decision making, following the literature that emphasizes the often important role of informal caregivers of older adults visiting the geriatric outpatient clinic\textsuperscript{9-13}.

Although the major strength of this research was the co-creation with the end users, i.e., geriatricians as well as older adults and their informal caregivers, the number of those involved was limited. However, proceeding through different rounds, each round presenting an improved version of either the training or the preparatory tool, led, in our opinion, to products that are tailored to the needs of end users.

**Conclusions**

This article describes the development, pilot testing and implementation of the evidence-based SDM\textsuperscript{MCC} intervention to improve SDM with older adults suffering from MCC. Through a process of co-creation, both training for geriatricians and a preparatory tool for older adults with MCC and their informal caregivers were developed, tailored to the needs of the end users and based on the ‘Dynamic model of SDM with frail older patients’.
References


Supplementary S1: Flowchart inclusion Phase III Implementation

- Eligible patients assessed (n=514)
- Excluded (n=104)
  - Insufficient mastery of Dutch language (n=34)
  - Cognitive impairment (n=26)
  - No permission clinician (n=8)
  - No response clinician (n=10)
  - Double appointments (n=9)
  - Other clinician (n=2)
  - Compulsory hospitalisation (n=1)
  - Logistic reasons (n=14)

- Eligible patients called in first round (n=410)
- Excluded after first round of calls (n=249)
  - Too stressful (n=52)
  - Didn’t want a record (n=2)
  - Not interested (n=23)
  - Cancelled appointment (n=30)
  - Could not be reached (n=137)
  - Didn’t receive the information letter (n=5)

- Interested patients received information letter (n=161)
- Excluded after second round of calls (n=53)
  - Didn’t want a record (n=2)
  - Not interested (n=16)
  - Too stressful (n=21)
  - Declined to participate in waiting room (n=14)

- Participants (n=108)
## Supplementary S2: GRIPP2 reporting checklist

<table>
<thead>
<tr>
<th>Section and topic</th>
<th>Item</th>
<th>Reported on page No</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1: Aim</strong></td>
<td>Report the aim of PPI in the study</td>
<td>6</td>
</tr>
<tr>
<td><strong>2: Methods</strong></td>
<td>Provide a clear description of the methods used for PPI in the study</td>
<td>7,8</td>
</tr>
<tr>
<td><strong>3: Study results</strong></td>
<td>Outcomes—Report the results of PPI in the study, including both positive and negative outcomes</td>
<td>12 - 14</td>
</tr>
<tr>
<td><strong>4: Discussion and conclusions</strong></td>
<td>Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects</td>
<td>15</td>
</tr>
<tr>
<td><strong>5: Reflections/ critical perspective</strong></td>
<td>Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience</td>
<td>15</td>
</tr>
</tbody>
</table>
## Supplementary S3 Heatmap Adaptions training SDM for geriatricians

The Dynamic model of SDM in frail old patients

<table>
<thead>
<tr>
<th>The Development of the SDMMCC Intervention</th>
<th>Recommendations from Phase I</th>
<th>In SDM training general practitioners</th>
<th>Remove or add to SDM training geriatricians</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Preparation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1a. History: did the patients previously discuss anything with regard to treatment or other issues?</td>
<td>Emphasises investigating the patient’s history</td>
<td></td>
<td>less attention in training</td>
</tr>
<tr>
<td>1b. Problem analysis: functional assessment of all current problems</td>
<td>Awareness of possible low health literacy or cognitive impairments &amp; consequences for tailoring information</td>
<td></td>
<td>more attention in training</td>
</tr>
<tr>
<td><strong>2. Goal talk</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a. Explains to the patient that a new problem has occurred and states that choices need to be made</td>
<td>Explicit invitation to participate in decision making</td>
<td></td>
<td>remains the same</td>
</tr>
<tr>
<td>2b. Explains that every patient is unique and has his own preferences and priorities</td>
<td>Addresses goals and expectations of patient, address quality of life</td>
<td></td>
<td>more attention in training</td>
</tr>
<tr>
<td>2c. Engages the patient in a dialogue to clarify several important general topics that require clarification before choices can be made: Identifies discussion partner, addresses patient willingness to make shared decisions and identifies patient values and goals.</td>
<td>Discuss how informal caregiver should/wants to be involved</td>
<td></td>
<td>more attention in training</td>
</tr>
<tr>
<td></td>
<td>Focuses on building a trust-relationship between clinician and patient</td>
<td></td>
<td>more attention in training</td>
</tr>
<tr>
<td><strong>3. Choice talk</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a. Summarizes the preceding steps and verifies if the recapitulation is correct</td>
<td>×</td>
<td></td>
<td>more attention in training</td>
</tr>
</tbody>
</table>
3b. Explains that there are several treatment possibilities and offers choice in different treatment possibilities.

3c. Invites the patient to formulate their treatment aims and supports the patient: there are 2 experts in the medical encounter, checks if patient has understood everything and continues to engage patient in a dialogue.

### 4. Option talk

| 4a. Lists personalised treatment options | remains the same |
| 4b. Discusses risks, benefits and side effects of every option | remains the same |
| 4c. Checks which risks and side effects the patient is willing to take | more attention in training |
| 4d. Observes how the patient reacts and continues to engage the patient | more attention in training |
| 4e. If possible uses decision aids | more attention in training |

### 5. Decision talk

| 5a. Inquires if the patient is ready to make a decision. If not, goes back to the preceding steps | much more attention in training |
| 5b. Focuses on engaging a dialogue. Focuses on the preferences of a patient and makes a decision with the patient | remains the same |

### 6. Evaluation

| 6a. Discusses the decision-making process. Is everybody satisfied? | much more attention in training |
Effects of the SDM\textsuperscript{MCC} intervention for older adults with multiple chronic conditions: the DICO study

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Bianca M. Buurman
Marjolein H. van de Pol
Jos W.R. Twisk
Linda R. Tulner
Mirella M. Minkman
Wilma J.M. Scholte op Reimer
Julia C.M. van Weert

Submitted
Abstract

Objectives: Evaluating the effects of the shared decision making (SDM) for older adults with multiple chronic conditions (MCCs) intervention on SDM in this patient group and their informal caregivers.

Design: In a pragmatic trial with video observations and pre- and post-consultation questionnaires effects of the SDM training for geriatricians and a preparatory tool for patients and caregivers were evaluated.

Setting and Participants: Two outpatient geriatric clinics in an academic and a non-academic teaching hospital. 216 Patients, 133 caregivers, and 9 geriatricians.

Methods: Researchers observed SDM using the OPTIONMCC tool during video-recorded consultations, and patient- and caregivers reported outcomes regarding patient participation, perceived SDM and decisional conflict. A mixed model analysis was used to assess the level of observed SDM. Patient participation and decisional conflicts were analyzed with a logistic mixed model.

Results: The mean age was 77.3 years, and 56.3% of patients were female. Although no significant difference was found between groups in the overall level of SDM as measured with the OPTIONMCC, we found significant differences for 5 out of 7 elements. Discussing goals, options, and decision making significantly improved after the intervention. However, discussing partnership and evaluating the decision-making process significantly decreased. There were no differences in patient reported outcomes. The process evaluation showed that the preparatory tool was completed by 52% of the patients, of which 64% appreciated the tool. However, discussing the results of the preparatory tool was not a regular part of the consultations (12%).

Conclusions and Implications: This study provides scope for improvement of SDM in geriatrics. Engaging older adults with MCC and informal caregivers in the decision making process should be an essential part of SDM training for geriatricians, beyond the SDM steps of explaining options, benefits and harms. Furthermore, attention should be paid to the integration of preparatory tools in the consultation.
Introduction

In the care for older adults with multiple chronic conditions (MCCs), shared decision making (SDM) is essential to reach health decisions that are in line with the personal goals and preferences of the patient1-5. However, the process of SDM is more complex in populations with older adults with MCCs than in younger populations for three main reasons. First, the concept of MCCs is difficult to handle within the mainstream SDM models, which were developed for treatment decisions that aim to reach disease-specific outcomes. However, for many older adults with MCCs, personal health outcomes such as maintaining (functional) independence, and reducing symptom burden become more important than disease-specific outcomes5. Second, for older adults with MCCs, it might be harder to participate in SDM due to the high prevalence of cognitive impairment, frailty, low health literacy and anxiety6-14. Third, the involvement of informal caregivers (from now on ‘caregivers’) in the decision making process, making SDM with older adults with MCCs a triadic process, may complicate the process. However, the role of the informal caregiver is often neglected.

To address this complexity, the ‘Dynamic model for SDM in frail older adults’ gives theoretical guidance to the SDM process with older adults with MCCs. This model emphasizes the clarification of personal goals, values and preferences, as well as the discussion of preferred roles and decision making capacities in decision making to identify personal health outcomes15 and fits with the recently published action steps for decision making for older adults with MCCs9,10. However, there is a gap between this theoretical model and the implementation in daily practice. Based on this model, we developed the SDM\textsuperscript{MCC} intervention to improve SDM for older adults with MCCs and their caregivers. The Medical Research Council framework for complex interventions16, 17, including a literature review and empirical research, was followed to design of the SDM\textsuperscript{MCC} intervention, comprising SDM\textsuperscript{MCC} training for geriatricians and a preparatory tool for older adults with MCCs and their caregivers18.

The aim of the current DICO (Decision making In Complex Older populations) study was to evaluate the effects of the SDM\textsuperscript{MCC} intervention on 1) observed SDM and 2) patient-reported outcomes. In addition, a process evaluation was conducted to evaluate the implementation of the intervention.

Methods

Design

A pragmatic trial design was carried out at the geriatric outpatient departments of two Dutch hospitals in Amsterdam: 1) the Academic Medical Center (AMC) and 2) the Medical Center Slotervaart (MC SLV). First, a video-observational study was conducted in a usual care group (n=108). Next, the SDM\textsuperscript{MCC} intervention was implemented. Subsequently, a second video-observational study was conducted among a new group of geriatric patients (n=108). The local institutional review board waived the requirement to obtain approval for this study (W16_107#16.125, W17_284#17.336).
Participants
The participants in this study were 216 geriatric patients and their 133 caregivers. To be eligible for the study, patients had to meet the following criteria: 1) sufficient mastery of the Dutch language, 2) a life expectancy of more than 3 months, 3) not having a severe stage of dementia (MMSE < 15).

Intervention Description
The SDM\textsuperscript{MCC} intervention comprised an SDM\textsuperscript{MCC} training for geriatricians and a preparatory tool for patients and caregivers (Figure A1). The training consisted of a 4-hour intensive training session including theory and role playing with a professional training actor. The aim of the training was to develop skills among geriatricians to involve older adults and their caregivers in SDM and to practice the steps of the ‘Dynamic model for SDM with frail older patients’. In addition, how to handle the patient preparatory tool was discussed. Six months after the SDM\textsuperscript{MCC} training, an individual feedback session was offered in which the trainer and the geriatricians reflected together on SDM-skills in (videorecorded) real consultations.

The patient preparatory tool included an explicit invitation to participate in SDM, an acknowledgement that the patient’s own knowledge is valuable, an invitation to form a partnership with the geriatrician, encouragement to share information about daily and social functioning and an exploration of possible goals. Furthermore, caregivers were invited to share their concerns. The rationale, goals, and a detailed description of the SDM\textsuperscript{MCC} intervention have been published elsewhere\textsuperscript{18}. Details regarding the implementation of the training and the preparatory tool are in Text A1.

Data collection
Eligible patients received an information letter with an informed consent form and the preparatory tool. A research assistant was present in the waiting room to assist with the pre- and post-consultation questionnaires, if needed. The consultations were videorecorded to enable rating by observers. The observers were not present during the actual consultation. Data concerning comorbidities were retrieved from the patients’ medical records. The geriatricians completed a baseline questionnaire and a short post-consultation questionnaire. Written informed consent was obtained from all participating patients, caregivers and geriatricians.

Outcomes
Primary outcome
The primary outcome measure was the level of observed SDM during consultations, as measured with the validated OPTION\textsuperscript{MCC} \textsuperscript{19}. The metric contains 7 items that measure the competences of geriatricians and the level of participation among older adults and their caregivers. The scores were allocated to increasing levels of achievement for the described competence of the geriatrician (range 0-4, transformed 0-100). The level of patient and caregiver participation was rated on three levels: (0) no participation, (1) responsive participation and (2) active participation. The video was assessed by three trained observers. To
avoid bias in rating the videos before and after the intervention, we involved a fourth, independent observer. Inter-rater reliability was assessed using intraclass correlation coefficients (ICCs). ICCs were .77, .77, and .88 (geriatricians, patients, and caregivers, respectively), which indicated substantial levels of agreement.

**Patient-reported outcomes**

1. **Preferred and perceived roles** of patients and caregivers were measured before and after the consultation using an adapted version of the Control Preference Scale containing seven response statements, divided among three categories: 1) an active role (patient- and/or caregiver-controlled), 2) a passive role (practitioner-controlled), and 3) a shared role (collaborative) (Table A1)\(^{20,21}\). The match between the participants’ preferred and perceived roles was calculated by the percentage of participants that had identical scores for the preferred and perceived roles (0=no match; 1=match).

2. **Preferred and perceived participation** of patients and caregivers in SDM was measured with Patients’ Perceived Involvement in Care Scale (PICS)\(^{22,23}\). Participants were asked to indicate the importance of eight statements concerning the upcoming consultation, using a 4-point Likert scale. Total scores ranged from 0 to 8, higher scores indicating a higher preferred resp. perceived participation during the decision making process\(^{22}\). The match between the participants’ preferred and perceived participation was calculated by subtracting the perceived participation scores from the preferred participation scores. Participants with discrepancy scores between -2 and 2 were categorized as having matched preferences. Participants with discrepancies < -2 or > 2 were categorized as unmatched preferences.

3. **The level of perceived SDM** was measured with CollaboRATE, containing three questions. Responses to each item range from 0 to 9. The CollaboRATE score was calculated as the proportion of participants who reported a score of nine on each of the three CollaboRATE questions, a higher % indicates a higher level of SDM\(^{24-26}\).

4. **Decisional conflict** was measured with the Decisional Conflict Scale (DCS), consisting of 16 items measured on a 5-point Likert scale\(^{27}\). The total score varies between 0 (no decisional conflict) and 100 (extremely high decisional conflict)\(^{27}\).

**Background characteristics**

Patients’ and caregivers’ baseline characteristics included: age, gender, education (low, middle, high), living situation and health literacy\(^{28}\). Clinical characteristics included frailty\(^{29}\), polypharmacy and comorbidity\(^{30}\).

**Process evaluation**

For each consultation, geriatricians reported the most important problem presented by the patient, and for the decision whether there were more options available and, if so, whether these options were equal, meaning subject to preference-sensitive decisions\(^{31}\). In the post-intervention questionnaire, patients and caregivers were asked whether they received the preparatory tool and whether they had completed it. In the video observations it was observed whether the tool was used or referred to.
**Statistical analysis**

We used descriptive statistics to summarize personal, clinical, and other outcomes of patients and caregivers and (consultation) characteristics for the process evaluation. The differences between groups regarding the level of observed SDM (OPTIONMCC) were analyzed with a mixed model analysis to adjust for the dependent observations within the geriatricians. For dichotomous outcomes (i.e., matches on preferred and perceived roles and participation), a logistic mixed model analysis was used. STATA (version 14) was used for all analyses.

**Results**

**Response**

In the study period, 1029 older adults visited one of the two hospitals for a geriatric consultation with a geriatrician of which 216 participated in the study. Figure 1 presents the flow chart of the study. There were no significant differences regarding age and gender between the participating patients and the non-responding patients.

**Baseline characteristics**

Table 1 summarizes the sociodemographic and clinical characteristics of patients and the characteristics of the consultations. The mean (standard deviation (SD)) age was 77.3 (7.9) years, and 56.3% were female. The main problem was cognition (45.2%), and the main decisions were about additional diagnostics (22.6%), follow-up (21.6%) and medication (18.7%). The mean duration of the consultations was 38.7 minutes (SD 33.5). The background characteristics of the caregivers are presented in Table A2.

**Primary outcome**

Table 2 shows the OPTIONMCC item response. There were no significant differences between the intervention group and the usual care group for the total mean OPTIONMCC scores. However, we observed significant differences in 6 out of 7 items. For both geriatricians and patients, we found a significant improvement in item 1: goal talk (geriatricians $B = .32$, 95% confidence interval (CI) .06; .58, patients $B = .27$, 95% CI .10; .44) and item 4: option talk (geriatricians $B = .25$, 95% CI .01; .48, patients $B = .22$, 95% CI .04; .39). For patients, we observed a significant improvement in items 5 and 6 regarding decision talk (elicit preferences and decide together) (patients item 5 $B = .39$, 95% CI .21; .57, item 6 $B = .24$, 95% CI .07; .41). However, for both geriatricians and patients, a significant decrease was observed for item 3: team talk (geriatricians $B = - .71$, 95% CI -1.01; -.40, patients $B = - .52$, 95% CI - .72; -.33, caregivers $B = - .52$, 95% CI - .72; -.33) and item 7: evaluation talk (geriatricians $B = - .46$, 95% CI -.70; -.21, caregivers $B = - .32$, 95% CI -.55; -.09).

**Patient-reported outcomes**

The match between preferred and perceived role in decision making and between preferred and perceived participation in SDM was not significantly different between usual care patients and intervention patients or their caregivers. Decisional conflict was low in both groups, and no significant differences were found (see Table 3).
Effects of the SDM\textsuperscript{MCC} intervention

Eligible patients assessed (n=1029)

- Insufficient mastery of Dutch language (n=55)
- Cognitive impairment (n=118)
- Patient in palliative care (n=1)
- No permission clinician (n=19)
- No response clinician (n=24)
- Double appointments (n=28)
- Other clinician (n=4)
- No multimorbidity (n=6)
- Compulsory hospitalisation (n=2)
- Logistic reasons (n=35)

Excluded after first round of calls (n=410)

- Too stressful (n=82)
- Didn’t want a record (n=9)
- Not interested (n=37)
- Moved to nursing home (n=1)
- Cancelled appointment (n=73)
- Could not be reached (n=201)
- Didn’t received the information letter (n=7)

Eligible patients called in first round (n=737)

Interested patients received information letter (n=327)

- Too stressful (n=43)
- Too much pressure (n=2)
- Could not be reached (n=2)
- Declined to participate in waiting room (n=24)

Excluded after second round of calls (n=111)

- Didn’t want a record (n=6)
- Not interested (n=31)
- No time for participation (n=3)
- Too stressful (n=43)
- Too much pressure (n=2)
- Could not be reached (n=2)
- Declined to participate in waiting room (n=24)

Participants (n=216)

Usual Care (n=108)
April 2016 - June 2017

Informal caregivers (n=68)

Excluded after analysis due to too much missing data (n=3)

Intervention (n=108)
Oct 2017 - June 2018

Informal caregivers (n=65)

Figure 1. Flowchart of patient inclusion
### Table 1. Baseline Characteristics by Group

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All Patients (N=213)</th>
<th>Usual Care Patients (n^a=105)</th>
<th>Intervention Patients (n^b=108)</th>
<th>Intervention vs. usual care patients p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>77.3(7.9)</td>
<td>78.0(8.2)</td>
<td>76.5(7.4)</td>
<td>.56</td>
</tr>
<tr>
<td>Female sex (n, %)</td>
<td>120(56.3)</td>
<td>55(52.4)</td>
<td>65(62.6)</td>
<td>.25</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
<td></td>
<td></td>
<td>.45</td>
</tr>
<tr>
<td>Low (n, %)</td>
<td>31(15.2)</td>
<td>19(18.8)</td>
<td>12(11.1)</td>
<td></td>
</tr>
<tr>
<td>Middle (n, %)</td>
<td>118(57.8)</td>
<td>58(57.5)</td>
<td>60(55.6)</td>
<td></td>
</tr>
<tr>
<td>High (n, %)</td>
<td>55(27.0)</td>
<td>23(22.8)</td>
<td>32(29.6)</td>
<td></td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
<td></td>
<td>.63</td>
</tr>
<tr>
<td>Independent, alone (n, %)</td>
<td>91(43.5)</td>
<td>41(4.6)</td>
<td>50(46.3)</td>
<td></td>
</tr>
<tr>
<td>Independent, with others (n, %)</td>
<td>113(54.1)</td>
<td>58(57.5)</td>
<td>55(55.6)</td>
<td></td>
</tr>
<tr>
<td>Home for the elderly (n, %)</td>
<td>5(2.4)</td>
<td>2(2.0)</td>
<td>3(2.8)</td>
<td></td>
</tr>
<tr>
<td>Health literacy (SAHL-D22) b (mean,SD)</td>
<td>11.8(6.9)</td>
<td>1.7(6.9)</td>
<td>12.9(6.8)</td>
<td>.55</td>
</tr>
<tr>
<td>Polypharmacy c (≥4) (n, %)</td>
<td>137(64.3)</td>
<td>65(61.9)</td>
<td>72(66.7)</td>
<td>.93</td>
</tr>
<tr>
<td>Frailty (GFI) d mean, SD</td>
<td>4.3(2.5)</td>
<td>4.4(2.6)</td>
<td>4.2(2.4)</td>
<td>.69</td>
</tr>
<tr>
<td>Comorbidity (CCI) e mean, SD</td>
<td>1.9(1.9)</td>
<td>2.0(1.8)</td>
<td>1.65(1.9)</td>
<td>.09</td>
</tr>
<tr>
<td>Duration consultations (in min) mean (SD)</td>
<td>38.7(33.5)</td>
<td>4.9(26.8)</td>
<td>36.6(38.6)</td>
<td>.37</td>
</tr>
<tr>
<td>Main problems (n, %)</td>
<td></td>
<td></td>
<td></td>
<td>.29</td>
</tr>
<tr>
<td>cognition/dementia</td>
<td>98(45.2)</td>
<td>52(48.0)</td>
<td>46(41.4)</td>
<td></td>
</tr>
<tr>
<td>osteoporosis</td>
<td>27(12.4)</td>
<td>9(8.0)</td>
<td>18(16.2)</td>
<td></td>
</tr>
<tr>
<td>falls/mobility</td>
<td>17(7.8)</td>
<td>10(9.0)</td>
<td>7(6.3)</td>
<td></td>
</tr>
<tr>
<td>depression</td>
<td>9(4.1)</td>
<td>3(3.0)</td>
<td>6(5.4)</td>
<td></td>
</tr>
<tr>
<td>other (&lt;5%)</td>
<td>66(3.4)</td>
<td>34(32.0)</td>
<td>32(3.7)</td>
<td></td>
</tr>
<tr>
<td>Most frequently discussed decisions f (n, %)</td>
<td></td>
<td></td>
<td></td>
<td>.32</td>
</tr>
<tr>
<td>additional diagnostics</td>
<td>69(22.6)</td>
<td>31(24.2)</td>
<td>38(21.5)</td>
<td></td>
</tr>
<tr>
<td>follow-up</td>
<td>66(21.6)</td>
<td>27(21.6)</td>
<td>39(22.0)</td>
<td></td>
</tr>
<tr>
<td>medication</td>
<td>57(18.7)</td>
<td>28(21.8)</td>
<td>29(16.4)</td>
<td></td>
</tr>
<tr>
<td>referral to primary care</td>
<td>49(16.1)</td>
<td>19(14.8)</td>
<td>30(16.9)</td>
<td></td>
</tr>
<tr>
<td>lifestyle</td>
<td>29(9.5)</td>
<td>12(9.4)</td>
<td>17(9.6)</td>
<td></td>
</tr>
<tr>
<td>consultation other hospital specialist</td>
<td>26(8.5)</td>
<td>8(6.2)</td>
<td>18(1.2)</td>
<td></td>
</tr>
<tr>
<td>other</td>
<td>9(3.0)</td>
<td>3(2.3)</td>
<td>6(3.4)</td>
<td></td>
</tr>
</tbody>
</table>
### Table 1. Continued

<table>
<thead>
<tr>
<th>More options were available (according to geriatrician) (n,%)</th>
<th>167(78.4)</th>
<th>82(87.2)</th>
<th>85(78.7)</th>
<th>.17</th>
</tr>
</thead>
<tbody>
<tr>
<td>If so, options were considered equal (according to geriatrician) (n,%)</td>
<td>83(39.0)</td>
<td>36(43.3)</td>
<td>47(53.4)</td>
<td>.42</td>
</tr>
</tbody>
</table>

a Three patients were excluded after analysis, due to too much missing data (see flow chart) and n varies slightly due to missing data  

b Health literacy: SAHL-D22 (score 0-22; a higher score indicates higher health literacy)  
c Polypharmacy: use of >4 different medications  
d Frailty: GFI (score 0 - 15; score > 4 indicates frailty)  
e Comorbidity: CCI. A higher CCI-score (CCI-score > 5) is associated with higher morbidity and mortality  

SD = standard deviation  
f More decisions in 1 consultation were possible

### Table 2. Observer OPTION\textsuperscript{MCC} outcomes for geriatricians, patients and informal caregivers

<table>
<thead>
<tr>
<th></th>
<th>Usual care (n=100\textsuperscript{a})</th>
<th>Intervention (105\textsuperscript{a})</th>
<th>P-value B (95%CI)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Geriatricians</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OPTION scores on subitems (mean, SD) Range (0-4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Goal talk</td>
<td>1.6(1.1)</td>
<td>1.9(9)</td>
<td>.02*</td>
<td>.32(.06; .58)</td>
</tr>
<tr>
<td>2. Option talk: present options</td>
<td>1.8(.9)</td>
<td>1.9(.6)</td>
<td>.30</td>
<td>.11(-.10; .33)</td>
</tr>
<tr>
<td>3. Team talk: form partnership</td>
<td>1.2(1.2)</td>
<td>.5(1.0)</td>
<td>&lt;.001***</td>
<td>-.71(-1.01; -.40)</td>
</tr>
<tr>
<td>4. Option talk: discuss pro’s and con’s</td>
<td>1.6(.9)</td>
<td>1.9(.8)</td>
<td>.04*</td>
<td>.25(.01; .48)</td>
</tr>
<tr>
<td>5. Decision talk: elicit preferences</td>
<td>1.8(1.3)</td>
<td>2.0(.9)</td>
<td>.22</td>
<td>.18(-.11; .48)</td>
</tr>
<tr>
<td>6. Decision talk: decide together</td>
<td>1.6(1.2)</td>
<td>1.8(.9)</td>
<td>.16</td>
<td>.20(-.08; .49)</td>
</tr>
<tr>
<td>7. Evaluation talk</td>
<td>1.4(1.0)</td>
<td>.9(.8)</td>
<td>&lt;.001***</td>
<td>-.46(-.70; -.21)</td>
</tr>
<tr>
<td>Total OPTION score</td>
<td>1.6(.9)</td>
<td>1.6(.5)</td>
<td>.88</td>
<td>-.01(-.21; .18)</td>
</tr>
<tr>
<td><strong>Total Transformed OPTION score (0-100 score)</strong></td>
<td>39.7(21.4)</td>
<td>39.3(13.7)</td>
<td>.88</td>
<td>-.37(-5.2; 4.45)</td>
</tr>
<tr>
<td><strong>Patients</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>OPTION scores on subitems (mean, SD) Range (0-2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Goal talk</td>
<td>1.2(.7)</td>
<td>1.5(6)</td>
<td>.002**</td>
<td>.27(10; .44)</td>
</tr>
<tr>
<td>2. Option talk: present options</td>
<td>1.1(.6)</td>
<td>1.3(.6)</td>
<td>.10</td>
<td>.14(-.03; .30)</td>
</tr>
<tr>
<td>3. Team talk: form partnership</td>
<td>.9(.8)</td>
<td>.3(.6)</td>
<td>&lt;.001***</td>
<td>-.52(-.72; -.33)</td>
</tr>
<tr>
<td>4. Option talk: discuss pro’s and con’s</td>
<td>1.1(.7)</td>
<td>1.3(.6)</td>
<td>.02*</td>
<td>.22(04; .39)</td>
</tr>
<tr>
<td>5. Decision talk: elicit preferences</td>
<td>1.2(.7)</td>
<td>1.5(.6)</td>
<td>&lt;.001***</td>
<td>.39(21; 57)</td>
</tr>
</tbody>
</table>
Table 2. Continued

<table>
<thead>
<tr>
<th></th>
<th>Informal caregivers</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>OPTION scores on subitems (mean, SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Range (0-2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Goal talk</td>
<td>1.2(.6) 1.3(.7)</td>
<td>.45</td>
<td>.08(-.04;.21)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Option talk: present options</td>
<td>1.2(.7) 1.1(.6)</td>
<td>.32</td>
<td>-.12(-.34;.11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Team talk: form partnership</td>
<td>1.0(.8) .2(.5)</td>
<td>&lt;.001***</td>
<td>-.78(-1.01;.55)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Option talk: discuss pro’s and con’s</td>
<td>1.1(.7) 1.2(.7)</td>
<td>.57</td>
<td>.07(-.16;.30)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Decision talk: elicit preferences</td>
<td>1.2(.7) 1.3(.7)</td>
<td>.12</td>
<td>.18(-.05;.41)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Decision talk: decide together</td>
<td>1.1(.7) 1.3(.6)</td>
<td>.08</td>
<td>.20(-.02;.42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Evaluation talk</td>
<td>.9(.7) .5(.7)</td>
<td>.01**</td>
<td>-.32(-.55;.09)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total OPTION score</td>
<td>1.1(.5) 1.0(.5)</td>
<td>.20</td>
<td>-.10(-.26;.05)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a n varies slightly due to missing data
*< .05
**<.01
***<.001

Process evaluation

Table A3 presents the evaluation of the preparatory tool usage. Seventy-four (68.5%) older adults remembered that they had received the preparatory tool. The tool was completed by 56 older adults (51.9%). There were no significant differences in the total mean OPTIONMCC scores between the patients that had completed and used the preparatory tool and those that had not used the preparatory tool (Table A4).

Table 4 shows the mean OPTIONMCC score of each geriatrician (range -17.3 <> 24.08). Of the nine geriatricians who participated in the usual care group and in the intervention group, one received a higher mean overall OPTIONMCC score after the intervention (p = .01), one received a lower mean OPTIONMCC score (p = .01), and seven geriatricians showed no significant difference in their mean OPTIONMCC score after the intervention (range -7.92 <> 8.29). The one geriatrician with a lower score had a strongly deviating score (-17.3) compared to the other eight geriatricians. When we considered this as an outlier, a subgroup analysis of the remaining 8 geriatricians revealed a significant positive effect on the overall OPTIONMCC mean scores after the intervention (Table A5). On item level, we then found a significant improvement for both geriatricians and patients on 5 of the 7 subitems: item 1: goal talk, item 2: option talk (present options), item 4: option talk, item 5 decision talk (preferences) and item 6 decision talk...
Effects of the SDMMCC intervention

<table>
<thead>
<tr>
<th>Table 3. Participant reported outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Usual Care Patients</strong> (N(^a)=105)</td>
</tr>
<tr>
<td><strong>Usual Care Informal caregivers</strong> (N(^a)=68)</td>
</tr>
<tr>
<td><strong>Preferred role in the decision making process (CPS) n (%)(^b)</strong></td>
</tr>
<tr>
<td>• Active role</td>
</tr>
<tr>
<td>• Collaborative role</td>
</tr>
<tr>
<td>• Passive role</td>
</tr>
<tr>
<td><strong>Perceived role in the decision making process (CPS) n (%)(^b)</strong></td>
</tr>
<tr>
<td>• Active role</td>
</tr>
<tr>
<td>• Collaborative role</td>
</tr>
<tr>
<td>• Passive role</td>
</tr>
<tr>
<td><strong>Match Preferred and Perceived role in the decision making process (Match CPS) n (%)(^c)</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Preferred Involvement in Care (PICS) mean (SD)(^d)</strong></td>
</tr>
<tr>
<td><strong>Perceived Involvement in Care (PICS) mean (SD)(^d)</strong></td>
</tr>
<tr>
<td><strong>Match Preferred and Perceived Involvement in Care (Match PICS) n (%)(^e)</strong></td>
</tr>
<tr>
<td><strong>Level of perceived SDM (CollaboRATE) n (%)(^f)</strong></td>
</tr>
<tr>
<td><strong>Decisional Conflict (DCS) mean (SD)(^g)</strong></td>
</tr>
</tbody>
</table>
Table 3. Continued

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>a N varies due to missing data</td>
<td></td>
</tr>
<tr>
<td></td>
<td>b Decision Roles: Adapted Control Preference Scale with seven response statements, which are divided among three categories: 1) an active role (patient- and/or informal caregiver-controlled), 2) a passive role (practitioner-controlled), and 3) a shared role (collaborative).</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c Match CPS: The match between the participants’ preferred and perceived roles was calculated by the percentage of participants that had identical scores on the preferred and perceived roles.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>d PICS: Patients’ Perceived Involvement in Care Scale (score range 0 - 8) higher scores indicating a higher preferred resp. perceived participation during the decision making process</td>
<td></td>
</tr>
<tr>
<td></td>
<td>e Match Participation: PICS Match: participants with discrepancy scores between-2 and 2 were categorized as having matched preferences.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>f SDM: CollaboRATE % patients that have a top score, a higher % indicates a higher level of SDM</td>
<td></td>
</tr>
<tr>
<td></td>
<td>g Decisional Conflict: DCS: (score 0 - 100) a higher score indicates a higher level of decisional conflict</td>
<td></td>
</tr>
<tr>
<td></td>
<td>SD = standard deviation</td>
<td></td>
</tr>
</tbody>
</table>

(decision). For items 5 and 6, we also found a significant improvement in the caregiver scores. Similar to the overall analysis, a negative significant effect was found for item 3: team talk (geriatricians, patients and caregivers) and item 7: evaluation talk (geriatricians and caregivers).

Table 4. Total OPTIONMCC scores individual geriatricians (usual care vs. intervention)

<table>
<thead>
<tr>
<th>Geriatrician</th>
<th>Usual care (n=9) (mean score)</th>
<th>Intervention (n=10) (mean score)</th>
<th>Result</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>51.13</td>
<td>33.83</td>
<td>-17.3</td>
<td>.01</td>
</tr>
<tr>
<td>2</td>
<td>4.36</td>
<td>38.49</td>
<td>-1.87</td>
<td>.80</td>
</tr>
<tr>
<td>3</td>
<td>17.35</td>
<td>41.43</td>
<td>+24.08</td>
<td>&lt;.01**</td>
</tr>
<tr>
<td>4</td>
<td>41.67</td>
<td>43.11</td>
<td>-.24</td>
<td>.84</td>
</tr>
<tr>
<td>5a</td>
<td>38.57</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>53.87</td>
<td>45.95</td>
<td>-7.92</td>
<td>.21</td>
</tr>
<tr>
<td>7</td>
<td>34.18</td>
<td>39.29</td>
<td>+5.11</td>
<td>.79</td>
</tr>
<tr>
<td>8</td>
<td>3.10</td>
<td>38.39</td>
<td>+8.29</td>
<td>.31</td>
</tr>
<tr>
<td>9</td>
<td>32.65</td>
<td>38.57</td>
<td>+5.92</td>
<td>.37</td>
</tr>
<tr>
<td>10</td>
<td>32.14</td>
<td>34.69</td>
<td>+2.55</td>
<td>.68</td>
</tr>
</tbody>
</table>

<sup>a</sup> Geriatrician 5 did not participate in intervention

<sup>**<.01</sup>
Discussion

This study aimed to evaluate the effects of the SDM\textsuperscript{MCC} intervention for older adults and their caregivers on observed SDM. The overall mean score of the OPTION\textsuperscript{MCC} (range 0 - 100) in this study was higher both in the intervention and in the usual care group (39.7 - 39.3) than the mean scores of the OPTION in other studies; Couet (2014) found a mean OPTION-12 score of 23 in a review of 33 studies (mainly among general practitioners)\textsuperscript{32}. They also found that longer consultation durations were associated with higher scores on the OPTION scale\textsuperscript{32}. The mean duration of consultations (38.7 (SD 33.5) minutes) was much longer in our study compared to most studies in the Couet review (median 13 minutes), which might explain our higher scores.

No significant difference was found on the overall level of SDM as measured with the OPTION\textsuperscript{MCC}. However, there were significant differences at the item level in the OPTION\textsuperscript{MCC} between the intervention and usual care. The items discussing ‘goals’, ‘options’, and ‘decision making’ improved in the intervention group. Conversely, discussing ‘partnership’ and the ‘evaluation of the decision process’ decreased. This didn’t result in differences in patient reported outcomes.

The lack of a significant effect on the mean OPTION\textsuperscript{MCC} score might be explained by the great variety within the nine participating geriatricians, although they all received the same SDM\textsuperscript{MCC} training. A sub-analysis showed that this variety was not associated with the use of the patient preparatory tool, the availability of more options, the equality of the options, or with the hospital setting. Since the geriatricians improved on some of the items, while declining in others, an explanation can also be that geriatricians are forced to prioritize within the limited time of a consultation and that time taken for goal talk, option talk and decision talk (the elements that increased) occurs at the expense of the other elements. This is in line with Driever et al. (2019) who found that the hospital physicians focused more on discussing treatment options\textsuperscript{33} and gave less attention to actually involving the patient in the decision-making process. Another explanation might be that goal talk, option talk and decision talk are the easiest parts of SDM to improve rather than establishing a genuine partnership with the older adults and taking time to evaluate the decision-making process. Furthermore, although we did address all steps of the SDM\textsuperscript{MCC} model in the training, the part where geriatricians practiced SDM may have been more focused on goal talk than on engaging the patient in the decision-making process. Finally, we concur with Pieterse et al. (2019) that we might have to rethink the underlying relationship between the items and the construct that we measure; in other words—how are the SDM items related to each other?\textsuperscript{34} And should all items be given the same weight or, for example, should ‘goal talk’ be given more weight than ‘evaluation’?

Only a few interventions for SDM target both healthcare professionals and patients\textsuperscript{35}. Because training programs targeting both groups seem to benefit SDM more than interventions targeting only one of these groups\textsuperscript{36, 37}, our intervention focusing on both groups was justified. However, a disadvantage is that we don’t know what the effective ingredient of the intervention was. The effectiveness of the training could be further increased by using repeated video-based individual feedback sessions, as suggested by Geiger et al. (2017)\textsuperscript{38} and Geessink et al.
(2017), who also trained clinicians according to the dynamic model of SDM with frail older persons\textsuperscript{39}.

The process evaluation of the preparatory tool showed that although patients and caregivers were mostly positive about the preparatory tool, the tool was rarely used in consultations. Hence, people that had put effort in completing the preparatory tool often experienced that their input was not incorporated in the conversation with the geriatrician. Although we did include the preparatory tool in the training for geriatricians, we might have focused more on instructing the geriatrician on how to discuss the preparatory tool with the patients, in particular because QPSs may even have reverse effects when they are not acknowledged by the physician\textsuperscript{40}. The preparatory tool for this study was developed in collaboration with end users, i.e., older adults with MCCs, thus addressing the specific needs of a population in which cognitive decline and low health literacy are very common. This might elucidate other aspects of the process evaluation. First, cognitive decline (the most common problem in the patient group) could explain why almost one-third of the patients did not remember receiving the preparatory tool. Second, of the patients who remembered receiving the tool, a large majority (75\%) was able to complete the tool and almost two-third was positive. This suggests sufficient feasibility of the preparatory tool.

This pragmatic trial with videorecordings of real-life consultations provided a unique insight into SDM with older adults and their caregivers. However, there are some limitations. We experienced that scoring behavioral competences of SDM in geriatric consultations is challenging. The OPTION\textsuperscript{MCC} is designed to measure verbal SDM behavior; nonetheless, we also observed immeasurable, implicit SDM behavior—for example non-verbal behavior of a geriatrician or an empathic, attentive way of listening, thus empowering older adults to express themselves. Finally, we noted that often there was more than one problem that was discussed during a consultation. Although we asked geriatricians to define the most important problem, the multitude of problems discussed sometimes complicated the ratings of the observers.

**Conclusions and Implications**

This study shows that the SDM\textsuperscript{MCC} training for geriatricians improved the discussion of goals, options, and decision making. In addition, it provides scope for improvement—discussing partnerships and the evaluation of the decision-making process could be reinforced. Furthermore, it might be valuable to use a preparatory tool to prepare and support the patient and caregiver; however, more attention should be given to integrating this tool in the consultation.
Effects of the SDM\textsuperscript{MCC} intervention

References


18. Pel-Littel RE, van Weert JCM, Minkman MM, et al. The development of the
Chapter 7


Appendix Figure 1: Patient preparatory tool

Patient brochure

Dear Mr, Mrs

You will soon have an appointment with the doctor in the hospital. Would you like to fill in this brochure at home and take it with you to the appointment?

1. What does your day usually look like?

   - Activities
   - Social contacts

2. How would you rate your life at this moment? [0–10]

3. What needs to happen to raise this grade a point?

4. What would you like to discuss with the doctor?

You can ask these questions when you visit the doctor:

- Are there any other options other than the treatment or research you mention?
- What are the advantages and disadvantages of the different treatment options?
- What do these advantages and disadvantages mean for my daily life?
- What do these advantages and disadvantages mean for my other diseases?

For informal carers

The doctor is also interested in how it is going for informal caregivers (the partner, daughter, son, family member or friend) because their work is important and they must continue to sustain their health.

That is why the doctor will also ask about the health of the informal caregiver. When we think about health we think about how the caregiver is doing physically, mentally and emotionally.

As a carer I feel like I am:
Appendix Table A1. Adapted Control Preference Scale

Patients’ and informal caregivers’ preferred and perceived role in decision making was measured with the Control Preference Scale (CPS)\(^1\,\,^2\). The CPS is a widely used tool, and assesses the level of control patients and clinicians want to assume in decision making. The original CPS consists of one item with a five-point scale\(^3\). The answer options range from the patient selecting its own treatment through a collaborative model to a scenario where the physician alone makes the decision\(^1\). In this study, the CPS was adapted to include the informal caregiver as a potential partner in decision making. The adapted scale contained seven response statements, which were divided among three categories: 1) an active role (patient- and/or informal caregiver-controlled), 2) a passive role (practitioner-controlled), and 3) a shared role (collaborative). The response statements from the adapted scale, and their category (active/passive/collaborative) are shown, for both the patients and the informal caregivers.

<table>
<thead>
<tr>
<th>Adapted CPS scale, pre-consultation questionnaire</th>
<th>Preferred role of the patient</th>
<th>Preferred role of the informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>I prefer that the patient himself/herself makes the final decision</td>
<td>Active</td>
<td>Passive</td>
</tr>
<tr>
<td>I prefer that the clinician makes the final decision</td>
<td>Passive</td>
<td>Passive</td>
</tr>
<tr>
<td>I prefer that the informal caregiver makes the final decision</td>
<td>Passive</td>
<td>Active</td>
</tr>
<tr>
<td>I prefer that the patient makes the final decision after seriously considering the clinician’s opinion</td>
<td>Active</td>
<td>Passive</td>
</tr>
<tr>
<td>I prefer that the patient makes the final decision after seriously considering the informal caregiver’s opinion</td>
<td>Active</td>
<td>Active</td>
</tr>
<tr>
<td>I prefer that the informal caregiver makes the final decision after seriously considering the clinician’s opinion</td>
<td>Passive</td>
<td>Active</td>
</tr>
<tr>
<td>I prefer that the patient, the informal caregiver, and the clinician share responsibility for the final decision</td>
<td>Collaborative</td>
<td>Collaborative</td>
</tr>
</tbody>
</table>
### Adapted CPS scale, post-consultation questionnaire

<table>
<thead>
<tr>
<th>Response statement from adapted CPS</th>
<th>Preferred role of the patient</th>
<th>Preferred role of the informal caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient himself/herself has made the final decision during the consultation</td>
<td>Active</td>
<td>Passive</td>
</tr>
<tr>
<td>The clinician has made the final decision during the consultation</td>
<td>Passive</td>
<td>Passive</td>
</tr>
<tr>
<td>I prefer that the informal caregiver makes the final decision</td>
<td>Passive</td>
<td>Active</td>
</tr>
<tr>
<td>The patient has made the final decision during the consultation after seriously considering the clinician’s opinion</td>
<td>Active</td>
<td>Passive</td>
</tr>
<tr>
<td>The patient has made the final decision during the consultation after seriously considering the informal caregiver’s opinion</td>
<td>Active</td>
<td>Active</td>
</tr>
<tr>
<td>The informal caregiver has made the final decision during the consultation after seriously considering the clinician’s opinion</td>
<td>Passive</td>
<td>Active</td>
</tr>
<tr>
<td>The patient, the informal caregiver, and the clinician have shared responsibility for the final decision during the consultation</td>
<td>Collaborative</td>
<td>Collaborative</td>
</tr>
</tbody>
</table>

### Appendix Table A2: Baseline Characteristics Informal Caregivers

Baseline Characteristics Informal Caregivers

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>All Informal Caregivers (N=133)</th>
<th>Usual Care Informal Caregivers (N=68)</th>
<th>Intervention Informal Caregivers (N=65)</th>
<th>Intervention vs. usual care informal caregivers p=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>65.6(14.0)</td>
<td>66.5(13.1)</td>
<td>64.2(15.2)</td>
<td>.20</td>
</tr>
<tr>
<td>Female sex (n, %)</td>
<td>75(57.7)</td>
<td>43(64.2%)</td>
<td>32(50.0)</td>
<td>.10</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
<td></td>
<td></td>
<td>.12</td>
</tr>
<tr>
<td>Low (n, %)</td>
<td>5(3.9)</td>
<td>5(7.5)</td>
<td>0(0)</td>
<td></td>
</tr>
<tr>
<td>Middle (n, %)</td>
<td>78(60.9)</td>
<td>40(59.7)</td>
<td>38(60.3)</td>
<td></td>
</tr>
<tr>
<td>High (n, %)</td>
<td>45(35.2)</td>
<td>22(32.8)</td>
<td>23(35.5)</td>
<td></td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
<td></td>
<td>.59</td>
</tr>
<tr>
<td>Independent, alone (n, %)</td>
<td>14(10.7)</td>
<td>7(10.4)</td>
<td>7(10.9)</td>
<td></td>
</tr>
<tr>
<td>Independent, with others (n, %)</td>
<td>116(88.5)</td>
<td>60(89.6)</td>
<td>56(87.5)</td>
<td></td>
</tr>
<tr>
<td>Home for the elderly (n, %)</td>
<td>1(.8)</td>
<td>0(0)</td>
<td>1(1.6)</td>
<td></td>
</tr>
<tr>
<td>Relation to the patient (n, %)</td>
<td></td>
<td></td>
<td></td>
<td>.99</td>
</tr>
<tr>
<td>Husband/wife</td>
<td>71(56.3)</td>
<td>38(56.7)</td>
<td>33(52.4)</td>
<td></td>
</tr>
<tr>
<td>Daughter/Son</td>
<td>41(32.5)</td>
<td>22(32.8)</td>
<td>19(30.2)</td>
<td></td>
</tr>
<tr>
<td>Other relative</td>
<td>5(4.0)</td>
<td>3(4.5)</td>
<td>2(3.2)</td>
<td></td>
</tr>
<tr>
<td>Friend, neighbour, etc</td>
<td>9(7.1)</td>
<td>4(6.0)</td>
<td>5(7.9)</td>
<td></td>
</tr>
</tbody>
</table>

* a n varies slightly due to missing data
* SD = standard deviation
* < 0.05
** < 0.01
*** < 0.001
### Appendix Table A3: Evaluation of use of the preparatory tool in the intervention group (n=108)

<table>
<thead>
<tr>
<th></th>
<th>Yes (n,%), n=108</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patients:</strong> Did you receive the preparatory tool?</td>
<td>74(68.5)</td>
</tr>
<tr>
<td><strong>Patients:</strong> Did you complete the preparatory tool?</td>
<td>56(51.9)</td>
</tr>
<tr>
<td><strong>Patients:</strong> Did you discuss the preparatory tool with your relatives?</td>
<td>26(24.1)</td>
</tr>
<tr>
<td><strong>Observers:</strong> Was the preparatory tool used in the consultation?</td>
<td>11(10.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What did you think of the preparatory tool?</th>
<th>Patients that used the tool (n=56)</th>
<th>Informal caregivers that used the tool (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>good, clear or informative</td>
<td>64%</td>
<td>63%</td>
</tr>
<tr>
<td>confusing, difficult'</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>limited, too short'</td>
<td>7%</td>
<td>4%</td>
</tr>
<tr>
<td>not applicable to their situation</td>
<td>5%</td>
<td>19%</td>
</tr>
<tr>
<td>no opinion</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>other remarks (mainly logistic)</td>
<td>11%</td>
<td></td>
</tr>
</tbody>
</table>


Appendix Table A4: Observer OPTIONMCC scores with and without use of preparatory tool (intervention group)

<table>
<thead>
<tr>
<th></th>
<th>Total OPTION score geriatricians (Transformed 0-100 score) (mean, sd)</th>
<th>Total OPTION score patients (mean, sd)</th>
<th>Total OPTION score informal caregivers (mean, sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient completed preparatory tool at home (n=56)</td>
<td>39.3(13.1)</td>
<td>1.2(.4)</td>
<td>.9(.5)</td>
</tr>
<tr>
<td>Patient who <strong>NOT</strong> completed preparatory tool at home (n=52)</td>
<td>39.4(14.3)</td>
<td>1.1(.3)</td>
<td>1.0(.4)</td>
</tr>
<tr>
<td>Preparatory tool was used in consultation (n=11)</td>
<td>38.6(17.8)</td>
<td>1.1(.3)</td>
<td>.78(.3)</td>
</tr>
<tr>
<td>Preparatory tool was <strong>NOT</strong> used in consultation (n=97)</td>
<td>39.3(13.7)</td>
<td>1.1(.4)</td>
<td>1.0(.5)</td>
</tr>
</tbody>
</table>
Appendix Table A5: Observer OPTION\textsuperscript{MCC} outcomes for geriatricians, patients and informal caregivers (subgroup analysis of 8 geriatricians)

<table>
<thead>
<tr>
<th>OPTION scores on subitems (mean. sd)</th>
<th>Usual care (n=81\textsuperscript{a})</th>
<th>Intervention (n=86\textsuperscript{b})</th>
<th>P-value</th>
<th>B (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Geriatricians</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Goal talk</td>
<td>1.6(1.0)</td>
<td>2.0(0.9)</td>
<td>0.01*</td>
<td>0.39(0.10;0.67)</td>
</tr>
<tr>
<td>2. Option talk: present options</td>
<td>1.7(0.8)</td>
<td>2.0(0.6)</td>
<td>0.01*</td>
<td>0.29(0.08;0.50)</td>
</tr>
<tr>
<td>3. Team talk: form partnership</td>
<td>1.0(1.1)</td>
<td>0.6(1.1)</td>
<td>0.01*</td>
<td>-0.43(-0.75;-0.11)</td>
</tr>
<tr>
<td>4. Option talk: discuss pro’s and con’s</td>
<td>1.6(0.9)</td>
<td>1.9(0.7)</td>
<td>0.00***</td>
<td>0.39(0.15;0.64)</td>
</tr>
<tr>
<td>5. Decision talk: elicit preferences</td>
<td>1.7(1.2)</td>
<td>2.1(0.9)</td>
<td>0.01*</td>
<td>0.42(0.11;0.73)</td>
</tr>
<tr>
<td>6. Decision talk: decide together</td>
<td>1.5(1.1)</td>
<td>1.9(0.9)</td>
<td>0.01*</td>
<td>0.40(0.09;0.70)</td>
</tr>
<tr>
<td>7. Evaluation talk</td>
<td>1.3(1.0)</td>
<td>0.9(0.9)</td>
<td>0.00***</td>
<td>-0.43(-0.70;-0.16)</td>
</tr>
<tr>
<td>Total OPTION score</td>
<td>1.5(0.8)</td>
<td>1.6(0.6)</td>
<td>0.15</td>
<td>0.15(-0.05;0.34)</td>
</tr>
</tbody>
</table>

| **Patients**                          |                                       |                                       |         |           |
| 1. Goal talk                          | 1.1(0.6)                              | 1.4(0.6)                              | 0.00*** | 0.31 (0.13; 0.49) |
| 2. Option talk: present options       | 1.0(0.6)                              | 1.3(0.6)                              | 0.00*** | 0.30 (0.12; 0.48) |
| 3. Team talk: form partnership        | 0.7(0.7)                              | 0.4(0.7)                              | 0.00*** | -0.32 (-0.52; -0.12) |
| 4. Option talk: discuss pro’s and con’s | 1.0(0.6)                              | 1.3(0.6)                              | 0.00*** | 0.36 (0.18; 0.55) |
| 5. Decision talk: elicit preferences  | 1.0(0.7)                              | 1.5(0.6)                              | 0.00*** | 0.50 (0.31; 0.69) |
| 6. Decision talk: decide together     | 1.0(0.7)                              | 1.4(0.5)                              | 0.00*** | 0.39 (0.21; 0.57) |
| 7. Evaluation talk                    | 0.9(0.7)                              | 0.7(0.7)                              | 0.20    | -0.13 (-0.33; 0.07) |
| Total OPTION score                    | 0.9(0.5)                              | 1.1(0.4)                              | 0.00*** | 0.20(0.07; 0.33) |
### Informal caregivers

<table>
<thead>
<tr>
<th>OPTION scores on subitems (mean, sd)</th>
<th>Range (0-2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Goal talk</td>
<td>1.2(0.6)</td>
</tr>
<tr>
<td>2. Option talk: present options</td>
<td>1.3(0.7)</td>
</tr>
<tr>
<td>3. Team talk: form partnership</td>
<td>1.0(0.8)</td>
</tr>
<tr>
<td>4. Option talk: discuss pro’s and con’s</td>
<td>1.2(0.7)</td>
</tr>
<tr>
<td>5. Decision talk: elicit preferences</td>
<td>1.2(0.7)</td>
</tr>
<tr>
<td>6. Decision talk: decide together</td>
<td>1.1(0.7)</td>
</tr>
<tr>
<td>7. Evaluation talk</td>
<td>0.9(0.7)</td>
</tr>
<tr>
<td>Total OPTION score</td>
<td>1.1(0.5)</td>
</tr>
</tbody>
</table>

* n varies slightly due to missing data
* < 0.05
** < 0.01
*** < 0.001
Appendix Text A1: Description of the implementation of the SDM\textsuperscript{MCC} intervention

1. Training for geriatricians
In each hospital one 4-hour SDM\textsuperscript{MCC} training session was organized for which the geriatricians (n = 9) were invited. The SDM\textsuperscript{MCC} training was given by a teacher/researcher/general practitioner specialized in SDM with older adults with MCCs from the Radboud-university in Nijmegen. Theory about SDM in general and SDM with older adults was explained and demonstrated by several examples. In addition, a placemat with the steps of SDM with older adults with MCCs was distributed and the preparatory tool was shown and explained. A professional trainings-actor attended the meeting to provide training opportunities and the principle researcher guided the process. In the non-academic hospital, all five geriatricians followed the SDM\textsuperscript{MCC} training. In the academic hospital two geriatricians followed the 4-hour SDM\textsuperscript{MCC} training session, two geriatricians were not able to attend that day due to logistic reasons (1) and illness (1). Those two geriatricians received afterwards an adapted SDM\textsuperscript{MCC} training, that consisted of two informative video’s made by the trainer, about SDM in general and about the SDM\textsuperscript{MCC} model. This was followed by a meeting with the principal researcher so they could ask questions and discuss SDM. All geriatricians were offered a feedback session with the trainer to discuss the SDM process, using a videotape of one of their daily clinical consultations, six geriatricians were able to participate in this individual feed-back session.

2. Preparatory tool for patients and informal caregivers
The preparatory tool (patient folder) was sent by mail to all eligible patients and their informal caregivers (n=65) that were scheduled for a geriatric consultation in one of the two hospitals who wanted to participate in the study. In an information letter about the study, the purpose of the folder was explained and patients were requested to fill in the folder, if possible with their informal caregiver and bring it to the consultation.
Health literacy, anxiety and education influence shared decision making for older adults with multiple chronic conditions: the DICO-study

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Bianca M. Buurman
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Wilma J.M. Scholte op Reimer
Jos W.R. Twisk
Julia C.M. van Weert

Submitted
Abstract

**Introduction:** We explored the influence of the personal characteristics of older adults with multiple chronic conditions (MCCs) on perceived shared decision making (SDM) and decisional conflict, and investigated whether participation in SDM can mediate these SDM outcomes.

**Methods:** Two hundred-sixteen older adults with MCCs visiting the geriatric departments of two hospitals participated in a video-observational study. Data were collected on health literacy (measured with SAHL-D22), anxiety (STAI-6), frailty (GFI), education and age. The main outcomes were perceived level of SDM (CollaboRATE) and decisional conflict (Decisional Conflict Scale). The mediating variable was participation in the SDM process during consultations with geriatricians, measured as patients’ OPTION\textsuperscript{MCC} score. A twostep mixed effect multilinear regression and a mediation analysis were performed to analyze the data.

**Findings:** The mean age of the patients was 77.3 years and 56.3% were female. Health literacy (β = .01, p < .001) was significantly related to participation in the SDM process. Education (β = -2.43, p = .05) and anxiety (β = -26, p = .058) had a marginally significant direct effect on the patients’ perceived level of SDM. Furthermore, education (β = 12.12, p = .002), health literacy (β = -70, p = .005) and anxiety (β = 1.19, p = .004) had a significant direct effect on decisional conflict. The effect of health literacy on decisional conflict was mediated by participation in SDM.

**Conclusions:** Health professionals need to be aware of personal characteristics of older adults with MCC, since health literacy, anxiety and education are associated with decisional conflict. Moreover the effect of health literacy on decisional conflict is mediated by participation in SDM communication during consultation. This indicates that tailoring SDM communication to health literacy levels is important for high quality SDM communication and, consequently, better outcomes.
Effect of characteristics of older adults on SDM

Introduction

Shared decision making (SDM) requires capacity from both health professionals and patients. Many health professionals find it challenging to involve older adults with multiple chronic conditions (MCCs) in SDM, not only due to the complexity of interacting conditions, but also because there is a wide variation in both older adults and professionals in the way they are able to participate in SDM. Previous studies have suggested that the personal characteristics of patients, such as health literacy, anxiety, frailty, education, and age, may influence the SDM process and, consequently, patient outcomes. However, little is known about the exact influence of these characteristics on the actual participation of older adults with MCCs in SDM in health care consultations or on SDM outcomes.

Patient participation in a consultation is defined as ‘the extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction as well as the health care provider’s beliefs and behaviours’. When older adults participate more actively in the SDM process during health care consultations, better outcomes can result, such as a better perceived level of SDM and less decisional conflict. Perceived level of SDM refers to a patient reported level of SDM. Decision conflict is defined as “personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values”. The Dynamic model for SDM in frail older patients, a six-step conversation model for SDM, proposes an approach to enhance participation in SDM during consultation by discussing preferred decision roles and decision capacities, continually engaging the older adult and his/her informal caregiver in dialogue, observing the older adults’ reactions and evaluating the decision making process. However, to help health professionals engage older adults with MCCs optimally in SDM, we need to gain a better understanding of how and which factors influence SDM outcomes and whether these effects can be mediated by participation in SDM during a healthcare consultation. Additionally, older adults can be empowered in a personalized way if it can be demonstrated that this process leads to higher levels of perceived SDM and less decisional conflict.

The aim of this paper is to (1) describe the relationships between the personal characteristics health literacy, anxiety, frailty, education, and age, and SDM outcomes and (2) investigate whether participation in the SDM process during the consultation can mediate the effects of these characteristics on SDM outcomes.

Theoretical framework

Based on previous literature, we were primarily interested in the personal characteristics health literacy, anxiety, frailty, education, and age as potential variables that influence SDM.

Health literacy

Health literacy is defined as the ability to obtain, process, and understand the basic health information and services needed to manage one’s health and make appropriate health decisions. Low health literacy is especially prevalent among
older adults, with low rates of health literacy ranging from 30 - 68%\textsuperscript{8, 17, 18}. Low health literacy is associated with poor health\textsuperscript{16} and with more MCCs\textsuperscript{8}. Health literacy is even more affected when older adults experience cognitive decline, leading to increased difficulty making health choices\textsuperscript{9, 19}. Additionally, adults with low health literacy are more often acutely admitted to the hospital\textsuperscript{8, 18}. Some studies suggest that lower health literacy is associated with a higher chance of nonadherence as a result of a lack of understanding of the given instructions\textsuperscript{17}. Low health literacy among older adults is also associated with a poor SDM ability\textsuperscript{8}. Older adults with MCCs who lack the ability to understand and communicate health information may have trouble participating in parts of the SDM process, such as understanding the risks and benefits of procedures, which might lead to lower levels of perceived SDM and decisional conflict\textsuperscript{8, 9}. To this purpose we investigated the relation between health literacy and participation of older adults in the SDM process in relation to outcomes as the level of perceived SDM and decisional conflict.

**Anxiety**

The prevalence of anxiety symptoms ranges from 7-58% among older adults\textsuperscript{5, 20}. Anxiety is highly prevalent among older adults with MCCs\textsuperscript{5, 6}. Anxiety is associated with considerable distress, impairment of quality of life, disability, poor health, increased mortality and increased use of health services\textsuperscript{5, 21, 22}. Common anxiety symptoms are nervousness, restlessness, being tense and feelings of danger or panic. In a patient-centred care approach, alleviation of fear and anxiety is seen as an important indicator of quality and safety\textsuperscript{23}. Anxiety may impact cognitive focus, energy and motivation and is expected to affect adults’ willingness and ability to decide to undergo medical treatment, possibly resulting in the exacerbation of illness or incorrect diagnoses\textsuperscript{5}. When there is a high level of anxiety, older adults may not be able to process all relevant information to make the best decision\textsuperscript{24}. Anxiety may leave the patient wanting to surrender decision making to the clinician\textsuperscript{25}. Some studies report that providing knowledge, a common intervention to empower adults, may have a contradictory effect in adults with anxiety\textsuperscript{25-27}. The effect of anxiety on participation in SDM, the perceived level of SDM and decisional conflict is poorly understood, but, we expect that older adults with high levels of anxiety are less likely to participate in SDM which may result in lower perceived levels of SDM and more decisional conflict. To this purpose we investigated the relation between the participation of older adults with anxiety in the SDM process in relation to outcomes such as the level of perceived SDM and decisional conflict.

**Frailty**

Frailty is widely recognized as a common exponent of biological age\textsuperscript{28, 29}. Although a universally accepted definition of frailty is lacking, more recent studies have shifted from a physical definition towards a more multidimensional definition of frailty that includes psychological and social domains\textsuperscript{29, 30}. In this view, frailty can be defined as “a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes.”\textsuperscript{31} It is estimated that approximately 20-30% of
adults over 75 years are frail, and women are at higher risk for frailty than men. Frailty is associated with the loss of functional independence, a higher risk of falling, reduced quality of life and higher hospitalization and mortality. For adults who are frail, balancing the benefits and harms of a treatment is important, since resilience is often low. Treatment choices, such as surgery may have consequences for care giving needs due to, sometimes indefinite, functional loss. Faced with complex health decisions a dialogue about the goals of care and quality of life is of the utmost relevance to frail adults. However, due to their frail condition, frail adults might not be able to participate fully in SDM. When a patient is very ill, their ability to understand information and to participate in decision making is affected. On the other hand, previous experiences of frail older adults in dealing with conditions and decision making acts as a facilitator to participate in SDM. In order to get a better insight into SDM with frail older adults we investigated the relation between the participation of frail older adults in the SDM process in relation to outcomes as the level of perceived SDM and decisional conflict.

**Education**

In general, higher levels of education are often associated with higher preferences for SDM. It is assumed that a higher level of education increases patient confidence to participate in SDM and that higher educated patients are more motivated to participate in SDM. In order to gain more insight into this, we wanted to investigate the actual influence of the educational level of older adults on participation in the SDM process in relation to outcomes such as the level of perceived SDM and decisional conflict.

**Age**

Ageing influences the way and speed with which adults process information regarding their illness and treatment. Health professionals encourage older adults to participate in SDM less often than middle-aged patients and older patients find themselves less assertive when it comes to participating in SDM. Although older adults prefer involvement in their care, they see this involvement more in the relationship and in receiving information than in actual participation in SDM. In this study we investigated the effect of age differences on participation in the SDM process and in relation to outcomes such as the level of perceived SDM and decisional conflict.

**The current study**

To summarize, we discussed the possible influence of the personal characteristics health literacy, anxiety, frailty, education and age on participation in the SDM process and, consequently, the perceived level of SDM and decisional conflict. To address our goals we empirically test which of these personal characteristics contribute to outcomes of SDM and investigate whether participation in the SDM process during consultation can mediate these effects.
Methods

Design
This video observational study with surveys was part of the "Decision making In Complex Old populations (DICO)" study. This study was carried out at geriatric outpatient clinics in two hospitals in Amsterdam, 1) the Academic Medical Center (AMC) and 2) the Medical Centre Slotervaart, a non-academic teaching hospital (MC SLV), between 2016 and 2018. The Institutional Review Board of the AMC waived the requirement to obtain approval for this study (W16_107#16.125, W17_284#17.336).

Participants
The participants in this study were 216 geriatric patients divided in two groups (usual care and intervention) who visited the outpatient clinic of one of the participating hospitals between April 2016 and June 2017 and between Oct 2017 and June 2018. The intervention group received a preparatory tool, and the geriatricians received SDM training. Since there were no significant differences in perceived level of SDM and decisional conflict and participation in SDM between the usual care and the intervention groups, both groups were included in this study (Pel-Littel RE, Buurman BM, van de Pol MH, Twisk JWR, Tulner LR, Minkman MM, et al. Effects of the SDMMCC intervention for older adults with multiple chronic conditions: the DICO study. submitted). The inclusion criteria for this study were: 1) sufficient mastery of the Dutch language, 2) a life expectancy of more than 3 months, and 3) not having a severe stage of dementia (MMSE < 15) according to the medical file. Figure 1 presents the flow chart of the study.

Procedure
Eligible patients were contacted in advance by two research assistants. Interested patients received an information letter with an informed consent form. The consultations of the included patients were video recorded to enable rating by different observers. The observers were not present during the consultation. In addition, data were collected through pre- and post-consultation questionnaires. A research assistant was present in the waiting room to assist with the questionnaires if needed. The geriatricians completed a baseline questionnaire and a short post-consultation questionnaire. Written informed consent was obtained from all participating patients and geriatricians. Further details on the procedure are published elsewhere44, 45.

Measurements
Personal characteristics
The participants background characteristics included age, gender and education.
- Education was divided into the lower educational level (primary school or less), the middle educational level (lower vocational, preparatory secondary vocational, intermediate secondary vocational education, senior secondary vocational and university preparatory vocational education) and the higher educational level (higher vocational education and university).
- Health literacy was measured with the Short Assessment of Health Literacy in Dutch (SAHL-D22)46, 47. Participants were asked to select the correct meaning
Eligible patients assessed (n=1029)

Excluded (n=292)
- Cognitive impairment (n=118)
- Insufficient mastery of Dutch language (n=55)
- Logistic reasons (n=35)
- Double appointments (n=28)
- No response clinician (n=24)
- No permission clinician (n=19)
- No multimorbidity (n=6)
- Other clinician (n=4)
- Compulsory hospitalisation (n=2)
- Patient in palliative care (n=1)

Eligible patients called in first round (n=737)

Excluded after first round of calls (n=410)
- Could not be reached (n=201)
- Too stressful (n=82)
- Cancelled appointment (n=73)
- Not interested (n=37)
- Didn’t want a record (n=9)
- Didn’t received the information letter (n=7)
- Moved to nursing home (n=1)

Interested patients received information letter (n=327)

Excluded after second round of calls (n=111)
- Too stressful (n=43)
- Not interested (n=31)
- Declined to participate in waiting room (n=24)
- Didn’t want a record (n=6)
- No time for participation (n=3)
- Too much pressure (n=2)
- Could not be reached (n=2)

Participants (n=216)

Figure 1. Flowchart of the inclusion
Mediating variable
The level of participation in the SDM process during the consultation was measured with the Observer \textsc{OPTIONMCC} \textsuperscript{57}. The Observer \textsc{OPTIONMCC} was developed to measure triadic decision making in older adults with MCCs. The scale consists of 7 items and measures the competences of geriatricians and the level of participation among older adults with MCCs and their informal caregivers. The items are: 1: Goal talk (identify the discussion partner, identify the patient’s values and the goals of care), 2: Option Talk (explaining that there are more options), 3: Team Talk (Support deliberation, forming a partnership), 4: Option Talk (information about options) 5: Decision Talk (eliciting preferences), 6: Decision Talk (integrating preferences), and 7: Evaluation talk (evaluating the SDM process, preparing the treatment plan). For the current study, we used the mean observer \textsc{OPTIONMCC} patient scores. The level of participation of the patients was rated on three levels: (0) no participation, (1) responsive participation and (2) active participation. The total scores ranged from 0 to 2.

Outcome variables
- The perceived level of SDM was measured with the patient reported experience measure (PREM): CollaboRATE. CollaboRATE assesses three core SDM tasks: (1) explanation about health issues, (2) elicitation of patient preferences and (3) integration of patient preferences into decisions. The responses to each item ranged from 0 (no effort was made) to 9 (every effort was made). CollaboRATE scores are calculated as the proportion of participants who report a score of nine on each of the three CollaboRATE questions\textsuperscript{14, 58, 59}.
- Decisional Conflict was measured with the Decisional Conflict Scale (DCS), a self-administered questionnaire developed by O’Connor et al\textsuperscript{60-62}. The DCS consists of 16 items clustered on 5 subscales: ‘information’, ‘clarification of values’, ‘support’, ‘uncertainty’ and ‘effective decision’. All the items are measured on a 5-point Likert scale\textsuperscript{60}. The answer options on this scale vary from ‘strongly agree’ (0) to ‘strongly disagree’ (4). For this study we used the total DCS score, which varies between 0 (no decisional conflict) and 100 (extremely high decisional conflict)\textsuperscript{60}. A lower total score indicates less decisional conflict. A total score lower than 25 is associated with effectively doing what was decided. A total score greater than 37.5 is associated with decision delay and feeling unsure about the implementation of the decision\textsuperscript{60, 62}.

Statistical analysis
Linear mixed model analyses were used to analyze the relationships among personal characteristics, participation in the SDM process and SDM outcomes (the perceived level of SDM and decisional conflict). First, the relationship of each personal characteristic with participation in the SDM process was analyzed. Second, the relationships among personal characteristics and the SDM outcomes were analyzed. Third, both personal relationships were analyzed with multivariable linear mixed model analyses in which all personal characteristics were analyzed together. Finally, a mediation analysis was performed to evaluate the mediating influence of participation in the SDM process in the relationship between personal...
characteristics and SDM outcomes. All analyses were performed with mixed models to take into account the correlated observations within departments and Stata (version 14) was used for all analyses.

Results

Response
During the study period, 1029 older adults visited one of the two hospitals for a geriatric consultation with a geriatrician of whom 216 (21%) participated in the study (see Figure 1). We found no significant difference in age or gender between the participating patients and the nonresponding patients.

Baseline characteristics
Table 1 summarizes the baseline characteristics of the patients. The mean age of the patients was 77.3 years (SD 7.9). The majority of participating patients were female (56.3%). Of the participating patients, 31 (15.2%) had a low education level. The mean health literacy of the patients was 11.8 (SD 6.9), indicating moderate health literacy levels. The mean frailty score of the patients was 4.3 (SD 2.5), indicating frailty, and the mean STAI-6 score was 11.1 (SD 4.2), indicating a moderate level of anxiety.

<table>
<thead>
<tr>
<th>Table 1. Participant Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 216</td>
</tr>
<tr>
<td>Mean age in years (SD) 77.3 (7.9)</td>
</tr>
<tr>
<td>Female sex (n, %) 120 (56.3)</td>
</tr>
<tr>
<td>Level of education</td>
</tr>
<tr>
<td>Low (n, %) 31 (15.2)</td>
</tr>
<tr>
<td>Middle (n, %) 118 (57.8)</td>
</tr>
<tr>
<td>High (n, %) 55 (27.0)</td>
</tr>
<tr>
<td>Health literacy (SAHL-D22)b (mean, SD) 11.8 (6.9)</td>
</tr>
<tr>
<td>Frailty (GFI)c mean, SD 4.3 (2.5)</td>
</tr>
<tr>
<td>Anxiety (STAI)d pre-consultation 11.1 (4.2)</td>
</tr>
</tbody>
</table>

a n varies slightly due to missing data  
b Health literacy: SAHL-D22 (score 0-22; a higher score indicates higher health literacy)  
c Frailty: GFI (score 0-15; score > 4 indicates frailty)  
d Anxiety: STAI-6 (score 6-24; a higher score indicates more anxiety)

Primary findings
Table 2 shows the relationship between each personal characteristic and observed participation in the SDM process. The multivariable analysis shows that health literacy ($\beta$ .02, $P < .001$) was significantly related to observed participation in the SDM process (mean OPTIONMCC). Although the univariable analysis shows that age ($\beta$ -.01, $P = .03$) was significant related to observed participation in the
SDM process (mean OPTION\textsuperscript{MCC}), this relationship was not significant in the multivariable analysis.

<table>
<thead>
<tr>
<th>Variable</th>
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<th>multivariable analysis\textsuperscript{a}</th>
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<td>(-.33;.17)</td>
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<td>.53</td>
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<td>(-.32;.18)</td>
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<td>p-value</td>
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<td>.60</td>
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<td>(-.25;.36)</td>
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<td>.72</td>
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<tr>
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<td>95% CI</td>
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<td>(-.44;.06)</td>
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<tr>
<td>p-value</td>
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<td>(-.40;.12)</td>
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<td>.30</td>
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<td>(-.16;.31)</td>
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<td>p-value</td>
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<tr>
<td>p-value</td>
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<td>Mean OPTION</td>
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<td>(-.24;.12)</td>
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<tr>
<td>p-value</td>
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<td>.53</td>
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<td>(-.02;.01)</td>
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<td>p-value</td>
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<td>(-.02;.00)</td>
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<td>(-.02;.00)</td>
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<td>-.01</td>
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<td>(-.02;.01)</td>
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<td>(-.01;.01)</td>
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<td>p-value</td>
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<td>OPTION 6</td>
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<td>-.01</td>
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<tr>
<td>95% CI</td>
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<td>(-.02;.01)</td>
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<td>(-.01;.00)</td>
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<td>(.01;.04)</td>
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<tr>
<td>p-value</td>
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<td>(.00;.03)</td>
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<td>.03*</td>
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<td>95% CI</td>
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<td>(.01;.03)</td>
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<tr>
<td>p-value</td>
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<td>.30</td>
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<tr>
<td>OPTION 4</td>
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<td>(.02;.05)</td>
</tr>
<tr>
<td>p-value</td>
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<td>&lt;.001***</td>
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<td>(.02;.05)</td>
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<td>p-value</td>
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<td>&lt;.001***</td>
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<td>(.01;.04)</td>
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<td>(.00;.03)</td>
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<tr>
<td>p-value</td>
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<td>.03*</td>
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<td>Mean OPTION</td>
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<td>95% CI</td>
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<td>(.01;.03)</td>
</tr>
<tr>
<td>p-value</td>
<td>&lt;.001***</td>
<td>&lt;.001***</td>
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</table>
The influence of personal characteristics on the perceived level of SDM and decisional conflict are depicted in Table 3. The multivariable analysis shows that anxiety ($\beta = .26, P = .06$) and education (high education level versus middle and lower education level) ($\beta = .243, P = .05$) had marginally significant effects on the perceived level of SDM, indicating that patients with less anxiety and a lower education perceived the SDM process to be better. Health literacy ($\beta = .01, P = .92$), frailty ($\beta = .25, P = .24$) and age ($\beta = .01, P = .83$) had no significant effect on the perceived level of SDM. Health literacy ($\beta = .70, P = .01$), anxiety ($\beta = 1.19 P < .001$) and education ($\beta = 12.12, P < .001$), had a significant effect on decisional conflict, indicating that patients with lower health literacy, more anxiety and higher education perceived more decisional conflict. Frailty ($\beta = .01, P = .99$) and age ($\beta = .04, P = .83$) had no significant effect on decisional conflict.
### Table 3: The influence of personal characteristics on the perceived level of SDM and decisional conflict

<table>
<thead>
<tr>
<th>Perceived level of SDM&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Univariable analysis</th>
<th>Multivariable analysis&lt;sup&gt;c&lt;/sup&gt;</th>
<th>N&lt;sup&gt;b&lt;/sup&gt;=155</th>
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<tr>
<td></td>
<td>N&lt;sup&gt;d&lt;/sup&gt;</td>
<td>B</td>
<td>95% CI</td>
</tr>
<tr>
<td>Education</td>
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<td>-2.20</td>
<td>(-4.32; -0.09)</td>
</tr>
<tr>
<td>Age</td>
<td>164</td>
<td>.01</td>
<td>(-1.0; 1.12)</td>
</tr>
<tr>
<td>Health literacy</td>
<td>159</td>
<td>-.05</td>
<td>(-1.9; 0.08)</td>
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<tr>
<td>Frailty</td>
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<td>-.38</td>
<td>(-0.75; -0.01)</td>
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<tr>
<td>Anxiety</td>
<td>159</td>
<td>-.32</td>
<td>(-0.56; -0.08)</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Decisional Conflict&lt;sup&gt;e&lt;/sup&gt;</th>
<th>Univariable analysis</th>
<th>Multivariate analysis</th>
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<td>144</td>
<td>4.05</td>
<td>(-3.43; 11.53)</td>
</tr>
<tr>
<td>Age</td>
<td>144</td>
<td>.20</td>
<td>(-1.18; 0.58)</td>
</tr>
<tr>
<td>Health literacy</td>
<td>140</td>
<td>-.47</td>
<td>(-0.91; -0.03)</td>
</tr>
<tr>
<td>Frailty</td>
<td>141</td>
<td>.88</td>
<td>(-2.92; 0.04)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>140</td>
<td>1.29</td>
<td>(0.53; 2.06)</td>
</tr>
</tbody>
</table>

<sup>a</sup> SDM: CollaboRATE % patients that have a T opscore, a higher % indicates a higher level of SDM
<sup>b</sup> N varies due to missing data
<sup>c</sup> Multivariable analysis: multivariable linear mixed model analyses in which all personal characteristics were analyzed together
<sup>d</sup> N for univariable analysis
<sup>e</sup> Decisional Conflict Scale: DCS: (score 0 - 100) a higher score indicates a higher level of decisional conflict

*< .05  
**< .01  
***< .001

Table 4 shows that the effect of health literacy on decisional conflict was mediated by participation in the SDM process. This finding means that the effect of health literacy on decisional conflict partly goes through participation in the SDM process. Table 5 shows that there was no meaningful mediating influence of participation in SDM on the relationship between personal characteristics and the perceived level of SDM.
### Table 4. The mediating influence of participation in the SDM process in the relationship between personal characteristics and decisional conflict

<table>
<thead>
<tr>
<th>Decisional Conflict</th>
<th>Education</th>
<th>Health Literacy</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β</td>
<td>95% CI</td>
<td>p-value</td>
</tr>
<tr>
<td>OPTION 1</td>
<td>12.10</td>
<td>(4.40; 19.80)</td>
<td>.00**</td>
</tr>
<tr>
<td>OPTION 2</td>
<td>11.98</td>
<td>(4.39; 19.57)</td>
<td>.00**</td>
</tr>
<tr>
<td>OPTION 3</td>
<td>12.38</td>
<td>(4.67; 20.09)</td>
<td>.00**</td>
</tr>
<tr>
<td>OPTION 4</td>
<td>11.39</td>
<td>(3.74; 19.03)</td>
<td>.00**</td>
</tr>
<tr>
<td>OPTION 5</td>
<td>11.38</td>
<td>(3.78; 18.98)</td>
<td>.00**</td>
</tr>
<tr>
<td>OPTION 6</td>
<td>11.82</td>
<td>(4.18; 19.47)</td>
<td>.00**</td>
</tr>
<tr>
<td>OPTION 7</td>
<td>12.22</td>
<td>(4.71; 19.72)</td>
<td>.00**</td>
</tr>
<tr>
<td>Mean OPTION</td>
<td>11.71</td>
<td>(4.15; 19.27)</td>
<td>.00**</td>
</tr>
</tbody>
</table>

* < .05
** < .01
*** < .001
Table 5. The mediating influence of participation in the SDM process in the relationship between personal characteristics and the perceived level of SDM

<table>
<thead>
<tr>
<th>Perceived level of SDM</th>
<th>Education</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>β</td>
<td>95% CI</td>
</tr>
<tr>
<td>OPTION 1</td>
<td>-2.15</td>
<td>(-4.34; .04)</td>
</tr>
<tr>
<td>OPTION 2</td>
<td>-2.16</td>
<td>(-4.35; .04)</td>
</tr>
<tr>
<td>OPTION 3</td>
<td>-2.45</td>
<td>(-4.62; -.27)</td>
</tr>
<tr>
<td>OPTION 4</td>
<td>-2.12</td>
<td>(-4.3; .07)</td>
</tr>
<tr>
<td>OPTION 5</td>
<td>-2.17</td>
<td>(-4.37; .03)</td>
</tr>
<tr>
<td>OPTION 6</td>
<td>-2.15</td>
<td>(-4.36; .05)</td>
</tr>
<tr>
<td>OPTION 7</td>
<td>-2.42</td>
<td>(-4.6; .23)</td>
</tr>
<tr>
<td>Mean OPTION</td>
<td>-2.23</td>
<td>(-4.44; -.02)</td>
</tr>
</tbody>
</table>

*<.05  
**<.01  
***<.001

Discussion

The aim of this study was to explore the possible influence of the personal characteristics health literacy, anxiety, frailty, education and age on the perceived level of SDM and decisional conflict and to investigate whether patient participation in the SDM process during a consultation mediates these outcomes. We found that anxiety and education marginally affect the outcomes of SDM as expressed by the perceived level of SDM and that health literacy, anxiety and education affect the outcomes of SDM as expressed by decisional conflict. Although age is not related to these SDM outcomes, higher age leads to less participation in SDM. Furthermore, we found that the effect of health literacy on decisional conflict was mediated by participation in the SDM communication during consultation mediated this effect for health literacy on decisional conflict.

Previous studies have focused on the relation between low health literacy and SDM outcomes regarding the use of decision aids, but comparing the results of these studies is difficult because our research focused on actual participation in the SDM process during a consultation. The reviews by McCafferty et al (2013) and Stacey (2017) et al provide evidence that lower literacy is related to higher decisional conflict in the context of using patient decision aids. Additionally, these reviews indicate that adults with low literacy levels have a lower desire to participate in SDM. By observing how older adults participated in the SDM process, we were able to reveal new insights for older adults with low health literacy. We found that if more participation in the SDM process was observed during the consultation, then it had a positive effect on the level of decisional conflict in older adults with lower levels of health literacy. The interventions described in the literature to promote the perceived level of SDM and to reduce
decision conflict in these specific groups, are characterized by the use of plain language and are concise, simple and tailored\textsuperscript{65}. However, these interventions mainly target patient decision aids, videos and patient training (pre-consultation). Future research should focus on how to improve participation in the SDM process during a consultation to enhance the positive effects on the perceived level of SDM and decisional conflict for older adults with low health literacy. Furthermore, we recommend to assess health literacy before SDM, to enable health professionals to adapt their communication. Although there exist numerous tools to assess health literacy, the challenge is to find short, usable assessment tools for daily clinical practice\textsuperscript{66}. Although there exist numerous tools to assess health literacy, the challenge is to find short, usable assessment tools for daily clinical practice, such as the Single Item Literacy Screener\textsuperscript{66, 67}.

In line with what we expected to find, patients with higher levels of anxiety perceive less SDM and experience more decisional conflict. We found in the literature that adults with anxiety would have more difficulty participating in SDM due to the impact of anxiety on cognitive focus, energy and motivation\textsuperscript{6}. We anticipated, therefore, that anxiety would be related to less participation in SDM, but this hypothesis was not confirmed in our analysis. Further research is needed to explore which components of participation in the SDM process should be addressed to reduce decision conflict and increase perceived levels of SDM among older adults with anxiety.

In the current study we did not find an association between frailty and participation in the SDM process and SDM outcomes. This finding might be explained by to the broad concept of frailty, allowing considerable heterogeneity in the population of frail patients. Furthermore, on the one hand we expected that the experience that frail older adults have of living with chronic conditions would allow them to better express their goals and preferences and thus participate in SDM\textsuperscript{7}. On the other hand the complexity of the situation of frail adults, such as the aspect of MCCs, may hinder their participation in SDM\textsuperscript{68, 69}. This situation might lead to mutually cancelling effects making it seem that there are no effects.

We found in our study that higher education led to less perceived SDM and more decisional conflict. This effect might be explained by the fact that more highly educated older adults are more aware of the complexity of the decisions they face. The literature is ambiguous on this issue. Some studies confirm this relationship\textsuperscript{70}, but other studies report that a higher level of education is associated with higher levels of perceived SDM\textsuperscript{71} and higher decisional conflict. However, these studies targeted other populations, psychiatric patients and younger adults, and thus are not fully comparable to our study. We hypothesized that more highly educated adults would participate more in SDM compared to less educated adults, but we did not find this relation. An explanation for this finding could be that for older adults, the timing of their education is usually decades ago which decreases the effect of education, depending on how one’s life has developed. Since we found a stronger effect of health literacy, this finding may be a more important factor to take into account than education.

Although age was not related to the perceived level of SDM and decision conflict, we found a direct relationship between age and participation in SDM in the univariable analysis. The older people are, the less they participate in
SDM. However, this relationship was not significant in the multivariable analysis, probably due to the relationship between age and health literacy. Additionally, this relationship does not seem to affect SDM outcomes. A possible explanation may be that in many cases, and possibly in more cases when people are very old, the informal caregiver is present during the consultation and may participate in SDM on behalf of the patient. However, we did not further explore these relationships in this study. Few studies focus on the participation of older adults in SDM, and most of these studies focus on preferences for SDM, not on actual participation in SDM, which was the focus of our study. However, Bynum et al (2015) reported on engaging the very old (80+) in decision making and found that very old adults participate to some degree in SDM, and that they “have the potential to be active participants in decision-making.” This process requires skills from health professionals to anticipate the barriers very old adults experience in SDM.

Strengths and limitations
The results of this study must be interpreted in the of some methodological considerations. Although we found no significant differences between participants and non-participants in regard to age and gender, the sample could be biased on other characteristics. Due to the frailty of the patient population and the size of the sample, we were limited in the number of characteristics that could be measured and analyzed. We, therefore, focused on, to our knowledge, the most relevant personal characteristics: health literacy, anxiety, frailty, education and age. However, other characteristics such as emotional wellbeing or gender, may also be associated with SDM outcomes and might be mediated by participation in SDM. In this study we did not analyze whether there was a relation between the type of decision, personal characteristics and participation in SDM. It could be argued that a decision about surgery has other impacts on participation in SDM compared to a decision about a small change in medication regime. Finally, in this study we focused solely on the personal characteristics of older adults. It would be interesting to also study in which way personal characteristics of health professionals influence their participation in SDM.

Conclusion
To our knowledge no similar studies that have found that health literacy, anxiety and education of older adults with MCCs are related with their perceived level of SDM and decisional conflict. By observing how older adults participated in the SDM process, we were able to reveal new insights for older adults with lower health literacy. We found that if more SDM communication takes place in the consultations, then it had a positive effect on the level of decisional conflict for older adults with lower health literacy. Therefore, we recommend performing a health literacy assessment before SDM and that health professionals adapt their communication so that older adults with low health literacy are more empowered to participate in SDM. Further research is recommended for SDM with anxious older people so that they experience less decisional conflict.
References


Chapter 8


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General discussion
Introduction

Shared decision making (SDM) is seen as a promising concept for making decisions that contribute to the desired personal health outcomes of older adults with multiple chronic conditions (MCCs). Personal health outcomes are considered from a broad definition of health, encompassing not only the bodily functions, but also daily functioning, mental functions, social participation, spirituality and quality of life. Although the benefits of SDM for older adults have been described in the literature, the implementation of SDM for older adults with MCCs and their informal caregivers faces several challenges.

In this dissertation we aimed to improve the implementation of SDM in geriatric outpatient clinics for older adults with MCCs and their caregivers and contribute to the scientific body of knowledge about this topic. For this purpose we developed and implemented the SDM\textsuperscript{MCC} intervention, based on the Dynamic model of SDM with frail older patients. Using the framework of the Medical Research Council (MRC) for the development of complex interventions, the SDM\textsuperscript{MCC} intervention was developed and evaluated step by step: (1) development phase, (2) feasibility phase, (3) implementation phase and (4) evaluation phase. By following the steps of this MRC framework, we were able to explore a wide range of methods to answer the research questions as formulated in the introduction. Both qualitative and quantitative methods were used, such as a stratified content analysis, a Delphi design, a systematic literature review, a video observational study, a pragmatic trial and a mediation analysis. This resulted in novel insights about SDM with older adults with MCCs and their informal caregivers.

Research overview

A schematic overview of the research is presented in Figure 1. In the development phase a theoretical basis for the SDM\textsuperscript{MCC} intervention was identified, through a systematic literature review of barriers to and facilitators of SDM as experienced by older adults with MCCs, informal caregivers and health professionals (chapter 2). This was expanded with empirical research in three studies. First, we investigated the personal health priorities for older adults with and without MCCs by analyzing the data from a study on older adults living at home by means of a qualitative content analysis of structured interviews (chapter 3). Secondly, through focus group discussions and surveys, we gained insight into the views of older adults on which and how personal health outcomes should be discussed in health care consultations and we reached consensus on this through a Delphi study (chapter 4). Thirdly, a video observation study among 108 geriatric patients and their informal caregivers at the geriatric outpatient clinic of two hospitals gave us an unique insight into how SDM is operationalized in daily practice. In addition, a measurement instrument, the OPTION\textsuperscript{MCC} was constructed (chapter 5). These studies guided the development of the SDM\textsuperscript{MCC} intervention (chapter 6), which consists of an SDM\textsuperscript{MCC} training for health care professionals and a preparatory tool for older adults and informal caregivers. In the feasibility phase the prototypes of the SDM\textsuperscript{MCC} training for health care professionals and the preparatory tool for older adults and informal caregivers were pilot tested with end-users: health care professionals, older adults and their informal caregivers. The implementation
A phase was conducted at the geriatric outpatient clinic of the two hospitals. The training was provided to geriatricians and the preparatory tool was sent to older adults with MCCs and their informal caregivers that were scheduled for a visit to the geriatrician in a selected period. The evaluation phase (chapter 7) consisted of a second clinical video observational study, in which SDM was measured by the newly constructed OPTIONMCC and compared to the ‘care as usual’ as measured in the first video observational study. Finally, by analysing the data of the two video observational studies, the relationship between personal characteristics of older adults with MCCs on participation in SDM and outcomes of SDM was explored (chapter 8). In the following sections, each study is briefly introduced, the main findings are presented and placed in context and methodological considerations and implications for future research are discussed. This chapter ends with an update on Phase V: Upscaling in which the long term implementation of the SDM\textsuperscript{MCC} intervention is described.

**Figure 2.** Overview of the phases of the Medical Research Council Framework that was used to answer the research questions.
Presentation and discussion of main findings

Phase I: Identifying existing evidence

Research question 1: What are the experienced barriers to and facilitators of SDM with older adults with MCCs?
SDM is not yet common practice, it is estimated that in only 10% of the situations in which health decisions are made SDM is used. Both health professionals, older adults and informal caregivers experience barriers in making shared decisions. Although in previous reviews barriers to and facilitators of SDM in general are explored, we expected that for older adults with MCCs additional barriers and facilitators might be found. These insights could support the implementation of SDM for older adults with MCCs.

Research
Therefore, we conducted a systematic literature review to identify the experienced facilitators of and barriers to SDM with older adults with MCCs, from the perspective of older adults, informal caregivers and health professionals (chapter 2).

We found in our review that personal characteristics, such as poor health and/or cognitive or physical impairments can form a barrier for older adults to participate in SDM. By contrast, when an older adult shares information about his/her personal priorities for health outcomes, this facilitates the SDM process. However, older adults need an explicit invitation to share personal information and preferences, since they often undervalue the importance of their own expertise. Also, many older adults state that living with MCCs gives them a lot of experience in how they cope with situations, what they prefer and what to expect from health care.

Most older adults with MCCs would like to have their informal caregiver involved in the SDM process and also informal caregivers themselves would like to participate in SDM. Informal caregivers can facilitate SDM by helping older adults with decision support, although informal caregivers can also complicate the SDM process, for example when they have a different view on the treatment or the older adult’s ability to be involved.

Health professionals can facilitate the SDM process when they tailor their information to the needs and capacities of the individual older adults and when they probe patient priorities. Also they can encourage informal caregivers to participate in SDM. Furthermore, in the case of care for older adults with MCCs there are often more professionals involved; a good coordination of care facilitates SDM. Barriers to SDM as experienced by health professionals are mostly about organizational constraints, such as time pressure or a high turnover of patients.

Findings in context
Some of the barriers and facilitators we found in our review are similar to other reviews not specifically focusing on older adults with MCCs, such as patients undervaluing their own expertise and thus the need to be explicitly invited to SDM. Our review adds to the existing knowledge with the finding that the experience of older adults living with MCCs, in fact enables them better to express their priorities.
compared to persons who are confronted with a disease for the first time. For example, an older adult who has been living with rheumatoid arthritis for over ten years, probably knows very well how to balance activity and rest compared to someone who has just been diagnosed with this disease.

Although the role of the informal caregiver was long underexposed in SDM literature, we were able to include some very recent studies which delineated a more detailed image of the participation of informal caregivers. We found that although informal caregivers are often the main caregivers for older adults with MCCs, they are often not seen as part of the team by health professionals. Yet, taking on the informal caregivers as ‘part of the team’ can be very challenging as there may be different views between informal caregivers and health professionals or conflicting views between informal caregivers and older adults. Furthermore, it can be very complex for informal caregivers to on the one hand act as a representative of the older adult while they have on the other hand own views and priorities that may differ from that of the older adult. Health professionals must take into account this potential complexity and try to respect both parties.

Finally, the organization barriers as experienced by health professionals echo other research findings, even though we found that health professionals perceive that more time is needed to build a trustful relationship with older adults in complex situations.

Methodological considerations and implications for future research
Although our review aimed to explore barriers to and facilitators of SDM among various type of health professionals, the majority of available literature described SDM for clinicians. However, in the care for older adults with MCCs there often are more than one health professional involved, such as nurses, physiotherapists, occupational therapists, dieticians, etc. Our findings may also be applicable to those health professionals. Yet, they often work in a different context (e.g. home care) and often have long standing relationships with their patients, which may affect the SDM process in various ways. ‘Knowing your patient’ is an important facilitator for SDM, but on the other hand, long-term relationships can cause health professionals to assume too much about the patient’s preferences. Research is needed about how SDM can be facilitated for these health professionals and their patients. Furthermore, research is needed to gain more detailed knowledge on how to empower informal caregivers in SDM. Informal caregivers feel uncomfortable when, in the conversation with the geriatrician, for instance when the older adult does not recognize the cognitive decline and its impact on daily life. Informal caregivers are often torn between loyalty and support for their beloved one and the burden they experience. Some geriatric clinics work with a hetero anamnesis, a separate conversation with the informal caregiver, in which they can speak freely. It is worthwhile to explore how a hetero anamnesis can facilitate the SDM process for informal caregivers.

Recommendations
The recommendation based on this literature review is to explicitly invite older adults to participate in shared decision making, and to emphasize that their knowledge and experience of their personal situation is important to bring into the conversation. As a result, health professionals are better able to propose
treatment options that fit the personal situation and preferences of patients. Informal caregivers should be made aware that they can make a significant contribution to the decision making process. More attention should also be paid to the complexity of the role of informal caregivers.

**Phase I: Gathering additional evidence**

**Research question 2: What are views of older adults with MCCs on personal health outcomes?**

Although SDM has several steps, in this dissertation we highlighted an underexposed step in many models: the discussion of personal health outcomes (chapters 3 and 4). For health professionals this means a significant change, from a disease-oriented approach to a personal health outcome-oriented approach. Knowledge about a range of topics that older adults consider important regarding their situation facilitates health professionals in starting the discussion about personal health outcomes and priorities with their older patients.

**Research**

To this aim we investigated the personal health priorities for older adults by performing a stratified content analysis on existing data from a study about older adults living at home (chapter 3). Our findings showed that regarding personal health priorities, older adults with MCCs often deal with the acceptance of aging and the associated deterioration. They are concerned about further limitations and social contacts, such as family. Regarding healthy aging, they feel it is important for them to have a healthy lifestyle, to keep busy, to maintain social contacts and to have a positive attitude. Older adults with and without multiple chronic conditions often mentioned the same issues when it came to ageing but an important difference was that older adults with multiple chronic conditions were more worried, looked more negatively to the future and were especially afraid of further physical decline and limitations.

**Findings in context**

Our research gives meaning to the ‘Action Steps for decision making for older adults with MCCs’, that emphasizes to start with identifying and communicating patients priorities regarding personal health outcomes⁷. Although older adults vary in whether they want and are able to participate in SDM, discussing preferred health outcomes is relevant for all older adults, regardless of who makes the decision⁸, ¹⁷-¹⁹. Tinetti (2019) found that working according to patients priorities in personal health outcomes led to less treatment burden and less unwanted healthcare²⁰. They also reported that initial fear among physicians that older adults would formulate unrealistic goals was unjustified; if older adults were guided through the SDM process, they formulated personal and realistic goals. This was confirmed by the study of Feder (2019) who also found that discussing personal goals led to a better relationship with physicians⁷. Our research facilitates the discussion of health outcomes goals by identifying a range of topics that many older adults find important in relation to their situation. Since we found that older adults with and without MCCs mostly share the same views on aging, our results
seem to apply to all older adults. However, health professionals should address the fact that older adults with MCCs have more concerns and more negative future expectations, in particular about further physical decline and limitations.

**Methodological considerations and implications for future research**

Our stratified content analysis provided insight in the views on aging of more than 500 older adults. The questions that had been used to gather the data could have been more specific about preferred personal health outcomes. Following their previous research on goals setting for older adults with MCCs in SDM, Elwyn and Vermunt (2019) recently proposed an integrated, goal-based SDM model using a Goal Board to prioritize collaborative goals and align goals with interventional options. This model describes three goal levels: fundamental, functional and symptomatic. Fundamental goals are about what people hope for in life, or are afraid of. Functional goals address the activities one wants to be able to do or to carry on doing. Symptom or disease specific goals concern the symptoms of disease someone wants to change, for example less pain. For future research it is interesting to explore how this Goal Board could be used. For example, we are currently exploring whether the patient preparatory tool could be adapted to support older adults thinking about their goals on these different levels. Also, we are exploring if this goal-based SDM model could be integrated with the 'Dynamic model of SDM for frail older patients'.

**Recommendations**

Based on this research, we recommend discussing with older adults what is important to them personally for their quality of life and what they are most concerned about. In this way health professionals can together with the older adults come to goals regarding personal health outcomes and discuss what (treatment or support) possibilities there are to achieve these goals.

**Research question 3: Which patient reported health outcomes (PRO’s) should be discussed in health care conversations according to older adults with MCCs?**

Patient Reported Outcome Measurements (PROMs) are questionnaires that provide information about a patients personal experience of his situation. Since PROMs could facilitate the discussion of personal health outcomes, we explored to which extent the TOPICS-MDS, a PROM used in Dutch geriatric care, covers the health domains which older adults value as important (chapter 3).

**Research**

We conducted a Delphi study in combination with focus group discussions and gained insight into the views of older adults with different education levels and different cultural backgrounds on which and how personal health outcomes should be discussed in health care consultations. We found that older adults agreed with all the domains addressed in the TOPICS-MDS: ‘functional limitations’, ‘emotional wellbeing’, ‘social functioning’ and ‘quality of life’. In addition, older adults also would like to discuss ‘coping with stress’ and ‘dealing with health conditions and the effects on life’. Furthermore, they provided recommendations on how to
adjust the TOPICS-MDS questionnaire to improve the comprehensibility of the questions.

Findings in context
The domains identified were in line with the findings of previous studies, including our study on views of older adults on personal health outcomes. For example, the importance of discussing functional limitations in health care communication has also been described in other studies on outcomes important for older adults¹⁹-²⁴. Furthermore, older adults stressed the importance of a trustworthy relationship between the healthcare professional and the older adult when discussing emotional well-being. These findings support the results of the study by Ridd et al (2009), who found that a long-term relationship and continuity of care are important when discussing sensitive subjects²⁵. As to the two additional domains recommended by older adults (‘coping with stress’ and ‘coping with health problems and the effects on life’) it is worth exploring whether the Brief Resilience Scale to assess a person’s resilience, defined as ‘the ability to bounce back and recover from stress’, could be added to the TOPICS-MDS²⁶. Our research provides evidence that the TOPICS-MDS is usable as a PROM to provide input for the discussion of personal health outcomes because it contains the health domains older people would like to discuss with the care professional. What is notable is that in addition to the domains already included in TOPICS-MDS, older people are particularly concerned about the impact of their health condition(s) on their daily lives.

Methodological considerations and implications for future research
By involving older adults in assessing the domains, we added value to the use of the TOPICS-MDS as a PROM. Although using focus groups within a Delphi design is not common (because of prevention of response bias), it enabled older adults with a low level of education and a culturally diverse background to express their views. The older adults in our groups with a culturally diverse background or a low level of education emphasized more than the older adults with a high level of education the importance of discussing all health domains with health professionals. The results of previous studies support our idea that in the Netherlands these groups make more frequent use of health care resources, and generally have more chronic conditions than older adults with a high level of education²⁷, ²⁸. This could mean that through frequent contact with health care providers, people feel more confident when discussing different areas of health. Recently the TOPICS-MDS has been adapted to a short-form (TOPICS-SF) version whilst maintaining the domains as indicated by the older adults. The TOPICS-SF which is now increasingly used as a PROM in Dutch geriatric care. The next challenge is to connect the use of a PROM into the SDM process. We are currently exploring how this can be facilitated and in particular how the additional domains can be addressed in the preparation for the SDM conversation.

Recommendations
The TOPICS-MDS, or preferably the short version (TOPICS-SF), when completed by older adults with MCCs, gives an overview of the current status of an older person regarding personal health outcomes that most older adults consider important.
The TOPICS-SF provides input for the ‘goal talk’, step 2 of the ‘Dynamic model of SDM in frail older patients’. However, it is important that health professionals ask older adults what the score on a personal health outcome means to them, for example: ‘I see in the TOPICS-SF that you have a few social contacts, how important are social contacts for you?’ This is a necessary step to come to goals on personal health outcomes. The Dutch Association of Clinical Geriatricians (NVKG) has recommended that an abbreviated version of the questionnaire, the TOPICS-Short Form (SF), be used in all Geriatric departments in the Netherlands. The NVKG particularly emphasizes the added value of the questionnaire if it is used for shared decision making with older adults in health care conversations. The questionnaire can be freely downloaded from www.topics-mds.eu.

**Research question 4: How can we measure observed SDM during consultations with older adults, their informal caregivers and health professionals, based on the steps of the ‘Dynamic model of SDM with frail older adults?’**

As a final step the development phase of the MRC framework, in which we gathered additional evidence, we explored whether, and if so, how SDM for older adults with MCCs is applied in daily practice. To this aim we conducted a video observational study: the Decision making In Complex Older populations (DICO I) study in two outpatient geriatric clinics of two Dutch hospitals.

Since we wanted in particular be able to observe the discussion of patient priorities regarding personal health outcomes as start of the SDM process, in other words: ‘goal setting’, we searched for an SDM model and measurement instrument that addressed these aspects. As explained before, the ‘Dynamic model of SDM in frail older patients’ explicitly describes goal setting in older adults with MCCs and thus proved to be a promising model to build our research on. Furthermore, SDM for older adults is a process that involves not only health professionals and older adults, but often also their informal caregivers. Although there are several patient-reported measurement instruments, to our knowledge there were no instruments that measured observed SDM, as demonstrated by health professionals, older adults and their informal caregivers. To address these issues, we developed an observation instrument.

**Research**

To be able to measure the level of SDM in daily practice, we developed and tested the observed OPTION\textsuperscript{MCC}, an observation instrument that builds on the existing Observer OPTION 5, but has been expanded to address issues in SDM that are specific to older adults with MCCs and incorporates the perspectives of geriatricians, older adults and informal caregivers (chapter 5). Based on our video observational study with 108 geriatric patients, 68 informal caregivers and 10 geriatricians we concluded that Observer OPTION\textsuperscript{MCC} seems sufficiently reliable for the assessment of triadic SDM for older adults with MCCs, their informal caregivers and geriatricians. The scores on the Observer OPTION\textsuperscript{MCC} showed that geriatricians apply SDM more compared to other specialists (39.9 versus 23, range 0 – 100), but the relative low scores show that there is still room for improvement. Also, the geriatricians in our study had more time
for their consultations compared to other specialists (average time 40.3 versus 13 minutes). Observer OPTIONMCC scores regarding participation of patients and informal caregivers in SDM (resp. 1.05 and 1.04, range 0 - 2), indicated a responsive level of participation (passive- responsive- active).

Findings in context
We built on the Observer OPTION 5 to develop the Observer OPTIONMCC. Kunneman et al (2019) conclude in their review that although there are over 40 instruments to measure SDM, the ‘discussion of patient priorities is underrepresented in SDM observer measurement instruments’. With the Observer OPTIONMCC we developed an instrument that clearly addresses the ‘discussion of patient priorities’ in SDM. The choice for the Observer OPTION 5 was supported by the review of Kunneman et al (2019) who stated that the four key elements of SDM: offering choice, discussing options and pros and cons, discussing views and priorities and making the decision, are best measured through the OPTION 5 and the DSAT. However, a reflection is needed on the effect of introducing new SDM steps (goal talk, evaluation talk) on an observation instrument. The Observer OPTIONMCC was constructed to measure a formative construct of SDM, while it is assumed that better performance on one item (e.g. goal talk) will automatically lead to better performance on other items (e.g. team talk). However, our findings show that a better performance on one item can go hand in hand with a worse performance on another item. In their reflection on the OPTIONMCC, Pieterse et al (2019) already suggested that the underlying relationship between the items and the construction we are measuring should perhaps be reconsidered; should SDM be measured through a reflective model (items are mutual interdependent) or a formative model (the items are independent from each other), in other words, how do the SDM items relate to each other?

Although there exist measurement instruments that measure patient and informal participation, items to score this do not distinguish between patients and informal caregivers. A strong advantage of the Observer OPTIONMCC is that we developed items to measure the participation of each party separately.

Methodological considerations and implications for future research
Although most health professionals favor SDM, many researchers warn that health professionals overestimate their own SDM skills. Therefore, we chose to make video recordings of real life consultations between geriatricians and older adults and informal caregivers to get insight in SDM in daily practice. The video-images enabled us to differentiate more clearly who was talking (e.g. difference between an older female patient and her female informal caregiver) and also to see nonverbal communication (smiling, nodding, tearful).

We encountered three issues that complicated rating of SDM with the Observer OPTIONMCC. First, we scored the patient and informal caregivers’ participation on three levels: no participation, responsive participation and active participation (0-2). Although this was a feasible way to rate their participation, it prevented us from calculating a composite end score on the Observer OPTIONMCC, since the scores of geriatricians have a different range (0-4). We suggest that future studies with the Observer OPTIONMCC should considering recalculating the patient and informal caregiver item scores to a 0-4 range, so that a total triadic
Observer OPTION MCC score can be calculated. Second, the multitude of problems that were discussed in a consultation made it difficult to complete a measurement scale that is designed for taking one decision. We compensated for this by asking the geriatrician what in his/her opinion was the most important problem discussed and focused our observations on this problem, but this excluded SDM observations on other problems, which could also be important.

Third, the observer OPTION MCC is a verbal instrument, e.g. in line with the scoring manual of the Observer OPTION 5, we scored on spoken language, on phrases demonstrating SDM skills. However, watching the video recordings of consultations, we noticed that there are non-verbal communicative skills that contribute to the SDM, such as empathic nodding, humming, listening, smiling etc. Those skills could not be scored with the Observer OPTION MCC, but we think they do contribute to SDM, for example by encouraging older adults to share their views. Future research could explore how this behavior should be assessed in the context of SDM and whether the Observer OPTION MCC should be further developed for measuring non-verbal signals.

**Recommendations**

The added value of the Observer OPTION MCC compared to existing measuring instruments for observing shared decision making is the measurement of discussing the personal goals of the older adult and the explicit measurement of the participation of the older adults and his or her informal caregivers in the shared decision making process. Therefore we recommend the Observer OPTION MCC for measuring SDM among older adults with MCCs. The Observer OPTION MCC can be freely downloaded via various websites (www.healthcommunication.nl, www.vilans.nl) and has been added to an international website where the various OPTION measuring instruments can be downloaded: www.glynelwyn.com.

**Phase II: Feasibility and Phase III: Implementation**

**Research question 5: Which theory- and evidence-based intervention can be developed, pilot-tested and implemented to improve the implementation of the ‘Dynamic model of SDM with frail older adults’**

The results of the previous chapters of this dissertation guided the development of the SDM MCC intervention (chapter 6) through the following recommendations:

- Use the ‘Dynamic model of SDM with frail older patients’ to guide the SDM process, and within this model the intervention specifically focused on:
  - an explicit invitation by the health professional to participate in SDM
  - appraisal of personal experiences of patients
  - discussion about personal goals that contribute to quality of life (‘what matters most to you’)
  - a trustful relationship
Research
The SDM\textsuperscript{MCC} intervention was systematically designed based on both theoretical and empirical evidence and consists of an SDM\textsuperscript{MCC} training for geriatricians and a preparatory tool for older adults and informal caregivers. Through the process of co-creating with the end users both products were tailored to the specific needs of older adults and geriatricians. The design of the training was presented in two consecutive rounds to 11 geriatricians working at various locations in the Netherlands (but not in AMC or MC Slotervaart). With the feedback of these geriatricians the final training was established. The training was given to four geriatricians in the AMC and five geriatricians in the MC Slotervaart. Key elements of the training for geriatricians in SDM\textsuperscript{MCC} include the exploration of personal attitude, knowledge and current use of SDM. Furthermore the 6-step SDM\textsuperscript{MCC} model was explained and practiced. The geriatricians gave the training an average grade of 8 (range 0-10). They indicated that they had learned to apply the steps of SDM and that they were particularly aware of the importance of discussing goals. The preparatory tool was submitted in three consecutive rounds to a total of ten elderly and informal caregivers and two geriatricians before it was finalized. The preparatory tool was sent to 108 geriatric patients who wanted to participate in the study and had an appointment at the geriatric outpatient clinic of the two participating hospitals. Key elements of the preparatory tool for older adults include an explicit invitation to participate in SDM, appreciation of older adults’ own knowledge and exploring possible goals. Finally, the concerns of informal caregivers are addressed by recognizing partnership and inquiring about the potential burden of informal care. Two third of the older adults and informal caregivers who had filled in the leaflet thought it was a good and informative leaflet.

Findings in context
With the development of the SDM\textsuperscript{MCC} intervention we provide guidance to what is needed for the support of SDM according to the ‘Dynamic model of SDM for frail older patients’. It connects to the increasing awareness of the need to explore personal goals in SDM in recent literature\textsuperscript{4, 33, 34}. For example, Vermunt and Elwyn (2017, 2018) make a strong plea for setting personal goals in the context of SDM\textsuperscript{35, 36}. The SDM\textsuperscript{MCC} intervention focuses on triadic decision-making by including the role of informal carers and is in line with recent literature that emphasizes the role of informal carers of older adults in the SDM process\textsuperscript{37-41}. 

- active involvement of informal caregivers and recognition of the potential burden of informal care
- forming a partnership between geriatrician, patient and informal caregiver
- reflecting on the decision making process, including making a treatment plan
- health professionals should tailor their information to a patients individual capacities and needs
Methodological considerations and implications for future research
Working according to the MRC framework for developing complex interventions led to a solid evidence base for what is needed to implement SDM for older adults with MCCs. Although we developed the intervention in co-creation with end users (older adults and geriatricians), the intervention was tailored to the general needs of geriatricians and older adults, and one size may not fit all. Further improvements on the SDM\textsuperscript{MCC} intervention could focus on a better connection to a person’s individual skills and needs, e.g. with regard to the skills needed to involve the older adult as a genuine partner in the SDM. For future research it would be interesting to study if the SDM\textsuperscript{MCC} training for geriatricians could be aligned to build on the geriatrician’s individual existing SDM skills and tailored to the specific skills that are lacking. Also, as shown by Nguyen et al (2018) the possibility to self-tailor the mode of the information presentation in patient tools (text, illustrations, video) may result in a patient preparation tool that is better in line with an individual person’s needs\textsuperscript{42}. As a result the patient preparatory tool might connect even better to older adults with a low level of education, cognitive decline or a culturally diverse background.

Recommendations
Based on this research, we can conclude that the SDM\textsuperscript{MCC} intervention, consisting of a training course for geriatric patients and a preparation instrument for patients, is feasible for use in daily practice.

Phase IV: Evaluation

Research question 6: What are the effects of an evidence based intervention, based on the steps of the ‘Dynamic model of SDM with frail older adults’, to improve the implementation of SDM for older adults with MCCs?
After implementing the SDM\textsuperscript{MCC} intervention, we investigated how effective the intervention was in terms of observed and perceived SDM in the care of older adults with MCCs (chapter 8).

Research
To this aim we conducted a second video observation study (DICO II) among 108 geriatric patients, 65 informal caregivers and 9 geriatricians (the same geriatricians as in the DICO I study). We studied if, compared to the first video observation study (DICO I) there were changes in observed SDM with OPTION\textsuperscript{MCC} during video recorded consultations and in patient and informal caregivers reported outcomes regarding patient participation, perceived SDM and decisional conflict. We found significant improvements on four item scores on the Observer OPTION\textsuperscript{MCC}, as well as significant decreases on two other item scores. On average, the combination of improvement on some items and deterioration on others did not lead to improvement, i.e. the total score on the OPTION\textsuperscript{MCC} did not show a significant difference after the implementation of the SDM\textsuperscript{MCC} intervention. On item level, 6 out of 7 items showed significant changes. The SDM items ‘eliciting goals’, ‘discussing pros and cons of options’ and ‘eliciting priorities of options’
and ‘deciding together’, significantly improved after the intervention. Oppositely, the scores on SDM items ‘forming a partnership’ and ‘evaluation of decision’ decreased significantly. One geriatrician with a lower score had a strongly deviating score (-17.3) compared to the other eight geriatricians. When we considered this as an outlier, a subgroup analysis of the remaining 8 geriatricians revealed a significant positive effect on the overall OPTIONMCC mean scores after the intervention. This indicates that a good implementation is important. The scores of the patients and informal caregivers on the observer OPTIONMCC were mostly in the same line as the score of the geriatricians, indicating that if a geriatrician scored high on an item, patients and informal caregivers usually also scored high on that item. Furthermore, there was a great variety within the group of participating geriatricians in how much SDM was observed after the intervention, compared to usual care. There were no significant changes on patient reported SDM outcomes. Finally, although completed in 51.9% of the cases, the preparatory tool was rarely discussed during consultations (12%), which may have biased the effect of the SDM intervention.

**Findings in context**
The level of SDM as demonstrated by the geriatricians in our study was higher (39.7<>39.3, scale 0-100) both before and after the intervention compared to observer OPTION scores in other studies. Couet et al (2014) found an average OPTION-12 score of 23 (0-100) in a review of 33 studies (mainly among general practitioners) using OPTION-12. However, it must be noted that the mean consultation time of the geriatricians in our study extended that of the studies in this review (39 <> 13 minutes), providing more opportunities to demonstrate SDM skills. This initial high SDM score might also explain why the improvement in our study is limited. There might be some explanations for our findings. First, our findings are echoed by other studies that urge to pay attention to scores on individual items, to discover SDM effects that are diluted by total mean scores. Furthermore, there was a wide range in individual geriatrician scores. Although the SDM training was tailored to the general needs of a geriatrician, we conclude (as for many interventions) in SDM one size does not fit all, and this applies to both geriatricians as well as older adults and informal caregivers. Additionally, almost 30% of the participating older adults did not remember receiving the paper preparatory tool and subsequently had not used it. Since the Dutch mail is very reliable, the cognitive problems that were present in almost half of the participating older adults may have been the cause of this. In addition, it must be noted that the older adults received more information, e.g. an information letter about the study and informed consent form, this multitude of information may have distracted the attention for the preparatory tool. Second, the older adults did not initiate the discussion about the preparatory tool by themselves. When the preparatory tool was discussed, this was always at the initiative of the geriatrician. The preparatory tool was completed by 56 patient, but only with 11 patients the findings of the tool were discussed in the consultation. We might have overestimated that geriatricians would bring it up for discussion. The use of a preparatory tools may even cause reverse effects when this is not endorsed by the physician. Finally, although in the training for geriatricians we focused on discussing personal goals, we underestimated that working according to this...
Chapter 9

SDM model, requires a behavioral shift from geriatricians in how to structure the consultation. Geriatricians that are used to start a consultation by inquiring about symptoms and problems, are expected to shift to start by discussing personal health outcomes, facilitated by the preparatory tool. Although SDM for older adults with MCCs meets many challenges due to the complexity of their situation, our study revealed a high level of observed SDM, demonstrated by geriatricians, older adults and informal caregivers in geriatric consultations. However, it also provides several issues that can be improved to facilitate further implementation of SDM.

Methodological considerations and implications for future research

Although geriatricians seem to demonstrate higher SDM skills compared to other clinicians, it might be questioned why overall scores on the OPTION instruments are still very far from reaching a top score of 100. On the one hand one could argue that future training should focus more on the items that showed a low score, such as ‘team talk’ and ‘evaluation’. On the other hand we might have to rethink if all items should bear the same weight, or that for example key items in the Dynamic Model such as ‘goal talk’ should gain more weight in relation to other items, such as evaluation of the SDM process.

Secondly, the issue must be addressed how the use of the preparatory tool can be improved, both in terms of patient preparation and in terms of bringing the tool up into the discussion. The patient preparatory tool could be made available in different versions, e.g. tailored to lower health literacy levels and both in a written as well as a digital version.

Finally, we conducted a pragmatic trial to study the effect of the SDM MCC intervention. The advantage of a pragmatic trial is that the usability of an intervention in real life is tested. This maximizes the applicability and generalizability of the results. Previous studies show that combined interventions (e.g. provider training combined with patient preparatory tools) are more effective compared to studies with a single intervention, the disadvantage of implementing a two-sided intervention in a non-blinded pragmatic trial, is that we have no information about which elements have which effect. Furthermore, since the intervention group was monitored almost a year after the usual care group, this might have caused bias due to external influences, such as an increased awareness of SDM in hospitals and in society. Also the non-blinded character of the study may have caused bias, as both the geriatricians and the patients were aware of the interventions (training and preparatory tool). Although the use of this design has given us several clues to a long term implementation, another research design, such as an RCT with a before-after design and a treatment and control arm, could have provided more information on the effectiveness of the different components of the intervention. Also, when using a multi-centre design, the condition of blinding could be met. Prevention of researcher bias was prevented by using a fourth, blinded, observer to assess a mixed sample of the video recorded consultations of both (DICO I and II) studies.

Recommendations

Based on this research we recommend that the SDM MCC intervention can be used to facilitate the discussion of personal health outcomes through SDM in geriatric
consultations. However, the SDM\textsuperscript{MCC} needs further development regarding several aspects of the SDM\textsuperscript{MCC} training (‘team talk’ and ‘evaluation’) and regarding the implementation of the patient preparatory tool in the consultations.

**Research question 7: Which personal characteristics of older adults with MCCs influence the participation in SDM and the outcomes of SDM?**

In our literature review we learned that personal characteristics of older adults with MCCs may hamper the participation in SDM. In order to facilitate health professionals in engaging older adults with MCCs in SDM, we need to gain a more detailed understanding of which characteristics influence participation of older adults in SDM, the experienced shared decision making afterwards and the experienced (un)certainty about a decision taken.

**Research**

To this aim, we analyzed the data from both the first and second video observation study (DICO I and DICO II study) to gain insight into the influence of personal characteristics of older adults, such as education, anxiety and health literacy, on the perceived level of SDM and decisional conflict (chapter 8). Perceived level of SDM refers to how the patients have experienced SDM. Decision conflict is defined as ‘personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values’. We investigated whether SDM communication during the consultation could have a mediating effect for these characteristics on the perceived level of SDM and decisional conflict and built a model for this. Results showed that a lower education level and less anxiety are associated with higher perceived SDM. Higher education, lower health literacy and more anxiety were associated with more decisional conflict. Regarding the mediator, higher age and lower health literacy were related to less participation in SDM. For older adults with lower health literacy, increased participation in SDM process reduced decisional conflict. Thus, decisional conflict is mediated by participation in SDM in older adults with lower health literacy.

**Findings in context**

To our knowledge there are no similar studies that have analyzed the influence of education, anxiety and health literacy on the perceived level of SDM and decisional conflict. By observing how older adults participated in the actual SDM, we were able to reveal new insights for older adults with lower health literacy. We found that if more SDM communication takes place in the consultations, this has a positive effect on the level of decisional conflict for older adults with a lower level of health literacy. The review of Durand (2014) suggested that SDM interventions tailored to socially disadvantaged groups (e.g. poverty, ethnic minority status, lower health literacy, living in poorer areas) benefit participation in decision making and reduce decisional conflict. Those interventions were characterized by the use of plain language and were concise, simple and tailored to these specific groups. However, most interventions consisted of training of patients, patient decision aids and the use of videos. Although very few interventions in this review focused on decision
participation during the consultation, the characteristics as describe above are also likely to apply well to enhancing decision participation during the consultation. An explanation for the lower levels of perceived SDM and more decisional conflict among higher educated older adults may be that higher educated older adults are more aware of the complexity of the decisions they face. When they are better involved as partners in the decision making, for example in the exploration of health outcomes, when the options are presented more clearly and benefits and harms of the options are explained, this SDM communication was expected to have a positive effect on the perceived level of SDM and decisional conflict.

In addition, current SDM communication does not seem to benefit older adults with high levels of anxiety in terms of perceived level of SDM. Further research should focus on what is needed to increase the perceived level of SDM and decrease decisional conflict for these groups.

Methodological considerations and implications for future research
Due to the frail character of the population we were limited in the number of personal characteristics we could study in relation to the perceived level of SDM and decisional conflict. Future research might add other characteristics to this research question, for example emotional wellbeing. We were able to observe patient participation in the SDM communication with the observer OPTIONMCC. Since we focused on patient communication, we choose to use the patient OPTIONMCC score. However, for future research it could add value if an integrated OPTIONMCC score could be used.

Recommendations
The results of this study support the findings from the literature review (chapter 2) that it is important to adapt SDM communication to the personal characteristics of older adults, for example by using plain language, be concise and the use of teach-back methods51. This is especially true for older adults with lower health literacy. If it is possible to involve them better in the shared decision making process, this has a positive effect on the outcomes, especially decision conflict. Furthermore, we recommend to assess health literacy before SDM, to enable health professionals to adapt their communication. Although there exist numerous tools to assess health literacy, the challenge is to find short, usable assessment tools for daily clinical practice52. Although the Short Assessment of Health Literacy (SAHL) tool used in our study is a valid and reliable tool, it took the geriatric patients in our study quite some time to complete the 22 questions, which makes which makes it less usable for clinical practice. A single question tool to assess health literacy that could be further explored for this purpose is the Single Item Literacy Screener (SILS): “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?”53. Although this instrument targets reading ability, which is only one the elements of health literacy, we could study the validity of the SILS for clinical purposes.
General reflections

A research focus on implementation of SDM in the care for older adults with MCCs

Although there is increasing attention on SDM as a facilitator for person centered care, the implementation of SDM stays behind\textsuperscript{54, 55}. In 2016 ZonMw, the Netherlands Organization for Health Research and Development, plead for more focus on implementation of SDM in daily practice. This guided our choices for a pragmatic trial, for study designs focusing on the views and experiences of older adults, for developing implementation interventions and for a design with video observations in daily practice. We did not want to start from scratch but aimed to build on existing work, such as the ‘Dynamic model for SDM in frail older patients’, existing SDM trainings and existing patient preparatory tools. Although we gained knowledge about what is needed for the implementation, the actual implementation can be further improved. Changing daily practice requires also support on changing behavior of health professionals, for example how to change established routines in the structure of a consultation. Shifting from ‘what are your problems’ to ‘what matters to you most’ is a major change not to be underestimated, as geriatricians are trained to work in the first way. In addition, the strategies that enable older adults to prepare for a conversation with the geriatrician can be improved. Sending a preparatory instrument by post is just one of the ways we investigated in our study, but alternatives as a digital instrument or over the phone could also prove useful. However, our focus was mainly on the content of SDM. For future studies or implementation programs we recommend more focus on the impact of the changes that are required from health professionals when implementing SDM. Designing a patient journey with all healthcare professionals involved could provide insight into the changes needed in the regular workflow of a local hospital to facilitate SDM.

Does SDM really lead to improved personal health outcomes for older adults with MCCs?

Although the societal changes as described advocate SDM and ethical principles (e.g. autonomy of patients)\textsuperscript{56}, support the concept of SDM, the question is in which way SDM really contributes to better health outcomes for older adults with MCCs. In the field of SDM extensive research has been carried out to chart the benefits of SDM. Shay and Lafata (2015) distinguish three types of outcomes of SDM: (1) cognitive-affective, (2) behavioral and (3) health outcomes\textsuperscript{57}. Most studies report on cognitive-affective outcomes of SDM, such as knowledge and decisional conflict and the evidence points towards positive effects of SDM in this perspective\textsuperscript{3, 31, 57}. In particular the many studies about the effects of using patient decision aids provide evidence on these outcomes\textsuperscript{3, 58}. Also in our studies we reported on cognitive-affective outcomes of SDM, such as perceived level of SDM, participation in SDM, preferred and perceived roles in SDM and decisional conflict. There are fewer studies about behavioural outcomes such as compliance to treatment or adoption of health behaviours and about health outcomes such as quality of life\textsuperscript{57}. Also the positive effects of SDM were less evident in those studies\textsuperscript{59, 60}. Furthermore, SDM may lead to an increased use of patient reported
outcomes and possibly, due to the increased involvement of patients, less complaints and less legal procedures\textsuperscript{61}. A major challenge for future research on SDM for older adults with MCCs is to explore if the discussion of personal health outcomes as a starting point in SDM, really leads to attaining the goals that are set to reach those personal health outcomes. Although the PROM TOPICS-SF is intended to monitor health outcomes over a longer period, the connection must be improved between the use of this PROM and the SDM process, in particular regarding ‘goal talk’. For example, by linking PROM questions to the question of how important this topic (for example social functioning) is to someone and what he or she would consider a personal health outcome with regard to this topic.

Furthermore, the process of SDM goes beyond that what happens in the consultation between the health professional and the patient. Elwyn (2016) raises awareness about possible long term effects of SDM that are still rarely studied\textsuperscript{61}. For example, much is unknown about the effect of SDM on professionals; some may experience SDM as intrinsically rewarding but others may find SDM burdensome and impractical\textsuperscript{61}. Also, SDM is closely connected to value based health care, and value-based health care has many implications for production-driven health organisations. The impact of SDM needs to be further studied in order to understand its contribution to value-based healthcare. To conclude, SDM seems to be a promising concept regarding cognitive-affective patient outcomes, but the implications of SDM should be studied in a broader, long term perspective and in relation to personal health outcomes.

**Older adults with MCCs as target population**

We observed a lack of knowledge and a lack of tools to facilitate SDM in older adults with MCCs. This could be explained by the lack of evidence in guidelines on the benefits and harms of treatment options for older adults. Further challenges in SDM for older adults with MCCs lie in the variety of health problems, not merely in the physical domain, but also in the functional, psychological and social domain. Although, due to different barriers, older adults continue to be underrepresented in studies, we took up the challenge to involve older adults with MCCs in our research projects\textsuperscript{62-64}. To involve as many older adults as possible, we carefully planned the recruitment, through a personal approach, offering optional assistance in completing questionnaires, involving informal caregivers in logistic arrangements and to minimize the study burden for participants. In our studies we sought for representative samples of older adults with MCCs. Since we know that older adults with a lower education or a different cultural background often are underrepresented in studies, we put extra effort in engaging those participants (chapter 4)\textsuperscript{64}. For the main studies, the observational DICO I and DICO II study, we recruited a sample of geriatric patients. Although we found no significant differences between participants and non-participants on age and gender, the sample could be biased on other characteristics. Finally, a strength of this study is that we were able to involve many informal caregivers, who often have an important role in the SDM process.
Reflections on the ‘Dynamic model of SDM with frail older patients’

This thesis builds on the model for SDM, the ‘Dynamic model of SDM with frail older patients’. We investigated how the model could best be implemented in the daily practice of geriatric patients and we gained the first experiences with working according to this model. For the future, we think that it might be of added value to make the item goal talk, in our opinion one of the most important strengths of this model, more explicit. For example, in the proposed line of Elwyn and Vermunt, by differentiating goals on the level of life goals, functional goals and symptom goals. Furthermore, we wondered whether discussing partnership should be further elaborated as a separate measurement item, or more integrated in the other items, such as goal talk. We learned in our study that this item is difficult to measure, but if the goal talk is conducted well, it also shows to the patient that his or her input with regard to personal health outcomes is just as important as the knowledge and experience of the health professional.

Implications for policy

There is an increasing awareness in the care for older adults with MCCs that is important to discuss with each individual person what his or her desired personal health outcomes are. Although this research has focused on care in an outpatient geriatric clinic, we recommend that these discussions could start much earlier than the moment that an older adult (often in an acute situation and bad condition) is admitted to the hospital. For home dwelling older adults, the General practitioner, the General practice-based nurse specialist or the district nurse, often have a long-standing relationship with their older patients. Here, the conversation about preferred personal health outcomes should start and this information should be used throughout the ‘patient journey’ that older adults with MCCs make (encountering a variety of (health) professionals in a variety of care or social settings). And since priorities on personal health outcomes may change over time, regularly and in particular after life events, the conversation about preferred health outcomes should be updated and recorded in the medical file. Although in the last decade much progress has been made in the coordination of the care for older adults, to our knowledge there are not yet person-following PROMs through the care chain. This requires further exploration and coordination between social, primary and secondary care which and how PROMs could contribute to discussing preferred personal health outcomes.

Secondly, there is an urging need in the Netherlands to better align care to the needs of persons with chronic conditions. The ‘Right Care in the Right Place’ movement (2018) and the integrated care movement (www.integratedcarefoundation.org) is a movement towards organizing care around the patients or clients and communities instead of organizing care from the perspective of healthcare providers, with a focus on daily functioning of people. In this movement it is stated that ‘SDM is in this the guiding principle’, but ‘a prerequisite to this is available information about (patient reported) health outcomes’. Although this stresses the need for information about health outcomes for older adults, in the report ‘More attention towards older adults in the hospital’ (2019) researchers and clinicians addressed the issue of a lack of knowledge about...
health outcomes for older adults, and the urge to develop patient decision aids tailored to older adults with MCCs. This dissertation provides information about important personal health outcomes for older adults with MCCs and how these can be integrated in SDM resulting in decisions that contribute to the achievement of personal health goals. Moreover, SDM could even reinforce these movements, as SDM encourages older adults to express their preferences in care.

Thirdly, the development of the SDM intervention is in line with the recommendations as formulated in the ‘Vision on SDM’ (2019) by the Federation of Medical Specialists. As the report states that 64% of medical specialists expressed needs for an SDM training, more attention should be paid to SDM in continuing training of medical specialists. Positive signs are that SDM is now included in the curriculum of most medical studies and also in the curriculum of Bachelor Nursing 2020. However, the report ‘Vision on SDM’ points out that there are more barriers to be crossed in SDM implementation, mainly in the organizational and financial context. As the studies from this dissertation provide guidance to improve the implementation of SDM in the primary process, further research should address these organizational and financial issues, also as a prelude to explore other, more long-term effects of SDM.

Implications for practice

Phase V: Upscaling

The results described in this dissertation can be used to reach out to a broader implementation of SDM for older adults with MCCs, in particular at geriatric wards. The Dutch Geriatric Society (NVKG) should be a key factor in this, together with the Dutch Nurses Society (V&VN Geriatrics & Gerontology). Also senior organisations and organisations for informal caregiver support should raise awareness among older adults and caregivers that it is important to prepare for and to participate in SDM. In cooperation with different stakeholders, I developed and applied several implementation strategies to reach this aim which I will describe below.

Health professionals

Our first step in facilitating a larger group of health professionals, and in particular geriatricians, in SDM was to use an existing online platform to digitalize the SDM training, by creating interactive online scenarios in which consultations with older adults are translated into conversations with virtual trainings actors. The online SDM training has been piloted at the department of geriatrics in five other Dutch hospitals and is now free available for all health professionals (https://samenbeslissen.dialoguetrainer.com/). In addition to the original training, the online training includes 3 follow ups and contains a self-assessment for geriatricians. They are encouraged to assess their own audiotapes of real life consultations with an adapted practice version of the observer OPTION MCC. Furthermore, together with the Dutch Geriatric Society (NVKG) and the Dutch Nurses Society (V&VN Geriatrics & Gerontology) and the largest Dutch senior organisation KBO-PCOB, we initiated an implementation programme to facilitate both health professionals as well as older adults and their informal caregivers.
in SDM with the TOPICS-SF (a short version of the TOPICS-MDS). Within the implementation programme geriatricians use the online training to train in SDM. Also, a toolbox has been created, containing change management information but also communication tools such as posters, postcards, reminders, patient information, infographics, etc. The toolbox is free available at www.zorgvoorbeter.nl/samenbeslissen.

**Older adults with MCCs**

Our aim is to empower older adults to prepare for a consultation and to share their priorities on personal health outcomes with health professionals. To this aim we adapted the layout of the patient preparatory tool to align with the implementation of the TOPICS-SF and in coordination with the Dutch patient association we aligned the layout to the national ‘Ask3questions’ campaign to enhance the recognizability for the Dutch older population. Furthermore, we developed a short, animated information film, to inform and motivate older adults to prepare for SDM with help of the TOPICS-SF. Also, similar as the online training platform for health professionals, we developed, in co-creation with older adults, a scenario with conversations with a virtual trainings ‘doctor’ (De Oefendokter). ‘De Oefendokter’ is free available in the same portal: https://samenbeslissen.dialoguetrainer.com/

Within the implementation programme we work closely together with the Dutch senior organization KBO-PCOB and NOOM, the Dutch organization for older migrants. The KBO-PCOB has 800 local organisations. They provide both online and offline information sessions to inform older adults and informal caregivers about SDM and the importance to prepare for a conversation with the health professional. Finally, we published in May 2020 an information article about SDM for older adults in the KBO-PCOB magazine (250.000 circulations)

**Informal caregivers**

This dissertation showed that informal caregivers should be empowered to participate in SDM. To this aim we want to raise awareness of their role and possible challenges in SDM. Together with the Dutch caregivers association MantelzorgNL we published in Oct 2019 an article in their magazine about how informal caregivers could participate in SDM and we developed a list of ‘eight tips for caregivers in SDM’ (50.000 circulations). Also MantelzorgNL provides support for overburdened informal caregivers. Furthermore, in the SDM MCC e-learning for geriatricians (that we developed based on the SDM MCC training) we addressed the role of informal caregivers in one special part of the e-learning (follow-up 3). Finally, as mentioned above, the Dutch senior organization KBO-PCOB organized information sessions throughout the Netherlands to empower both older adults as well as informal caregivers to prepare for and participate in SDM.

**Conclusion**

The person-centred care that is needed for older adults with MCCs should be guided by personal health outcomes. When the SDM starts with the exploration of personal health outcomes, this directs the following SDM steps as presenting and discussing options to decisions that align with the older adult’s desired personal
health outcomes. The findings of this dissertation emphasize that older adults with MCCs should be more explicitly invited to participate in SDM, and that their personal experiences and knowledge about their personal situation is important to share with the health professional. PROMs that provide insight into personal health outcomes of older adults provide input for the discussion of personal health outcomes goals. Such a PROM should include the health domains as the older adults stated in our studies: functional limitations, emotional well-being, social functioning, quality of life, coping with stress and coping with the effect of their health status on daily life. The added value of the observer OPTIONMCC compared to other SDM measurements is that it measures triadic decision-making (including the participation of patients and informal caregivers) and that it measures items that are particularly relevant for older adults with MCCs, such as goal talk. The SDM\textsuperscript{MCC} intervention proved feasible in daily clinical practice, although the effects could be enhanced by tailoring both geriatric training and the preparation tool for older adults to individual needs. Since we found that increased participation in SDM leads to less decisional conflict among older adults with lower health literacy, we recommend that a brief health literacy assessment is made prior to the consultation so that the geriatrician can tailor the communication for this patient. Based on this dissertation, we recommend adding to the current implementation strategy change management tools, such as designing patient journeys for the local situation. Finally, our findings also lead to new research questions, such as exploring the complex role of informal caregivers in SDM, how the scope of SDM can be broadened from clinician focused to other health professionals in the care for older adults, and how goal based SDM can be further developed.
General discussion

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Epilogue
On Monday morning Mr. Hendriks visits the geriatrician in the outpatient clinic. Mr. Hendriks, 81 years old, is married to Mrs. Hendriks (79), who accompanies him on this appointment. The geriatrician has read the medical history of Mr. Hendriks. He suffers from diabetes, cognitive disorders, high blood pressure, arthrosis and stomach complaints. The geriatrician asks about the preparatory tool and the PROM. Mrs. Hendriks hands it over and says: ‘We completed it together’. The geriatrician reads that Mr. Hendriks rates his quality of life very low and that he would like to discuss this with the geriatrician. ‘What matters most to you?’ Mr. Hendriks thinks a bit before answering the question. ‘I like to go out, take a good walk through the park. I like having my family around me, my grandchildren.’ ‘What are you worried about?’ the geriatrician asks. ‘I don’t dare go outside anymore because sometimes I get lost. And I’m worried about how long I can stay with my wife, because….well…. I forget a lot...’ Mrs. Hendriks nods in the affirmative. The geriatrician summarizes: ‘So it’s important that you go out regularly, that you see your family and that you feel supported in dealing with your memory problems?’ The couple agrees on these goals. The geriatrician discusses different options for Mr. Hendriks and explains the advantages and disadvantages of each option. They look at which options best contribute to the goals of Mr. Hendriks. They agree to suggest to relatives and friends to take Mr. Hendriks outside for a walk, instead of sitting down and having a cup of coffee during their visit. They also look for a volunteer, who could go for a walk with him a few times a week. Because Mr. Hendriks is reluctant to take more pain medication, they discuss the use of a walker with a comfortable seat, so that he gets more support while walking and can rest if necessary. More regular exercise can also have a positive effect on blood pressure and stomach complaints. They also agree to do some memory tests to gain more insight into the seriousness of the memory problems and to get a better idea of what support is needed to keep the couple independent for as long as possible. Maybe a case-manager could support Mrs. Hendriks in the situation. At the next visit they will evaluate the blood pressure and then decide whether medication is really needed, because Mr. Hendriks has a lot of problems with taking medication.

The couple leave the consultation room satisfied and relieved, and the geriatrician also feels that she has really been able to do something for them.
Summary

Chapter 1: Introduction

The aim of this dissertation is to explore shared decision making with older adults and their informal caregivers. In the introduction it is explained that as people get older they experience more often several long-term (chronic) diseases at the same time, also called multiple chronic conditions. Multiple chronic conditions can lead to geriatric syndromes, such as falling, pain, incontinence and decreased independence. Health care is primarily focused at treating a ‘single’ disease. However, for older adults with multiple chronic conditions, treating all diseases separately can lead to an excessive treatment burden, whereby the advantages of a treatment no longer outweigh the disadvantages, such as side effects of medication. In other words, in this group the best treatment for a disease may not always be the best treatment for the patient as a person. Therefore, in the case of older adults with multiple chronic conditions, a goal-oriented approach is preferred over a disease-oriented approach. In the case of a goal-oriented approach, the health professional and the older adult discuss together what the treatment should yield (a personal health outcome), such as being able to remain independent and quality of life. So instead of asking ‘What is the matter with you?’, health professionals might want to ask ‘What matters to you in your life?’.

The conversation in which health professionals explore what the older adult’s goal is, inform about possible treatment options, explain their benefits and harms and decide together what fits best to the preferences of the patient, is called ‘shared decision making’. However, shared decision making is not yet common practice in the care for older adults. The following chapters describe the research that has been done to develop and evaluate an intervention to improve the process of shared decision making. We based our research on the ‘Dynamic model for shared decision making with frail older patients’. The development and evaluation was guided by the Medical Research Council framework for the development of complex interventions. This implies that both a literature review (chapter 2) and empirical research (chapters 3, 4 and 5) were conducted to develop the intervention (chapter 6). The empirical research included a video observational study of conversations between older patients and geriatricians. This study was called DICO I study, where DICO stands for ‘Decision making In Complex Old populations’. The intervention consisted of a training for geriatricians and an information leaflet for older adults and their informal caregivers. Finally, the intervention was tested in practice and monitored through a second video observational study of conversations between older patients and geriatricians (DICO II study), the results of which are described in chapter 7. Chapter 8 examined the influence of personal characteristics, such as education and health literacy, on shared decision making. Finally, Chapter 9 reflects on the whole study and provides recommendations for research, practice and policy.

When ‘older adult’ in this dissertation is used, this always refers to older adults with multiple chronic conditions, unless otherwise specified.
Chapter 2: Barriers to and facilitators of shared decision making for older adults with multiple chronic conditions: a systematic literature review

Chapter 2 deals with barriers to and facilitators of shared decision making that older adults, their informal caregivers and health professionals experience in shared decision making. A systematic literature review has been carried out in the international literature on this subject. Based on keywords related to this subject, 3838 articles were found in literature databases of which 28 articles were included that reported on shared decision making and the barriers and facilitators experienced. We found 149 barriers and 67 facilitators which were described using an existing framework. The most important barriers that older adults experience in shared decision making are cognitive and physical limitations. Older adults also indicate that if there is acute health deterioration it is difficult for them to participate actively in shared decision making. Health professionals are less able to decide together with patients if their communication skills are underdeveloped and if they experience organizational barriers such as insufficient time or a high production pressure. Shared decision making is promoted when older adults share information about what they find important; their personal health outcome goals and health care preferences. Sharing information about quality of life and daily functioning also facilitates shared decision making. Informal caregivers promote shared decision making by assisting older adults to share and understand information. However, informal caregivers can also hinder shared decision making, for example when there are different opinions about what is best for the older adult or about the older adult’s decision-making capacity. When health professionals adapt their information to the level of the patient (taking into account e.g. cognition and education) this facilitates shared decision making. Because multiple chronic conditions often involves different health professionals, good coordination of care and treatment is important to enable shared decision making. The recommendation based on this literature review is to explicitly invite older adults to participate in shared decision making, and to emphasize that their knowledge and experience of their personal situation is important to bring into the conversation. As a result, health professionals are better able to propose treatment options that fit the personal situation and preferences of patients.

Chapter 3: Do multiple chronic conditions influence personal views on the ageing process, a qualitative analysis

Chapter 3 describes the themes that people find important when they get older and whether this changes when multiple chronic conditions occur. In the process of shared decision making exploring ‘what matters’ in a person’s life is an important first step, which contributes to prioritizing health outcome goals and health care preferences. However, health professionals may often be more focused on exploring problems than on exploring what is important in a person’s personal life. Older adults are also not often used to discussing these issues with a health professional. Gaining insight into which issues are important in ageing makes it easier for health professionals to ask about them. For example, by asking: ‘Many people think about their self-reliance as they grow older, what do you find important in this?’ As part of a larger study on geriatric problems,
547 over-70s living at home were asked what they thought was important when it came to ageing, what they were worried about, how they looked to the future, how they thought they would grow old as healthy as possible and what they thought of their quality of life. The personal insights most frequently communicated were the association of aging with (further) loss of function, acceptance of aging and concerns about limitations and their family. A healthy lifestyle, keeping busy, maintaining social contacts and a positive attitude were seen as prerequisites for a good old age. The ability to continue doing what you want to do, good health and social contacts contribute to quality of life. Older adults with and without multiple chronic conditions often mentioned the same issues when it came to ageing but an important difference was that older adults with multiple chronic conditions were more worried, looked more negatively to the future and were especially afraid of further physical decline and limitations. Based on this research, we recommend discussing with older adults what is important to them personally for their quality of life and what they are most concerned about. In this way health professionals can together with the older adults come to health related goals and discuss what (treatment) possibilities there are to achieve these goals.

Chapter 4: Recommendations of older adults for the use of the PROM TOPICS-MDS in care conversations: a Delphi study
Chapter 4 then examines whether a research based questionnaire for older adults about their health, the TOPICS-MDS, can also be used in daily conversations between health professionals and older adults. The questionnaire provides insight into the health and welfare situation of older adults and can therefore be a starting point for discussions about care and treatment. We aimed to investigate whether the topics in this questionnaire that are considered important from research perspective are also considered important by older adults themselves to discuss with their health professional. In addition, a number of questions from the questionnaire were often not or incompletely filled in. We wanted to discuss with older adults what could be causing this and ask for suggestions to make the questions easier to understand. Because it is important that not only higher educated older adults would participate in this research, a method was sought in order to be able to also involve migrants and older adults with a lower level of education. By means of a Delphi study, which consisted of three consecutive rounds, research was carried out partly via internet questionnaires and partly via focus groups. The aim was to reach consensus with older adults on the topics that should be in the questionnaire, these could be the topics that were in the existing questionnaire or new topics that the older adults themselves added. After three rounds more than 75% of older adults agreed that ‘functional limitations’, ‘emotional wellbeing’, ‘social functioning’ and ‘quality of life’ were topics that should remain in the questionnaire. In addition, more than 75% agreed that ‘coping with stress’ and ‘coping with health conditions and their effects on life’ were topics that should be added to the questionnaire. With regard to the (in)clarity of the questions, older adults gave suggestions to use less difficult words, make less long sentences and think carefully about the formulation of sensitive questions, such as incontinence. We found that older adults of migrant origin and older
adults with a low level of education want to discuss more topics with their health professional than native older adults with a higher level of education. One of the strengths of this research is that it has succeeded in involving older adults who often do not participate in studies. The Dutch Association of Clinical Geriatrists (NVKG) has recommended that an abbreviated version of the questionnaire, the TOPICS-Short Form (SF), be used in all Geriatric departments in the Netherlands. The NVKG particularly emphasizes the added value of the questionnaire if it is used for shared decision making with older adults in health care conversations. The questionnaire can be freely downloaded from www.topics-mds.eu.

Chapter 5: Measuring triadic decision making in older patients with multiple chronic conditions: Observer OPTION$^{\text{MCC}}$

Chapter 5 examines how to measure shared decision making with older adults and their informal caregivers. In the previous chapters of this dissertation, it was established that in shared decision making with older adults it first should be discussed what they consider important regarding their personal health outcome goals, before treatment options are presented and discussed. It was also found that the role of informal caregivers is very important in shared decision making with older adults. The ‘Dynamic model for shared decision making with frail older patients’ offers extra steps for this, which most common models for shared decision making do not have, or not in this order. In this study we developed and tested a measuring instrument for shared decision making according to the steps of the ‘Dynamic model for shared decision making with frail older patients’. Our instrument is based on an internationally widely used measuring instrument for shared decision making, the Observer OPTION scale. Because the existing instrument only measures the shared decision making of the clinician, but in the case of older adults the input of both the older adults themselves and their relatives is of great importance, observational items were added to measure the participation of older adults and their informal caregivers in the shared decision making process. The new measuring instrument is called the Observer OPTION$^{\text{MCC}}$, where ‘MCC’ stands for ‘Multiple Chronic Conditions’. The Observer OPTION$^{\text{MCC}}$ counts seven items and a total score is calculated per group (geriatricians, patients, informal caregivers). In order to test the Observer OPTION$^{\text{MCC}}$, a video observational study, the DICO I study, was set up at the outpatient geriatric clinic of the AMC and the MC Slotervaart in Amsterdam. The conversation with the geriatrician was recorded on video with 108 older adults and 53 informal caregivers. A total of three different observers then scored with the OPTION$^{\text{MCC}}$ the extent to which shared decision making took place. Using statistical analyses, we were able to establish that the new instrument is sufficiently reliable to be used with older adults with multiple chronic conditions. The added value of the Observer OPTION$^{\text{MCC}}$ compared to existing measuring instruments for observing shared decision making is the measurement of discussing the personal goals of the older adult and the explicit measurement of the participation of the older adults and his or her informal caregivers in the shared decision making process. The Observer OPTION$^{\text{MCC}}$ can be freely downloaded via various websites (www.healthcommunication.nl, www.vilans.nl) and has been added to
an international website where the various OPTION measuring instruments can be downloaded: www.glynelwyn.com. In addition, as part of an e-learning on shared decision making, a Dutch-language practical version of the instrument has been developed in which health professionals fill in part of the OPTION MCC by means of self-observation of their own recorded consultations (https://samenbeslissen.dialguetrainer.com/).

Chapter 6: The development of the evidence-based SDM MCC intervention to improve shared decision making in geriatric outpatients: the DICO-I study

This chapter describes the development of the SDM MCC intervention, an intervention that aims to promote shared decision making with older adults and their informal caregivers. Because this was a complex intervention, with aspects aimed at older adults, their informal caregivers and health professionals, we worked according to the steps of the ‘Medical Research Council framework for developing complex interventions’.

I Development phase: on the basis of the literature review from chapter 2 (theoretical basis), and the research findings from chapters 3, 4 and 5 (empirical basis), the intervention was composed. The intervention consists of a training for health professionals in shared decision making with older adults and an information leaflet for patients and informal caregivers in order to prepare for the discussion with the healthcare professional. The aim was to implement the intervention at geriatric outpatient clinics.

II Feasibility phase: the design of the training was presented to 11 geriatricians working at various locations in the Netherlands. After two improvements, the final training was established. The leaflet was submitted in three consecutive rounds to a total of ten older adults and informal caregivers and two geriatricians before it was finalized.

III Implementation phase: the training was given to four geriatricians in the AMC and five geriatricians in the MC Slotervaart. The leaflet was sent to 108 older patients who wanted to participate in the study and had an appointment at the geriatric outpatient clinic of these two hospitals. The geriatricians gave the training an average grade of 8 (range 0-10). They indicated that they had learned to apply the steps of shared decision making and that they were particularly aware of the importance of discussing goals. Being able to practice with a training actor was valuable to them. Two thirds of older adults and informal caregivers who had filled in the leaflet thought it was a good and informative leaflet. To determine whether the training and the leaflet actually contributed to more and better shared decision making, a second video observational study was conducted, the DICO II study. The results are described in chapter 7.

Chapter 7: The effects of the SDM MCC intervention for older adults with multiple chronic conditions: the DICO-II study

This chapter describes the effects of the SDM MCC intervention (the training for geriatricians and the leaflet for older adults and informal caregivers). For this purpose, the results of the first video observational study, the DICO I study, were compared to a second video observational study, the DICO II study. Three
observers observed the video recordings of conversations between geriatricians and older patients and their informal caregivers with the OPTIONMCC to measure whether more shared decision making was demonstrated. Using questionnaires before and after the interview with the geriatric patient, patients and informal caregivers were asked whether the way in which they had been involved in the interview (Perceived Involvement in Care Scale) and their role in the decision making process (Adapted Control Preference Scale) corresponded to how they would have liked to have been involved beforehand. In addition, they indicated to what extent they felt that a decision had been made together (CollaboRATE) and how certain they were about the decision that had been made (Decision Conflict Scale). Finally, a process evaluation kept track of how the intervention was implemented.

A total of 216 older patients, 133 informal caregivers and 10 geriatricians were recruited to participate in the two video-observation studies (pre- and post-observation). The average age of participants in both studies was 77 years and 56% was female. There were no significant differences in age and gender between the participants and the older patients who did not participate, nor were there any significant differences in background characteristics between the participants in the pre- and post-measurement studies. This means that the pre- and post-measurement groups are comparable and that the results of the study could also apply to older patients outside the study group. Shared decision making was observed and measured with the OPTIONMCC (see chapter 5). For three items we observed a significant improvement after the intervention. These are the items that were about ‘discussing goals with patients’, ‘explaining the options’ and ‘making the decision’. However, on two items we observed a significant decline. These are the items about ‘discussing that the input of the patient is just as important as the input of the geriatrician (so-called ‘partnership’), and about evaluating the decision-making process. On average, the combination of improvement on some items and deterioration on others did not lead to improvement, i.e. the total score on the OPTIONMCC did not show a significant difference after the implementation of the SDM intervention. Also, the personal experiences of patients and informal caregivers in the decision making process did not change compared to the pre-measurement. The process evaluation showed that patients were predominantly positive about the leaflet, but that their preparation for the interview (the answers to the questions in the folder) only came up in 12% of the interviews with the geriatrician.

What do we learn from this research? We see that the intervention leads to a better discussion of personal goals, a better explanation of treatment options and that the patient and informal caregiver are more involved in shared decision making. The real gain may be that the decisions made contribute better to the personal health goals of the patient. However, this gain is only visible in the longer term and we have not been able to measure that in this study. There are several possible explanations as to why we did not find any important difference between the pre- and follow-up measurement with the Observer OPTIONMCC. One explanation is that when geriatricians spend more time on one step, within the set time period of a conversation at the outpatient clinic, this may be at the expense of the other steps. Another explanation is that discussing goals and explaining options are easier to improve than discussing that you want to enter
into a ‘partnership’ with the patient in which everyone’s input is equally important. Evaluating the decision-making process can also be tense because of the vulnerability of the geriatrician: ‘Did I discuss it with you properly as a doctor?’. We will pay more attention to these two topics in follow-up training sessions. Because the results of one geriatrician were very different from the other geriatricians, we performed a subgroup analysis without this geriatrician. This analysis showed that the overall results (total Observer OPTIONMCC score) of the other doctors had improved significantly. This indicates that a good implementation is important. In addition, it is striking that the leaflet was often filled in, but was not discussed. Other research shows that this can even have a counterproductive effect, because the patient’s expectations (discussing what he has filled in) are not met. In the follow-up projects, we therefore devote more attention to the role of the geriatrician in discussing the leaflet.

**Chapter 8: The influence of health literacy, education, frailty and anxiety of older adults with multiple chronic conditions in shared decision making**

Finally, we investigated the extent to which personal characteristics of older adults play a role in shared decision making. Therefore, in this chapter, we were particularly interested in the influence of education, anxiety, frailty and health literacy on how older adults experience shared decision making and on their (in)certainty about the decision taken. We also investigated the mediating role of patient participation during the consultation in how older adults experienced the shared decision making afterwards and how (un)certain they felt about the decision taken.

For this study, the data of the 216 older adults who participated in the DICO I and DICO II studies (chapters 5 and 7) were analysed. The personal characteristics of older adults were measured by using existing instruments: education (low, medium, high), anxiety (STAI-6), frailty (GFI) and health literacy (SAHL-D22). The ‘experienced’ shared decision making was established with the CollaboRATE and the ‘(un)certainty about the decision’ with the Decisional Conflict Scale. The participation of patients in shared decision-making was measured with the patient part of the Observer OPTIONMCC. A stepwise mixed multilinear regression and a mediation analysis were conducted to answer the research questions.

The results of these analyses are that older adults with a lower level of education and less anxiety were more positive about how they had experienced the shared decision making process afterwards. A higher level of education, lower health literacy and more anxiety were associated with more uncertainty about the decision. In addition, a higher age and lower health literacy were associated with lower participation in shared decision making during the consultation. The mediation analysis showed that older adults with lower health literacy who participated more actively in shared decision-making during the consultation reported less uncertainty about the decision after the consultation. The results of this study support the findings from the literature review (chapter 2) that it is important to take the personal characteristics of older adults into account in shared decision making. This is especially true for older adults with poor health literacy. If it is possible to involve them better in the shared decision making process, this
has a positive effect on the outcomes, especially uncertainty about the decision.

**Chapter 9: Discussion**

This last chapter discusses the most important findings from this dissertation and justifies the methodological choices. Finally, recommendations are made for further research, policy and practice. This dissertation describes the importance of discussing personal health outcome goals with older adults with multiple chronic conditions. We found that for many older adults being able to function independently, social contacts, emotional well-being, quality of life and being able to cope with illness and limitations in daily life are important topics to discuss. Inviting older adults to share knowledge about their personal situation and what they find important is an important condition for shared decision making. Informal caregivers can support older adults in shared decision making, but sometimes they also have their own preferences and needs that should be taken into account when making decisions. Health professionals experience organizational limitations in shared decision making but they also indicate that there is often a lack of evidence for the effect of treatments in older adults. The ‘Dynamic model for shared decision making with frail older patients’ was implemented at two geriatric outpatient clinics by means of a training for geriatricians and a leaflet for patients.

Using the measuring instrument Observer OPTION$^{MCC}$, it was found that discussing personal goals and discussing the different treatment options, with their benefits and harms, and making the final decision together significantly improved after the intervention. Because in the earlier chapters of this thesis it was established that exploring personal goals in older adults with multimorbidity should be the starting point for the discussion about treatment possibilities, it is an important gain that this indeed improved significantly after the intervention. We expect that treatments that have been chosen on the basis of the starting point ‘To what extent does this contribute to a person’s personal health goals?’ will be of greater significance for older adults in the longer term than if they are only reasoned on the basis of an illness or disorder. However, shared decision making can still be further improved, especially with regard to discussing cooperation (partnership) and evaluating the decision. For the future, this means that more attention should be paid to these aspects, for example in training courses on shared decision-making with older people, and to take health literacy levels into account in communication. It is also recommended to pay more attention to the change management issues of shared decision making for health professionals in their daily practice, such as discussing the leaflet with patients. This dissertation provides a number of recommendations for future research, such as broadening the scope of shared decision making to other health professionals as clinicians and to explore how informal caregivers can be more involved in shared decision making. Also it is interesting to investigate how PROMs can add value to shared decision making and how personal goals can be monitored over time. Finally, the use of the OPTION$^{MCC}$ has raised new issues regarding the measurement of shared decision making, such as the current lack of a composite end-score and the issue of assessing non-verbal behavior in the context of shared decision making. The findings of this dissertation support and provide practice recommendations regarding various current policy developments in the care for
older adults in the Netherlands, such as the ZonMw report ‘More attention for older adults in the hospital; opting for care with better outcomes for the older patient’ (2019) and the ‘Vision document Shared Decision Making’ of the Federation of Medical Specialists (2019). In addition to research-based recommendations it is described how the results of this dissertation further find their way into the daily practice of departments of geriatrics in the Netherlands. The Dutch Society for Clinical Geriatrics (NVKG) has embraced shared decision making with the PROM TOPICS-SF and strives for a national implementation of shared decision making with the TOPICS-SF in all geriatric departments in cooperation with knowledge organization Vilans. The training developed in this study (now available as e-learning on https://samenbeslissen.dialoguetrainer.com/) and the patient leaflet are important priorities in this implementation programme. All this in close collaboration with the older adults themselves, represented by senior organization KBO-PCOB and migrant organization NOOM. The aim is to use information to stimulate older adults to prepare for healthcare conversations. As a spin-off of this dissertation, tips and an article have been published in cooperation with MantelzorgNL to support informal caregivers in shared decision making with older adults. These efforts together contribute to person-oriented, valuable care for older adults with multimorbidity; care that ‘matters’!
Samenvatting

Hoofdstuk 1: Inleiding

Dit proefschrift gaat over samen beslissen met ouderen en hun naasten in de gezondheidszorg. In de inleiding wordt uitgelegd dat naarmate mensen ouder worden, er vaker sprake is van meerdere langdurige (chronische) aandoeningen tegelijkertijd, ook wel multimorbiditeit genoemd. Multimorbiditeit kan leiden tot geriatrische syndromen, zoals vallen, pijn, incontinentie en afgenomen zelfstandigheid. De gezondheidszorg is er vooral op ingericht om een ‘enkelvoudige’ ziekte zo goed mogelijk te behandelen. Bij ouderen met multimorbiditeit kan het apart behandelen van alle ziekten en aandoeningen echter leiden tot een te grote behandellast, waarbij de voordelen van een behandeling niet meer opwegen tegen de nadelen, zoals bijwerkingen van medicijnen. De beste behandeling voor een ziekte is misschien niet altijd de beste behandeling voor de patiënt als mens. Daarom past bij ouderen met multimorbiditeit beter een doelgerichte behandeling dan een ziektegerichte behandeling. Bij een doelgerichte behandeling bespreken de zorgverlener en de oudere samen wat de behandeling zou moeten opleveren (een gezondheid gerelateerde uitkomst), zoals onafhankelijk kunnen blijven en kwaliteit van leven. In plaats van te vragen ‘Wat is er met u aan de hand?’ kunnen zorgverleners beter vragen ‘Wat doet er toe voor u in het leven?’.

Het gesprek waarin zorgverleners samen met patiënten verkennen wat het persoonlijke doel van de oudere is (waaraan moet de behandeling bijdragen), wat mogelijke behandelingen zijn met hun voor- en nadelen en wat dan het beste bij hem of haar past, wordt ‘samen beslissen’ (shared decision making) genoemd. In de volgende hoofdstukken wordt het onderzoek beschreven dat gedaan is om een interventie te ontwikkelen en te evalueren om het proces van samen beslissen te verbeteren. We baseerden ons hierbij op het ‘Dynamisch gespreksmodel voor samen beslissen met kwetsbare ouderen’. Het onderzoek is systematisch uitgevoerd aan de hand van een model voor het ontwikkelen van complexe interventies. Dit houdt in dat er zowel literatuuronderzoek (hoofdstuk 2) als praktijk onderzoek (hoofdstuk 3, 4 en 5) is uitgevoerd om de interventie te ontwikkelen (hoofdstuk 6). Het praktijkonderzoek bestond onder meer uit een video-observatie studie van gesprekken tussen oude patiënten en geriaters. Deze studie werd de DICO I studie genoemd, waarbij DICO staat voor ‘Decision making In Complex Old populations’. De interventie bestond uit een training voor geriaters en een invulfolder voor oudere patiënten en hun naasten. Tenslotte is de interventie uitgetest in de praktijk en gemonitord door middel van een tweede video-observatie studie van gesprekken tussen oude patiënten en geriaters (de DICO II studie). De resultaten daarvan zijn beschreven in hoofdstuk 7. In hoofdstuk 8 is onderzocht wat de invloed is van persoonlijke kenmerken, zoals opleiding en gezondheidsvaardigheden op samen beslissen. Tenslotte worden in hoofdstuk 9 de conclusies beschreven waarna op het hele onderzoek gereflecteerd wordt en aanbevelingen worden gedaan voor onderzoek, praktijk en beleid.

Wanneer in dit proefschrift de term ‘ouderen’ wordt gebruikt, wordt gerefereerd aan ouderen met multimorbiditeit, tenzij anders aangegeven.
Hoofdstuk 2: Belemmerende en bevorderende factoren bij samen beslissen met ouderen met multimorbiditeit: een systematische literatuurstudie

Hoofdstuk 2 gaat over belemmerende en bevorderende factoren die ouderen, hun naasten en zorgprofessionals ervaren bij het samen beslissen. In de internationale literatuur over dit onderwerp is een systematisch literatuuroverzicht uitgevoerd. Op basis van trefwoorden die betrekking hebben op dit onderwerp zijn in de database 3838 artikelen gevonden, waarvan 28 artikelen zijn geïncludeerd die rapporteerden over samen beslissen en de bevorderende en belemmerende factoren die daarbij ervaren worden. We vonden 149 belemmerende factoren en 67 bevorderende factoren, die vervolgens met behulp van een bestaand framework beschreven zijn. De belangrijkste belemmeringen die ouderen zelf ervaren in het samen beslissen zijn cognitieve en fysieke beperkingen. Ook geven ouderen aan dat als er sprake is van een acute gezondheidsverslechtering, het moeilijk voor hen is om actief mee te doen in samen beslissen. Zorgverleners kunnen minder goed samen beslissen met patiënten als ze zelf minder communicatieve vaardigheden hebben en als ze organisatorische belemmeringen ervaren zoals onvoldoende tijd of hoge productiedruk. Samen beslissen wordt bevorderd wanneer ouderen informatie delen over wat zij belangrijk vinden: hun persoonlijke waarden, doelen en voorkeuren. Ook het delen van informatie over kwaliteit van leven en dagelijks functioneren helpt bij het samen beslissen. Naasten kunnen het samen beslissen bevorderen doordat zij de ouderen helpen bij het delen en begrijpen van informatie, maar naasten kunnen het samen beslissen ook belemmeren, bijvoorbeeld wanneer er verschillende mening zijn over wat het beste past bij de oudere of over de besluitvormingscapaciteit van de oudere. Wanneer zorgverleners hun informatie aanpassen aan het niveau van de patiënt (bijv. rekening houden met geheugen en opleiding), helpt dit het samen beslissen. Omdat bij multimorbiditeit vaak verschillende zorgverleners betrokken zijn, is goede coördinatie van zorg en behandeling belangrijk om het samen beslissen mogelijk te maken.

Hoofdstuk 3: Hoe beïnvloedt multimorbiditeit persoonlijke opvattingen over het ouder worden: een kwalitatieve analyse

In hoofdstuk 3 worden de thema’s beschreven die mensen belangrijk vinden wanneer zij ouder worden en of dit verandert bij multimorbiditeit. Bij het proces van samen beslissen is het verkennen van ‘wat ertoe doet’ in iemands leven een belangrijke eerste stap, die bijdraagt aan de prioriteren van behandelwensen en doelen. Echter, zorgverleners zijn vaak meer gericht op het verkennen en oplossen van problemen, dan op het verkennen van wat iemand belangrijk vindt in zijn of haar persoonlijke leven. Ook ouderen zijn niet gewend om deze zaken met een zorgverlener te bespreken. Door inzicht te krijgen in welke thema’s belangrijk zijn bij het ouder worden, kunnen zorgverleners hier makkelijker naar gaan vragen. Bijvoorbeeld door te vragen: ‘Veel mensen denken na over hun zelfredzaamheid bij het ouder worden, wat vind u daarin belangrijk?’. Als onderdeel van een grotere studie over geriatrische problemen werd aan 547 thuiswonende 70+-ers gevraagd wat zij belangrijk vonden als het gaat om ouder worden, waar zij
zich zorgen over maakten, hoe ze naar de toekomst keken, hoe ze dachten zo gezond mogelijk oud te worden en wat ze vonden van hun kwaliteit van leven. De persoonlijke inzichten die het meest werden gecommuniceerd waren de associatie van ouder worden met (verder) functieverlies, acceptatie van het ouder worden en zorgen over beperkingen en over hun familie. Een gezonde leefstijl, bezig blijven, het behoud van sociale contacten en een positieve houding werden gezien als voorwaarden om goed oud te kunnen worden. De mogelijkheid om te kunnen blijven doen wat je wilt doen, een goede gezondheid en sociale contacten dragen bij aan kwaliteit van leven. Ouderen met en zonder multimorbiditeit noemden veelal dezelfde onderwerpen als het gaat om het proces van ouder worden, maar een belangrijk verschil was dat ouderen met multimorbiditeit zich meer zorgen maakten, negatiever naar de toekomst keken en vooral banger waren voor verdere fysieke achtergang en beperkingen. Op basis van dit onderzoek bevelen we aan om met ouderen te bespreken wat er voor hen persoonlijk belangrijk is voor hun kwaliteit van leven en waar zij zich het meeste zorgen over maken. Hierdoor kunnen zorgprofessionals samen met ouderen tot gezondheid gerelateerde doelen komen en bespreken welke (behandel) mogelijkheden er zijn om die doelen te bereiken.

**Hoofdstuk 4: Aanbevelingen van ouderen voor het gebruik van de PROM TOPICS-MDS in zorggesprekken: een Delphi studie**

In hoofdstuk 4 wordt vervolgens onderzocht of een voor de wetenschap ontwikkelde vragenlijst voor gesprekken met ouderen over hun gezondheid, de TOPICS-MDS, ook bruikbaar is in de dagelijkse gesprekken tussen zorgverleners en oudere patiënten. De ingevulde vragenlijst geeft inzicht in de gezondheids- en welzijnssituatie van ouderen en kan daarmee een startpunt zijn voor gesprekken over zorg en behandeling. We wilden onderzoeken of de onderwerpen die vanuit de wetenschap belangrijk worden gevonden voor ouderen, ook door ouderen zelf als belangrijk gezien worden om te bespreken met hun zorgverlener. Daarnaast werden een aantal vragen uit de vragenlijst vaak niet of onvolledig ingevuld. We wilden met ouderen bespreken wat de oorzaak daarvan zou kunnen zijn en vragen om suggesties om de vragen begrijpelijkker te maken. Omdat het belangrijk is dat niet alleen hoger opgeleide ouderen mee zouden doen aan dit onderzoek, werd een andere methode gezocht om ook migranten ouderen en ouderen met een lager opleidingsniveau hierbij te kunnen betrekken. Door middel van een Delphi-studie, die bestond uit drie opeenvolgende rondes, werd deels via internet-vragenlijsten en deels via gespreksgroepen onderzoek uitgevoerd. Het doel was om overeenstemming te krijgen met ouderen over de onderwerpen die in de vragenlijst zouden moeten zitten. Dit konden de onderwerpen zijn die in de bestaande vragenlijst stonden, of nieuwe onderwerpen die de ouderen zelf toevoegden. Na drie rondes was meer dan 75% van de ouderen het erover eens dat ‘functionele beperkingen’, ‘emotioneel welzijn’, ‘sociaal functioneren’ en ‘kwaliteit van leven’ onderwerpen waren die in de vragenlijst moesten blijven. Daarnaast was meer dan 75% het erover eens dat ‘omgaan met stress’ en ‘omgaan met gezondheidsaandoeningen en de effecten daarvan op het leven’ onderwerpen waren die toegevoegd zouden moeten worden aan de vragenlijst. Met betrekking
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tot de (on)duidelijkheid van de vragen gaven de ouderen suggesties om minder moeilijke woorden te gebruiken, minder lange zinnen te maken en gevoelige vragen, zoals bijvoorbeeld over incontinentie, anders te formuleren. Tenslotte onderzochten we of er verschillen waren tussen ouderen van migranten afkomst, ouderen met een laag opleidingsniveau en ouderen die hoger opgeleid waren. Daaruit kwam naar voren dat ouderen van migranten afkomst en ouderen met laag opleidingsniveau over meer onderwerpen willen praten met hun zorgverlener dan ouderen die hoger opgeleid zijn. Het is een kracht van dit onderzoek is dat het is gelukt om ouderen te betrekken die vaak niet meedoen aan onderzoeken. De Nederlandse Vereniging van Klinisch Geriaters (NVKG), heeft inmiddels aanbevolen om een verkorte versie van de vragenlijst, de TOPICS-Short Form (SF), te gebruiken op alle afdelingen Geriatrie in Nederland. De NVKG benadrukt daarbij vooral de meerwaarde van de vragenlijst als deze gebruikt wordt bij het samen beslissen met ouderen in de spreekkamer. De vragenlijst is vrij te downloaden via www.topics-mds.eu.

Hoofdstuk 5: Het meten van samen beslissen bij ouderen met multimorbiditeit: de Observer OPTIONMCC
In hoofdstuk 5 is onderzocht hoe samen beslissen met ouderen en hun naasten kan worden gemeten. Bij het samen beslissen met ouderen is in de voorgaande hoofdstukken van dit proefschrift vastgesteld dat eerst met ouderen besproken zou moeten worden wat zij belangrijk vinden; hun persoonlijke waarden, doelen en voorkeuren, en dat vervolgens pas besproken wordt welke behandelmogelijkheden daarbij passen. Tevens werd geconstateerd dat de rol van naasten heel belangrijk is bij het samen beslissen met ouderen. Het ‘Dynamisch gespreksmodel voor samen beslissen met kwetsbare ouderen’ biedt hiervoor extra stappen, die de meeste gangbare gespreksmodellen voor samen beslissen niet hebben, of niet in deze volgorde. In deze studie ontwikkelden en testten we een meetinstrument om samen beslissen volgens de stappen uit het ‘Dynamisch gespreksmodel voor samen beslissen met kwetsbare ouderen’ te meten. Ons instrument is gebaseerd op een internationaal veel gebruikt meetinstrument voor samen beslissen, de Observer OPTION schaal. In het onderzoek werden aan deze schaal extra items toegevoegd om de aanvullende stappen van samen beslissen te meten. Omdat de bestaande schaal alleen het samen beslissen van de arts meet, maar bij ouderen de inbreng van zowel de ouderen zelf als van hun naasten van groot belang is, werden observatie items toegevoegd om de participatie van ouderen en naasten in het samen beslissen te meten. Het nieuwe instrument heet de Observer OPTIONMCC, waarbij ‘MCC’ staat voor ‘Meerdere Chronische Condities’. De Observer OPTIONMCC telt zeven items en hierover wordt een totaalscore berekend. Om de Observer OPTIONMCC te testen, werd een video-observatie studie opgezet, de DICO I studie, op de poliklinieken geriatrie van het Amsterdam UMC (locatie AMC) en het MC Slotervaart in Amsterdam. Bij 108 ouderen en 53 naasten namen we het gesprek met de arts op video op. Drie verschillende observatoren scorend vervolgens aan de hand van de OPTIONMCC hoeveel er samen beslist werd en door wie. De validiteit en betrouwbaarheid werd vastgesteld door het meten van de inter-beoordelaarsbetrouwbaarheid en een factor analyse. Op basis hiervan stelden we vast dat het nieuwe meetinstrument voldoende betrouwbaar is.
om te gebruiken bij het observeren van samen beslissen door zorgprofessionals met ouderen met multimorbiditeit en hun naasten. De meerwaarde van de Observer OPTIONMCC ten opzichte van bestaande meetinstrumenten voor het observeren van samen beslissen is het meten van het bespreken van de persoonlijke doelen van de oudere en het expliciet meten van de deelname van de ouderen en naasten aan het samen beslissen. De Observer OPTIONMCC is vrij te downloaden via verschillende websites (www.healthcommunication.nl, www.vilans.nl) en is toegevoegd aan een internationale website waar de verschillende OPTION meetinstrumenten te downloaden zijn: www.glynelwyn.com. Daarnaast is, als onderdeel van een e-learning over samen beslissen, een Nederlandstalige praktijkversie van het instrument ontwikkeld waarbij zorgprofessionals een deel van de OPTIONMCC invullen d.m.v. zelfobservatie van hun eigen opgenomen consulten (https://samenbeslissen.dialoguetrainer.com/).

Hoofdstuk 6: De ontwikkeling van de evidence-based SDM MCC interventie ter bevordering van samen beslissen bij poliklinische geriatrische patiënten: de DICO-I studie

In dit hoofdstuk wordt de ontwikkeling van de Shared Decision Making for Multiple Chronic Conditions (SDM MCC) interventie beschreven, een interventie die tot doel heeft om samen beslissen met ouderen en hun naasten te bevorderen. Omdat dit een complexe interventie is, met aspecten gericht op ouderen, hun naasten en zorgprofessionals, werkten we volgens de principes van het ‘Medical Research Council framework for developing complex interventions’. We volgden hierin drie fasen.

I Ontwikkelfase: op basis van de literatuurreview uit hoofdstuk 2 (theoretische basis), en de onderzoeksbevindingen uit hoofdstuk 3, 4 en 5 (empirische basis) werd de interventie samengesteld. De interventie bestaat uit een training voor zorgprofessionals over samen beslissen en een invulfolder voor patiënten en naasten om zich voor te bereiden op het gesprek met de zorgprofessional. Het doel was om de interventie te implementeren op poliklinieken geriatrie.

II Haalbaarheidsfase: de opzet van de training is voorgelegd aan 11 geriaters die op verschillende plekken in Nederland werken. Na twee verbeterslagen werd de definitieve training vastgesteld. De invulfolder werd in drie opeenvolgende rondes voorgelegd aan in totaal tien ouderen en naasten en twee geriaters voordat de folder definitief was.

III Implementatiefase: de training werd gegeven aan vier geriaters in het Amsterdam UMC (locatie AMC) en vijf geriaters in het MC Slotervaart. De invulfolder werd aan 108 oude patiënten gestuurd die mee wilden doen aan het onderzoek en een afspraak hadden op de polikliniek geriatrie van deze twee ziekenhuizen. De geriaters gaven de training gemiddeld het rapportcijfer 8. Ze gaven aan dat ze met name geleerd hebben om de stappen van samen beslissen toe te passen en zich vooral bewust zijn geworden van het belang van het bespreken van doelen. Het kunnen oefenen met een trainingsacteur vonden ze waardevol. Twee derde van de ouderen en naasten die de folder hadden ingevuld vond het een goede en informatieve folder. Om vast te stellen of de training en de invulfolder daadwerkelijk bijdroegen aan meer en beter samen beslissen, werd een tweede video-observatie studie uitgevoerd, de DICO II studie. De resultaten
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daarvan worden beschreven in hoofdstuk 7.

**Hoofdstuk 7: De effecten van de SDM\textsuperscript{MCC} interventie voor ouderen met multimorbiditeit: de DICO-II studie**

Dit hoofdstuk beschrijft de effecten van de SDM\textsuperscript{MCC} interventie (de training voor geriaters en de invulfolder voor ouderen en naasten). Hiervoor zijn de resultaten van de eerste video-observatie studie, de DICO I studie, vergeleken met een tweede video-observatie studie, de DICO II studie. Drie observatoren analyseerden de video opnames van gesprekken tussen geriaters en oudere patiënten en hun naasten met de OPTION\textsuperscript{MCC} om te meten of er meer samen werd beslist. Ook is met behulp van vragenlijsten voor en na het gesprek met de geriater aan patiënten en naasten gevraagd of de manier waarop zij betrokken waren geweest in het gesprek (Perceived Involvement in Care Scale) en hun rol bij het nemen van een besluit (adapted Control Preference Scale) overeenkwam met hoe zij dat vooraf zelf graag hadden gewild. Daarnaast gaven ze aan in hoeverre er naar hun idee samen beslist was (CollaboRATE) en hoe zeker ze waren over het besluit dat was genomen (Decision Conflict Scale). Tenslotte werd met een procesevaluatie bijgehouden hoe de interventie geïmplementeerd werd.

Voor de beide video-observatie studies (de voor- en nameting), werden in totaal 216 oudere patiënten, 133 naasten en 10 geriaters geworven om deel te nemen aan de studies. De gemiddelde leeftijd van de patiënten die deelnamen aan beide studies was 77 jaar en 56% was vrouw. Er waren geen belangrijke verschillen qua leeftijd en geslacht tussen de deelnemers en de patiënten die niet meededen en er waren ook geen belangrijke verschillen in achtergrondkenmerken tussen de deelnemers aan de voor- en nameting. Dat betekent dat de groepen van de voor- en nameting vergelijkbaar zijn en dat de resultaten van het onderzoek ook van toepassing zouden kunnen zijn op oudere patiënten buiten de onderzoeksgroep.

Het samen beslissen is geobserveerd en gemeten met de OPTION\textsuperscript{MCC} (zie hoofdstuk 5). Bij drie items observeerden we na de interventie een significante verbetering. Dat zijn de items die gingen over het bespreken van doelen met patiënten, het uittegen van de verschillende behandelmogelijkheden met hun voor- en nadelen, en het samen nemen van een besluit. Echter, bij twee items observeerden we een significante achteruitgang. Dat zijn de items die gingen over het bespreken dat de inbreng van de patiënt net zo belangrijk is als de inbreng van de geriater (zgn. ‘partnerschap’), en over het evalueren van het besluitvormingsproces. De combinatie van verbetering bij sommige items en achteruitgang bij andere items leidde gemiddeld genomen niet tot verbetering, dat wil zeggen dat er onder de streep (de totale score op de OPTION\textsuperscript{MCC}) geen belangrijk verschil leek te zijn na de implementatie van de SDM\textsuperscript{MCC} interventie. Ook de persoonlijke ervaringen van patiënten en naasten in de nameting met betrekking tot het samen beslissen veranderden niet in vergelijking met de voormeting. Uit de procesevaluatie kwam naar voren dat de invulfolder door patiënten overwegend positief beoordeeld werd, maar dat hun voorbereiding op het gesprek (de antwoorden op de vragen in de folder) slechts in 12% van de gesprekken met de geriater aan de orde kwam.

Wat leren we van dit onderzoek? We zien dat de interventie leidt tot het beter bespreken van persoonlijke doelen, een betere uitleg van behandelmogelijkheden en dat de patiënt en naaste meer betrokken zijn bij het gezamenlijk nemen van
een beslissing. De echte winst die dit kan opleveren is dat de genomen besluiten beter bijdragen aan de persoonlijke gezondheidsdoelen van de patiënt. Deze winst is echter pas op langere termijn zichtbaar en hebben we in dit onderzoek niet kunnen meten. Er zijn verschillende mogelijke verklaringen waarom we gemiddeld genomen geen verschil vonden tussen de voor- en nameting met de OPTIONMCC. Eén verklaring is dat wanneer geriaters, binnen de vastgestelde tijdsperiode van een gesprek op de polikliniek, meer tijd besteden aan het ene onderwerp dit mogelijk ten koste gaat van het andere. Een andere verklaring is dat het bespreken van doelen en het beter uitleggen van mogelijkheden makkelijker te verbeteren is dan bespreken dat je met de patiënt een ‘partnerschap’ wilt aangaan waarbij ieders inbreng even belangrijk is. Ook het evalueren van het besluitvormingsproces kan spannend zijn omdat de geriater zich daarbij kwetsbaar opstelt: ‘Heb ik het als dokter goed met u besproken?’ We zullen bij vervolging van de handelsoordeel besteden aan deze twee onderwerpen. Omdat de resultaten van één geriater sterk afwijken van de andere geriaters, hebben we een subgroep analyse uitgevoerd. Daaruit kwam naar voren dat de totale score bij de andere artsen wel significant was verbeterd. Dit suggereert dat een goede implementatie belangrijk is. Tenslotte is het opvallend dat de folder wel werd ingevuld maar bijna niet ter sprake kwam. Dit kwam doordat de ouderen niet zelf het initiatief namen om de folder te bespreken met de geriater, en omdat de geriater niet vroeg naar de folder. Uit onderzoek blijkt dat dit zelfs een averechts effect kan hebben omdat aan de verwachtingen van de patiënt (het bespreken van wat hij ingevuld heeft) niet voldaan wordt. In de vervolgprojecten zullen we daarom veel aandacht aan de rol van de geriater bij het bespreken van de folder.

Hoofdstuk 8: De invloed van gezondheidsvaardigheden, opleiding, kwetsbaarheid en angst op samen beslissen met ouderen

Tenslotte onderzochten we in hoeverre persoonlijke kenmerken van ouderen een rol spelen bij het samen beslissen. We waren in dit hoofdstuk met name geïnteresseerd in de invloed van opleiding, angst, kwetsbaarheid en gezondheidsvaardigheden op hoe ouderen het samen beslissen ervaren en op hun (on)zekerheid over het genomen besluit. Tevens is onderzocht welke rol participatie van de patiënt tijdens het gesprek speelde bij hoe ouderen het samen beslissen achteraf ervaarden en hoe (on)zeker zij zich voelden over het genomen besluit.

Voor dit onderzoek zijn de data geanalyseerd van de 216 ouderen die aan de DICO I en de DICO II studie (hoofdstuk 5 en 7) deelnamen. Met bestaande meetinstrumenten werden de persoonlijke kenmerken van de ouderen in kaart gebracht: opleiding (laag, middel, hoog), angst (STAI-6), kwetsbaarheid (GFI) en gezondheidsvaardigheden (SAHL-D22). Het ‘ervaren van samen beslissen’ werd vastgesteld met de CollaboRATE en de ‘(on)zekerheid over het besluit’ met de Decisional Conflict Scale. De participatie van patiënten in het samen beslissen werd gemeten met deObserver OPTIONMCC. De samenhang tussen de verschillende factoren werd met statistische analyses (een stapsgewijze gemixte multilineaire regressie en een mediatie analyse) berekend.
De uitkomsten van deze analyses zijn dat ouderen met een lager opleidingsniveau en minder angst positiever waren over hoe zij achteraf het samen beslissen proces ervaren hadden. Een hoger opleidingsniveau, lagere gezondheidsvaardigheden en meer angst werden geassocieerd met meer onzekerheid over de beslissing. Daarnaast hingen een hogere leeftijd en lagere gezondheidsvaardigheden samen met een lagere participatie in samen beslissen tijdens het consult. De mediatie-analyse liet vervolgens zien dat ouderen met lagere gezondheidsvaardigheden die actiever participeerden in samen beslissen tijdens het consult na afloop van het consult minder onzekerheid over de beslissing rapporteerden. De resultaten van deze studie onderbouwen de bevindingen uit het literatuuronderzoek (hoofdstuk 2) dat het bij het samen beslissen belangrijk is om rekening te houden met de persoonlijke kenmerken van ouderen. Dit geldt vooral voor ouderen met weinig gezondheidsvaardigheden. Als het lukt om hen beter te betrekken bij het samen beslissen heeft dit een gunstig effect op de uitkomsten, met name bij onzekerheid over de beslissing.

Hoofdstuk 9: Discussie

Dit laatste hoofdstuk bespreekt de belangrijkste bevindingen uit dit proefschrift en verantwoordt de methodologische keuzes. Tenslotte worden aanbevelingen gedaan voor verder onderzoek, beleid en praktijk. Dit proefschrift over samen beslissen benadrukt het belang van het bespreken van persoonlijke doelen (gezondheid gerelateerde uitkomsten) met ouderen met multimorbiditeit. We vonden dat voor veel ouderen het zelfstandig kunnen functioneren, sociale contacten, emotioneel welzijn, kwaliteit van leven en het kunnen omgaan met ziekte en beperkingen in het dagelijks leven belangrijke onderwerpen zijn om te bespreken. Het inbrengen van de kennis die ouderen zelf hebben over hun persoonlijke situatie en wat ze daarbij belangrijk vinden is een belangrijke voorwaarde voor samen beslissen. Naasten zoals familieleden en vrienden kunnen ouderen ondersteunen in het samen beslissen. Maar naasten hebben soms ook hun eigen wensen en behoeften die soms tegenstrijdig kunnen zijn. Het is daarom belangrijk om ook de naaste goed te betrekken bij het gesprek en aan de verschillende overwegingen aandacht te schenken. Zorgverleners ervaren enerzijds organisatorische beperkingen rondom samen beslissen, anderzijds geven zij ook aan dat er vaak onvoldoende wetenschappelijk bewijs is over de voor- en nadelen van behandelingen bij ouderen wat het samen beslissen gesprek kan bemoeilijken. Het ‘Dynamisch gespreksmodel voor samen beslissen met kwetsbare ouderen’ werd geïmplementeerd op twee poliklinieken geriatrie door middel van een training voor geriaters en een invulfolder voor patiënten. Met behulp van het observatie instrument Observer OPTION\textsuperscript{MCC} werd geconstateerd dat het bespreken van persoonlijke doelen en het bespreken van de verschillende, daarbij van toepassing zijnde, behandelmogelijkheden met hun voor- en nadelen en het gezamenlijk nemen van de uiteindelijke beslissing significant verbeterden na de interventie. Omdat in de eerdere hoofdstukken van dit proefschrift is vastgesteld dat het verkennen van persoonlijke doelen bij ouderen met multimorbiditeit het uitgangspunt moet zijn voor het gesprek over behandelmogelijkheden, is het een belangrijke winst dat dit ook inderdaad na de interventie significant verbeterd is. We verwachten dat behandelingen die gekozen zijn op basis van het uitgangspunt ‘In hoeverre draagt dit bij tot iemands
Samenvatting

persoonlijke gezondheidsdoelen?’ op langere termijn van grotere betekenis zijn voor ouderen dan wanneer alleen vanuit een ziekte of aandoening geredeneerd wordt. Het samen beslissen kan echter nog wel verder verbeterd worden, met name met betrekking tot het bespreken van de samenwerking (partnerschap) en het evalueren van de beslissing. Dit betekent voor de toekomst dat aan deze aspecten meer aandacht moet worden besteed, bijvoorbeeld in trainingen over samen beslissen met ouderen. Daarbij wordt tevens aanbevolen om meer aandacht te besteden aan de veranderkundige aspecten van het samen beslissen voor zorgverleners in hun dagelijkse praktijkvoering, zoals het bespreken van de folder met patiënten. Dit proefschrift geeft een aantal aanbevelingen voor toekomstig onderzoek, zoals meer aandacht voor het samen beslissen bij andere zorgprofessionals dan artsen en meer onderzoek naar het beter betrekken van naasten bij het samen beslissen. Ook is het interessant om te onderzoeken hoe PROM’s optimaal gebruikt kunnen worden bij het samen beslissen en om te vervolgen in hoeverre persoonlijke doelen m.b.t. gezondheidsuitkomsten ook echt bereikt worden in de loop van de tijd. Tenslotte heeft het gebruik van de OPTIONMCC tot nieuwe aandachtspunten geleid, zoals de behoefte aan een geïntegreerde totaal score voor het samen beslissen en de uitdaging om non-verbaal gedrag in relatie tot samen beslissen te meten. De bevindingen van dit proefschrift zijn ondersteunend aan diverse actuele beleidsontwikkelingen in de ouderenzorg in Nederland, zoals het ZonMw rapport ‘Meer aandacht voor ouderen in het ziekenhuis; kiezen voor zorg met beter uitkomsten voor de ouderen patiënt’ (2019) en het ‘Visiedocument Samen beslissen’ van de Federatie Medisch Specialisten (2019). Aanvullend op de onderzoeksmatige aanbevelingen wordt beschreven hoe de resultaten van dit proefschrift verder hun weg vinden in de dagelijkse praktijk van afdelingen geriatrie in Nederland. De Nederlandse Vereniging voor Klinische Geriatrie (NVKG) heeft het samen beslissen met de PROM TOPICS-SF omarmd en streeft naar een landelijke implementatie van het samen beslissen met de TOPICS-SF op alle afdelingen geriatrie in samenwerking met kennisorganisatie Vilans. De in dit onderzoek ontwikkelde training (inmiddels beschikbaar als e-learning via https://samenbeslissen.dialoguetrainer.com) en de patiëntentfolder (www.zorgvoorbeter.nl/samen-beslissen) zijn belangrijke speerpunten in dit implementatie programma. Dit in samenwerking met ouderen zelf, vertegenwoordigd door senioren organisatie KBO-PCOB en migranten organisatie NOOM. Inzet is om door middel van informatie bijeenkomsten en nieuwsberichten ouderen te stimuleren om zich voor te bereiden op gesprekken in het ziekenhuis. Als spin-off van dit proefschrift zijn in samenwerking met MantelzorgNL tips en een artikel gepubliceerd om naasten te ondersteunen bij het samen beslissen met ouderen. Deze inspanningen dragen bij aan persoonsgerichte, waardevolle zorg voor ouderen met multimorbiditeit; zorg die ‘er toe doet’!
PhD Portfolio

Name: Ruth Pel-Littel
PhD period: 2014 - 2020
PhD supervisors: Prof. dr. W.J.M. Scholte op Reimer
Prof. dr. J.C.M. van Weert
PhD co-supervisors: Prof. dr. B.M. Buurman
Prof. dr. M.M. Minkman

Courses

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<tr>
<th>Course</th>
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<td>Medical Literature: Searching for a Systematic Review</td>
<td>2014</td>
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<td>Medical Literature: Endnote</td>
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<td>SPSS basis</td>
<td>2015</td>
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<td>Clinical Epidemiology: Systematic Reviews</td>
<td>2015</td>
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<td>Narratief Onderzoek</td>
<td>2016</td>
<td>0.7</td>
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<tr>
<td>Observational clinical epidemiology</td>
<td>2016</td>
<td>0.6</td>
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<tr>
<td>Scientific Writing in English for Publication</td>
<td>2015</td>
<td>1.5</td>
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<td>Clinical Data Management</td>
<td>2017</td>
<td>0.3</td>
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<td>Practical Biostatistics</td>
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<tr>
<td>Qualitative Health Research.</td>
<td>2018</td>
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<tr>
<td>Clinimetrics: assessing measurement properties of health measurement instruments</td>
<td>2018</td>
<td>0.9</td>
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Seminars, workshops and masterclasses

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<th>Seminar/message</th>
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<th>Workload</th>
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<tr>
<td>Masterclass ‘Research into Shared Decision making’ by prof.dr. Glyn Elwyn</td>
<td>2015</td>
<td>0.1</td>
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<tr>
<td>Spinoza lecture ‘Dare to Share’ by prof.dr. Glyn Elwyn</td>
<td>2015</td>
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<tr>
<td>Researchmeeting ‘The general philosophy behind the development of conversation aids’ by prof. dr. Victor Montori</td>
<td>2017</td>
<td>0.1</td>
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<tr>
<td>Spinoza lecture ‘a call for SDM’ by prof.dr. Victor Montori</td>
<td>2017</td>
<td>0.5</td>
</tr>
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### Oral presentations (selection)

- Implementing shared decision making in outclinic elderly patients with MCC, what is needed, when and by whom? Masterclass 'Research into Shared Decision making', AMC, Amsterdam  
  2015 0.5
- Hoe betrek je de patient bij keuzes? V&VN Oncologiedagen, Ede  
  2015 0.5
- Zie de persoon achter de patiënt: doe iets wat er toe doet! Verenso najaarscongres ‘Start & Stop’, Ede  
  2015 0.5
- Samen beslissen, beslist zo makkelijk nog niet! Een nieuwe generatie ouderenzorg, Nieuwegein  
  2015 0.5
- Shared decision making in much needed: Comparing the Health State Preferences of Older Persons, Informal Caregivers and Healthcare professionals: A Vignette Study & Beyond survival: what matters to older persons with multiple chronic conditions. 1st International Conference of Primary Care and Public Health, Congress of Person Centred Medicine, London  
  2015 0.5
- What matters to older persons with multiple chronic conditions 5th European Nursing Congress, Rotterdam  
  2016 0.5
- Shared Decision Making. Werkvelddebat #3-Zelfmanagement: Kracht of Last? Hogeschool van Amsterdam, Amsterdam  
  2016 0.5
- Samen beslissen (shared decision making) met kwetsbare ouderen. Geriatriedagen, Den Bosch  
  2016 0.5
- Shared decision making during geriatric consultations, an observational study. Research meeting 'The general philosophy behind the development of conversation aids', AMC, Amsterdam  
  2017 0.5
- Does multimorbidity influence personal views on the ageing process: a qualitative analysis 9th International Shared Decision Making Conference, Lyon  
  2017 0.5
- Barriers and facilitators to implementing shared decision-making in older patients with multiple chronic conditions; a systematic review. 9th International Shared Decision Making Conference, Lyon  
  2017 0.5
• The DICO study: Decision making In Complex Old populations; an observational study. 9th International Shared Decision Making Conference, Lyon 2017 0.5
• De Oefendokter. Een nieuwe generatie ouderen(zorg), Nieuwegein 2018 0.5
• In gesprek met de patiënt II - Communicatie in de spreekkamer. 3rd Annual conference of the Nederlands Geheugenpoli Netwerk, Utrecht 2018 0.5
• Samen beslissen met ouderen en naasten. Tussen Weten en Doen II (ZonMw), Nijmegen 2018 0.5
• Shared decision making with older people and informal caregivers; a video observational study. 16th International Conference on Communication in Healthcare (ICCH), Porto 2018 0.5
• Samen beslissen bij ouderen met multimorbiditeit. Conference ‘Samen beslissen met kwetsbare mensen: een uitdaging’, Utrecht 2018 0.5
• The Option-Old: Measuring the Extent to Which Clinicians Involve Older Patients and Informal Caregivers in Triadic Decision-Making. 17th Biennial European Conference of the Society for Medical Decision Making, Leiden 2018 0.5
• Samen beslissen met behulp van patient reported outcome measure (PROM): TOPICS. Geriatriedagen, Den Bosch 2019 0.5
• Samen beslissen met de TOPICS-SF Geriatriedagen, Den Bosch 2020 0.5
• The influence of personal characteristics of older adults on shared decision making. ICCH 2020 online conference 2020 0.5

Poster presentations (selection)
• ADappt; Ondersteuning voor arts en patiënt in het gesprek rondom MCI en dementie. Nederlands Geheugenpoli Netwerk Congres, Utrecht 2017 0.5
• Barriers and facilitators of shared decision making in older patients with chronic conditions; a systematic review. 16th International Conference on Communication in Healthcare (ICCH), Porto 2018 0.5
• Eerste ervaringen met de TOPICS-SF en samen beslissen in de geriatrie. Geriatriedagen, Den Bosch 2020 0.5
• Samen beslissen in de geriatrie. Geriatriedagen, Den Bosch 2020 0.5

Teaching

Lecturing

Amsterdam School of Health Professions, School of Nursing 2017 0.1
• Scholing Samen beslissen TZB
Zorggroep Apeldoorn e.o. 2019 0.9
• Scholing samen beslissen voor paramedici
Nascholing huisartsen regio Friesland (UwZorgWeg) 2020 0.1
• Scholing samen beslissen met ouderen

Supervising

• Nelly Teppich, Master thesis 2016
• Gizem Nida Yilmaz, Research internship 2016
• Esther Moscoviter, Master thesis 2017
• Marieke van Buchem, Research internship 2017
• Liesje Yu, Master thesis 2017
• Ashly Baboeram Panday, Research internship 2017
• Linda Kamperman, Research internship 2018
• Monique van Weeren, Master thesis 2019
• Rebecca van Kleef, Master thesis 2019
• Diny Stekelenburg, Master thesis 2020

E-learning

• De Oefendokter 2018
  www.oefendokter.nl
• Samen beslissen voor zorgprofessionals 2019
  https://samenbeslissen.dialoguetrainer.com

Media

• Vier filmpjes en een brochure: Samen bouwen aan vertrouwen 2016
  www.netwerkpalliatievezorg.nl/rotterdam/Zorgverleners/Samen-Bouwen-aan-Vertrouwen
• Infographic Samen beslissen met ouderen; de ins & outs volgens zorgprofessionals
  www.zorgvoorbeter.nl/samen-beslissen
  2017
• Quiz samen beslissen
  www.zorgvoorbeter.nl/samen-beslissen
  2017
• Patientenfolder samen beslissen
  www.zorgvoorbeter.nl/samen-beslissen
  2018
• Uitleg gespreksmodel samen beslissen met ouderen www.youtube.com/
  watch?v=InqLiAeHo8&t=14s
  2018

Interviews/News

Skipr coverstory; Polderen in de spreekkamer
  2017
NPO Radio 1: Spraakmakers, reactie op de stelling:
  ‘Ziekenhuizen moeten ouderen screenen om
  overbehandeling te voorkomen’.
  2018
Plus magazine: Zelf beslissen over je lichaam
  2018
ZonMw: Gezamenlijke besluitvorming; Effectiviteit
  van de inzet van tools voor samen beslissen met
  ouderen, Interview met projectleider Ruth Pel-Littel
  2019
Magazine Mantelzorger: Hoe stel je je als
  mantelzorger op in gesprekken met de dokter
  2019
Netwerk Courant Dementiezorg voor elkaar: ‘Samen
  beslissen’ toepassen bij mensen met dementie
  2020
KBO-PCOB magazine: ‘SAMEN BESLISSEN’
  2020

Grants (selection)

• ZonMw, programma Kwaliteit van Zorg: Versnellen,
  verbreden, vernieuwen, subsidieronde: Kwaliteit van
  Zorg: Samen Beslissen, projecttitel: DICO Studie:
  Decision making In Complex Old Populations
  2017
• Zorg Instituut Nederland, subsidieregeling
  Transparantie over de Kwaliteit van Zorg, Jaargang
  2018: ‘Gebruiken van uitkomstinformatie bij
  Samen beslissen’, project: Samen beslissen
  bij ouderen met multimorbiditeit: invoering van
  een gespreksmodel op basis van persoonlijke
  uitkomstinformatie.
  2018
Publication list

Scientific publications

1. **Pel-Littel RE**, Buurman BM, Minkman MM, Twisk JWR, Scholte op Reimer WJM, van Weert JCM. The influence of health literacy, education, frailty and anxiety of older adults with multiple chronic conditions on shared decision making: the DICO-study. submitted for publication


11. Kunneman M, Smets EMA, Bouwman FH, Schoonenboom NSM, Zwan MD,


**Practice publications**


voor Elkaar, Utrecht; 2020.
8. **Pel-Littel RE.** 6 tips voor samen beslissen in tijden van Corona. Website KBO-PCOB; 2020.
10. **Pel-Littel RE,** van de Pol MHJ, Hoofdstuk 56 Samen beslissen met kwetsbare ouderen. In: Visser M, Kok AAL, Spiers PE, Buurman BM. Inleiding in de gerontologie en geriatrie. 6e, herziene druk Houten, Bohn Stafleu van Loghum; 2020. p. 345-351
23. **Pel-Littel RE.** Casemanagement voor patiënten met complexe multimorbiditeit *De Praktijk* 2013: 7-9.
33. Pel-Littel RE, Spieker P. De kracht van methodisch werken; ervaringen met het verbetertraject Probleemgedrag Denkbeeld 2010: 30-32.
Dankwoord

'Ik zeg altijd maar: het gaat er niet alleen om wat je kan, maar vooral ook om wie je kent!'

Chiel-Jan Littel

Een proefschrift schrijven is niet alleen een proeve van bekwaamheid om wetenschap te bedrijven, maar ook een proeve in de samenwerking met velen. En dat laatste aspect verschafte mij zeker zoveel (zo niet meer) plezier als het eerste. Allereerst wil ik alle ouderen bedanken die aan de verschillende onderzoeken hebben meegedaan. Vooral de ouderen bij wie video opnames gemaakt mochten worden van hun gesprek met de arts, dank voor uw openheid! In de tweede plaats wil ik de geriaters van het AMC en van het voormalig MC Slotervaart bedanken, het getuigt van durf en lef als je tijdens je gesprekken met patiënten gefilmd wil worden terwijl je weet dat zo’n opname later nog eens kritisch onder de loep genomen wordt. Jullie hebben geholpen om het samen beslissen in de geriatrie op de kaart te zetten.

Mijn (co)promotoren, Prof. Bianca Buurman, dank voor dat telefoontje in 2013 “Zou jij er misschien voor voelen om…”, het was het begin van een prachtige reis. Als het gaat om de oudere patiënt zitten wij op één lijn, en elkaar niet in de weg, maar juist aanvullend. Jij begreep altijd heel goed de focus van mijn onderzoek en hielp om daar stappen in te maken. Ik zie uit naar mooie vervolgprojecten met jou. Prof. Julia van Weert, wat is een promovenda met jou goed af! Als hoogleraar communicatie ben je ook echt een ster in communiceren, ‘you practice what you preach’, bemoedigend, bereikbaar en bekwaam. De directe begeleiding van de meeste onderzoeken was bij jou in goede handen, samen met Bianca. Ook met jou gaan er mooie vervolgonderzoeken komen, dat weet ik zeker! Prof. Wilma Scholte op Reimer, daar waar ik nog weleens wat tunnelgericht naar de eindstreep dacht te marcheren, prikelde jij mij om na te denken over andere paden binnen het promotietraject. Juist het nadenken daarover bracht meer diepgang in mijn proefschrift, veel dank daarvoor! Last but zeker not least: Prof. Mirella Minkman, je zult maar zo’n toppen als ‘baas’ hebben! Dank voor de kans die je me gaf om in dit promotietraject te stappen, en dat je altijd zeker wist dat ik het zou kunnen. Ook jij stimuleerde me tot diepgang in dit proefschrift, daar waar ik tevreden ben met een greppeltje, denk jij in ravijnen! Laten we het erop houden dat dit proefschrift een mooi dal-gehalte heeft.

Ik wil graag alle leden van de oppositiecommissie hartelijk danken voor hun tijd om het proefschrift te beoordelen en mij hier kritisch op te bevragen.

Naast mijn (co)promotoren wil ik ook graag al mijn mede-auteurs bedanken voor hun samenwerking bij de verschillende publicaties: Marjolein Snaterse, Nelly Marela Teppich, Faridi van Etten, Marjon van Rijn, Paulien Vermunt, Gerben ter Riet, Cynthia Hofman, Liesje Yu, Silke Metzelthin, Franca Leeuwis, Jeanet Blom, Marjolein van de Pol, Nida Yilmaz, Linda Tulner, Jos Twisk en Glyn Elwyn.
Dankwoord

Marjolein van de Pol, dankjewel dat ik mijn onderzoek mocht doorbouwen op jouw onderzoekswerk in het Radboudumc naar het ‘Dynamisch model voor samen beslissen met kwetsbare ouderen’. Er lag voor mij een prachtige basis waar ik mee verder kon. Inmiddels hebben wij al verschillende kennisproducten en artikelen voor vakbladen geschreven, we kunnen wel een lijntje ‘Pel&Pol’ producties opzetten denk ik!

Bij de dataverzameling voor de verschillende studies hebben onderzoeksassistenten en studenten een belangrijke rol gespeeld, met name de DICO studie was een intensief project. Zonder Nida Yilmaz, Esther Moscoviter, Liesje Yu en Fatma Isguzarer waren de >200 video opnames er niet gekomen, dank. Nelly Teppich, Ashley Baboeram Panday en Linda Kamperman, dank voor jullie inzet bij andere onderdelen van de studies.

Dit onderzoek was onderdeel van het Complex Care onderzoeksprogramma van het AMC en de HvA, waarin ook Lotte Verweij, Patricia Jepma, Margriet van Iersel en Sara Daliri aan het promoveren zijn. Het was me een genoegen en ik zie uit naar jullie proefschriften!

Mijn paranimfen: Cynthia Hofman, mijn ‘partner in crime’ bij Vilans, jij ziet kansen voordat iemand anders ze ziet. Dankzij de door jou binnengehaalde subsidie kon ik de Delphi studie (Hoofdstuk 4) uitvoeren. Wie kan ik beter naast me hebben op de dag van de verdediging dan jou, met je oog voor detail? Ritsaert Pel, mijn ‘partner in life’, natuurlijk sta je aan mijn zijde op dit belangrijke moment! Als de stelling over de WBGÖ moet worden voorgelezen, dan mag jij als rechtgeaarde jurist dat doen.

Zonder de facilitering van Vilans in tijd, geld en bemoedigende woorden, was ik waarschijnlijk niet aan dit proefschrift begonnen en was het zeker nooit afgekomen. Mogen promoveren in werktijd is op mijn leeftijd een ongekende luxe. Mirella Minkman, Henk Nies, Astraia Ruhl, Annelies Versteegden, dank voor de kans en de mogelijkheid om mij in te zetten voor het onderwerp waar mijn passie ligt! Voor de praktische en mentale support bedank ik mijn collega’s van team Persoonsgerichte Zorg, de vakgroep Onderzoek en Validatie, afdeling Marcom en het secretariaat. Te veel namen om op te noemen, maar Cynthia, Annemarie, Margreet, Seline en Mieke…. jullie zijn toppers!!

Eenmaal in de week toog ik naar het AMC en voelde mij in de volle werkkamer van de promovendi altijd hartelijk welkom. Marjon, Isabel, Lotta, Rosanne, Lucienne, Janet en alle andere promovendi, dank voor de gezelligheid, raad en daad! Jasper, jij bent zo ongeveer de huisopmaker van de AMC geriatrie-proefschriften, dank voor de mooie opmaak en vormgeving van dit boekje.

Het thema samen beslissen met ouderen en de doelgroep geriatrische patiënten, waren niet alleen verankerd in mijn onderzoek, maar ook in verschillende praktijk en ontwikkelprojecten, waarbij praktijk en onderzoek elkaar weer versterkten. Een plezierige samenwerking had ik met het VUmc in het ABIDE project, met DialogueTrainer bij het bouwen van de Oefendokter en de e-learnings, met de
NVKG, KBO-PCOB en NOOM in het implementatie project ‘Samen beslissen met de TOPICS-SF’ en met alle medebestuursleden van het Nederlands Geheugenpoli Netwerk.

In dit dankwoord mogen zeker niet Prof. Marieke Schuurmans en Marianne Lensink ontbreken. Lang geleden stimuleerden jullie mij vanuit de afdeling Geriatrie in het UMCU om verpleegingswetenschap te gaan studeren, en veel ontwikkelkansen tijdens en na deze studie heb ik aan jullie te danken.

Mijn familie en vrienden wil ik bedanken voor hun steun en belangstelling de afgelopen jaren. Tante Tine, als oud-verpleegkundige en actieve 90-jarige kan iedereen een voorbeeld aan u nemen (in de corona tijd leerde u nog met facetime omgaan); u leefde mee met alle ups en downs de afgelopen jaren, dank! Lieve zus Simone, mijn zielsverwant, als ik jou niet had gehad! Hannah, mijn promovenda nichtje in Brighton, ook jij komt er!

Wat had ik graag dit proefschrift aan mijn ouders en schoonouders willen laten zien. Aan mijn moeder Coby, die mij ooit op het pad van de verpleegkunde zette, en aan mijn vader Wim, die de eerste paar jaren van het promoveren nog meeleefde. In het kader van ouderenparticipatie hadden wij afgesproken dat hij paranimf zou zijn bij de verdediging. Van hen beiden leerde ik om lief te hebben en het beste uit jezelf te halen. Mijn schoonvader Piet had het zeker heel leuk gevonden dat er weer een dr. Pel in de familie komt en mijn schoonmoeder Ine was, zelfs in de laatste schemerjaren van haar leven, altijd belangstellend naar hoe het ging met de promotie.

Het laatste woord is natuurlijk gericht tot de parels van mijn hart. Je weet dat je promotie onderzoek ook is doorgedrongen tot je gezin als je dochters steeds vaker zeggen: "Dit is niet echt samen beslissen, hè mama?!". Elisabeth, we begonnen en eindigden ongeveer tegelijk, jij een gymnasium afgerond en ik een proefschrift, niet gek. Dank voor je correctie werk bij de laatste versies van het proefschrift. Wat leuk dat je bij het VUmc je profielwerkstuk ging doen over ‘APOL1 als biomarker voor frontotemporale dementie’. Ik begreep er niet eens alles meer van, maar één ding weet ik zeker, jij komt er wel! Josephine, wat heerlijk om mee te leven in jouw leven van zang, muziek en musical. Allemaal talenten die mij ontbreken, maar je deelt ze gul met ons. Wij dromen samen van de 'Van-life', misschien gaat het ons ook wel lukken om dat project te realiseren. Jij bent altijd positief en bemoedigend, dank! Louise, mijn kleine-lange paardrijmaatje. Eigenlijk is er niets leukers dan met jou te paard door het bos te crossen. Met jouw sociale voelsprieten weet jij hoe ik me voel voordat ik dat zelf door heb, dat is soms lastig, maar meestal prachtig. Ik citeer jouw briefje (bij de bruisballen) tijdens de laatste weekend-proefschriftloodjes: “Voor mama, de promotiekanjer! Als je proefschrift af is ga je maar lekker in bad.”

Ritsaert, mijn liefste. Jouw voorgestelde titel voor mijn proefschrift Liberum Senes (vrije ouderen), gebaseerd op jouw passie als jurist voor de Mare liberum is het helaas niet geworden maar het staat nu toch in dit proefschrift. Samen werken, samen zorgen is ons adagium. En daarmee hebben we een prachtig gezin en
Dankwoord

mooi werk. Dank voor je aanmoediging en steun. Schrijfretraites, congresbezoek en een studiereis naar de VS, jij zegt eerder dan ik: “Doen!” Om mijn lieve schoonmoeder te citeren: ‘Wie met jou getrouwd is, is goed af’.

Ik ben een gelukkig en dankbaar mens.
Curriculum Vitae


Sinds april 2008 werkt Ruth als adviseur en onderzoeker bij Vilans (landelijk kenniscentrum langdurige zorg) op de thema’s Kwetsbare ouderen, Persoonsgerichte Zorg en Samen Beslissen. Zij voerde projecten uit in de verpleeghuiszorg (Zorg voor Beter programma), de huisartsenzorg (Guided Care), het onderwijs (Kennisbundels voor ROC’s) en stond aan de start van het implementatie programma Beter Oud (NPO de markt op). Rode draad in al die projecten is Ruth’s blijvende passie om persoonsgerichte zorg te realiseren voor de oudere patiënt met meerdere aandoeningen (multimorbiditeit).

In 2014 ontstond voor Ruth de kans om vanuit een samenwerking tussen de afdeling Ouderengeneeskunde van het AMC en Vilans een promotie onderzoek te starten naar het onderwerp Samen beslissen met oudere met multimorbiditeit en hun naasten. Naast de wetenschappelijke output die een promotieonderzoek oplevert, kent dit project inmiddels een mooie spin-off naar praktische kennisproducten voor zorgverleners en voor ouderen, en zijn er mooie vervolgprojecten opgestart over dit onderwerp.

Ruth woont in Utrecht met haar man Ritsaert en hun drie tienerdochters Elisabeth, Josephine en Louise.

Haar promotie onderzoek was een vruchtbare samenwerking tussen de afdeling Ouderegeneeskunde van het AMC, Vilans, kenniscentrum ACHIEVE van de Hogeschool van Amsterdam, de afdeling Communicatiewetenschap van de Universiteit van Amsterdam en Tilburg University. De resultaten en aanbevelingen uit dit proefschrift worden inmiddels in verschillende ziekenhuizen gebruikt. Bij de verdere uitrol zijn de Nederlandse Vereniging voor Klinische Geriatrie en senioren organisatie KBO-PCOB betrokken, samen met Vilans.