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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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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 conditions¹⁻³. 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 condition⁵⁻⁸. Because of the worldwide ageing population, this number is increasing rapidly⁹. 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 pain⁷. 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 be¹.

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 treatment⁹ 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 patient¹⁷. 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 mass¹³. 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'.

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'¹⁸. 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 equity¹⁹.

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 symptom²⁰. 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?'²¹.

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.'*²². 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 possible²³.

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'²⁴. 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 life²⁵. 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 patients²⁶⁻²⁸. 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 dementia²⁹. Second, for older adults with MCCs, personal health outcomes became more determinative in choosing and weighing options than disease specific outcomes^{30, 31}. 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 healthcare³². 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^{31, 33}. 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^{34, 35}.

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:^{18, 19, 36}

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 process³¹. 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 professionals³⁷⁻⁴⁰.

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)³¹. 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'³⁵. Moreover, one additional last step, 'Evaluation', is added in the model. This model addresses specific issues as described above for SDM in older adults,

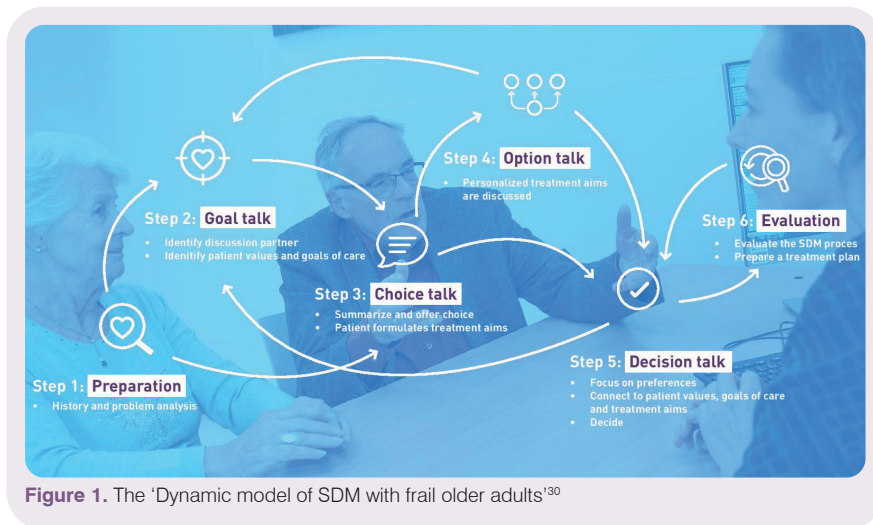


Figure 1. The 'Dynamic model of SDM with frail older adults'³⁰

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 applicable⁴⁹⁻⁵¹. 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 schedules⁵². 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*

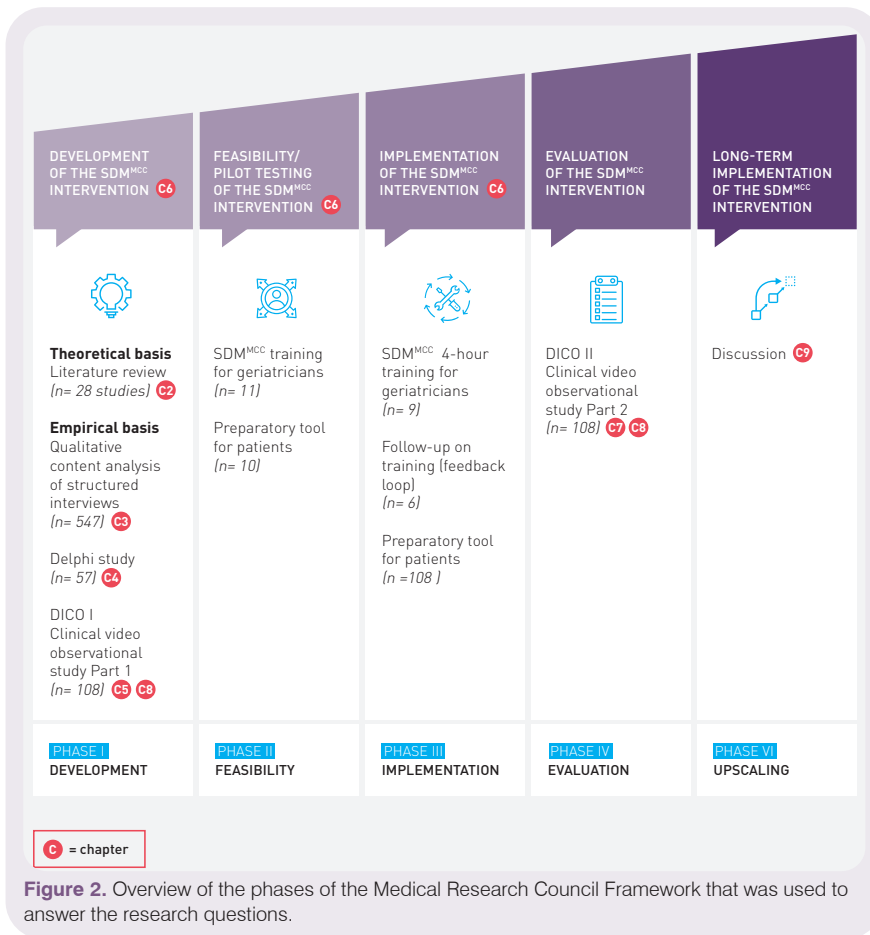


Figure 2. Overview of the phases of the Medical Research Council Framework that was used to answer the research questions.

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.'⁵³. 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 outcomes^{54, 55}. However, priorities on personal health outcomes may shift over time. There is an assumption that people who are already

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 yet⁵⁶. 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 state⁵⁶. 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 activities⁵⁷. 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 making⁵⁸. 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 MCCs⁵⁹. 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 conversations⁶⁰. 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 scales⁶¹⁻⁶⁴. 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'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 scales⁶⁵. 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 used^{41, 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 process^{13, 15, 39, 58, 66-70}. But older adults vary in whether they want and can participate in SDM^{67, 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

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 process⁷⁴⁻⁷⁸. 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 SDM⁷⁹.

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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