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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Publication date
2020

Document Version
Other version

License
Other

Citation for published version (APA):
Pel-Littel, R. E. (2020). 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. [Thesis, fully internal, Universiteit van Amsterdam].

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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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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...
Chapter 2

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)\(^1\).\(^2\)\(^3\),\(^4\). 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 < .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\(^4\).\(^1\)\(^-\)\(^5\)\(^9\), five studies used a quantitative design\(^6\).\(^0\)\(^-\)\(^6\)\(^4\) and four studies used a mixed-method design\(^6\)\(^5\)\(^-\)\(^6\)\(^8\). 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\(^4\).\(^1\)\(^,\)\(^4\)\(^3\)\(^,\)\(^4\)\(^5\)\(^,\)\(^4\)\(^6\)\(^,\)\(^4\)\(^8\)\(^,\)\(^4\)\(^9\)\(^,\)\(^6\)\(^2\)\(^-\)\(^6\)\(^4\)\(^,\)\(^3\), three studies (11%) focused on the informal caregiver perspective\(^4\)\(^2\)\(^,\)\(^5\)\(^7\)\(^,\)\(^6\), eight studies (29%) reported on the health professional perspective, and 7 studies (25%) reported more than one perspective\(^5\)\(^5\)\(^,\)\(^5\)\(^6\)\(^,\)\(^5\)\(^8\)\(^,\)\(^6\)\(^6\)\(^-\)\(^6\)\(^8\)\(^,\)\(^6\)\(^9\). Decisions were about medical treatment\(^4\)\(^4\)\(^,\)\(^4\)\(^5\)\(^,\)\(^5\)\(^7\)\(^,\)\(^5\)\(^8\)\(^,\)\(^6\)\(^1\), medication\(^4\)\(^1\)\(^,\)\(^5\)\(^3\), goals of care\(^5\)\(^0\)\(^,\)\(^5\)\(^2\)\(^,\)\(^5\)\(^4\)\(^,\)\(^5\)\(^6\)\(^,\)\(^6\)\(^8\), daily life and lifestyle\(^4\)\(^8\)\(^,\)\(^5\)\(^8\)\(^,\)\(^6\)\(^0\), hospital admission or discharge\(^4\)\(^2\)\(^,\)\(^4\)\(^3\)\(^,\)\(^5\)\(^1\)\(^,\)\(^6\)\(^1\) and ethical or end-of-life dilemmas\(^4\)\(^6\)\(^,\)\(^4\)\(^9\).

Ten studies were based in a hospital setting\(^4\)\(^2\)\(^-\)\(^4\)\(^5\)\(^,\)\(^5\)\(^0\)\(^,\)\(^5\)\(^1\)\(^,\)\(^5\)\(^3\)\(^,\)\(^5\)\(^8\)\(^,\)\(^6\)\(^4\)\(^,\)\(^6\)\(^7\), six in a primary care setting\(^4\)\(^1\)\(^,\)\(^4\)\(^7\)\(^,\)\(^5\)\(^5\)\(^,\)\(^5\)\(^9\)\(^,\)\(^6\)\(^2\)\(^,\)\(^6\)\(^5\), four in a community care setting\(^4\)\(^6\)\(^,\)\(^5\)\(^7\)\(^,\)\(^6\)\(^0\)\(^,\)\(^6\)\(^3\)\(^,\)\(^6\)\(^9\), one in a long-term care setting\(^4\)\(^8\), one in a hospice\(^4\)\(^9\), one in a post-acute residential care setting\(^6\)\(^1\), one in a rehabilitation setting\(^6\)\(^8\), and one in a geropsychiatry inpatient unit\(^5\)\(^2\). Three studies were based in a combined setting, e.g., hospital and primary care\(^5\)\(^4\)\(^,\)\(^5\)\(^6\)\(^,\)\(^6\)\(^6\). 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\(^6\)\(^3\).
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 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
| First author | Setting          | Country   | Design study | Reporting focus\(^a\): Barriers (B) and/or Facilitators (F) | Perspective\(^b\) | Participants (n) | % Female | Mean age of patients (years) (if not available: age range) |
|-------------|-----------------|-----------|--------------|-------------------------------------------------------------|------------------|------------------|----------|----------------------------------------------------------|
| Funk\(^48\), 2004 | LTC facilities | Canada    | Qualitative  | B & F                                                       | Patients         | 100 patients    | 82       | 85                                                      |
| Gauthier\(^49\), 2005 | hospital        | U.S.A.    | Qualitative  | B & F                                                       | Patients         | 13 patients     | 62       | 72                                                      |
| Naik\(^50\), 2011 | primary care    | U.S.A.    | Quantitative | B                                                            | Patients         | 100 patients    | 100      | 71                                                      |
| Belcher\(^41\), 2006 | primary care    | U.S.A.    | Qualitative  | B & F                                                       | Patients         | 51 patients,    | 63       | 77                                                      |
| Chi\(^43\), 2017 | community care  | U.S.A.    | Quantitative | B                                                            | Patients         | 2017 patients   | 57       | range 65 >85                                            |
| Dyrstad\(^43\), 2015 | hospital        | Norway    | Qualitative  | B & F                                                       | Patients         | 41 patients     | 46       | 86                                                      |
| Ekdahl\(^45\), 2010 | hospital        | Sweden    | Qualitative  | B & F                                                       | Patients         | 15 patients     | 67       | 84                                                      |
| Ekdahl\(^64\), 2011 | hospital        | Sweden    | Quantitative | B                                                            | Patients         | 156 patients    | 49       | 83.1                                                    |
| Erickson\(^46\), 1989 | community care  | U.S.A.    | Qualitative  | B (case study)                                              | Patients         | 1 patient       | 100      | 75                                                      |
| Petrillo\(^58\), 2018 | hospital        | U.S.A.    | Qualitative  | F                                                           | Patients and informal caregivers | 38 patients 31 informal caregivers | 48 (total group) | 78                                                      |
| Riffin\(^59\), 2018 | primary care    | U.S.A.    | Qualitative  | B                                                           | Patients and informal caregivers | 20 patients 20 informal caregivers | 61       | 82                                                      |
| Study                          | Setting               | Country       | Method          | Participants | SDM Role                       | Sample Size Details                                      |
|-------------------------------|-----------------------|---------------|-----------------|--------------|--------------------------------|----------------------------------------------------------|
| Kiselev66, 2017               | hospital & community  | Germany       | Mixed methods   | B&F          | Patients and health professionals | 283 patients (clinicians, nurses, therapists, psychologist, social worker) |
| Rose68, 2018                  | rehabilitation        | U.K.          | Mixed methods   | B            | Patients and health professionals | 40 patients (rehabilitation staff)                        |
| Ferris56, 2018                | health care users and | U.S.A.        | Qualitative     | B&F          | Patients, informal caregivers and health professionals | 6 patients or informal caregivers, rehabilitation staff, clinicians, therapists, social workers |
| Doekhie55                     | primary care          | The Netherlands | Qualitative     | B            | Patients, informal caregivers and health professionals | 19 patients (clinicians, nurses, therapists) |
| Puts67, 2017                  | hospital              | Canada        | Mixed methods   | B            | Patients, informal caregivers and health professionals | 29 patients (oncologists and family physicians) |
| Bragstad42, 2014              | hospital              | U.S.A.        | Qualitative     | B            | Informal caregivers              | 19 informal caregivers                                    |
| Menne60, 2008                 | community care        | U.S.A.        | Quantitative    | B&F          | Informal caregivers              | 215 informal caregivers                                   |
| Peacock57, 2017               | community care        | Canada        | Qualitative     | B            | Informal caregivers              | 18 informal caregivers                                    |

Notes:
- unk*: unknown
- 74.4
- 83
- unk.
- unk.
- unk.
- unk.
- Resp.
- n.a.**
- n.a.
- n.a.
| Study | Year | Setting | Country | Design | Focus | Perspective | N & Age | Participants |
|-------|------|---------|---------|--------|-------|-------------|--------|--------------|
| Ekdahl | 2012 | hospital | Sweden | Qualitative | B&F | Health professionals | 29 physicians | n.a. |
| Fried | 2011 | primary care | U.S.A. | Qualitative | B | Health professionals | 40 physicians | n.a. |
| Blaum | 2018 | primary care & hospital | U.S.A. | Qualitative | B | Health professionals | 9 general practitioners, 5 cardiologists | n.a. |
| Gopalraj | 2012 | hospital | U.S.A. | Qualitative (case study) | B&F | Health professionals | 1 patient | 100 94 |
| Milte | 2015 | geropsychiatry inpatient unit | Australia | Quantitative | B | Health professionals | 2 geriatricians | 59 n.a. |
| Schuling | 2012 | hospital | The Netherlands | Qualitative | B | Health professionals | 13 physicians | n.a. |
| Molinari | 2016 | geropsychiatry inpatient unit | U.S.A. | Qualitative (case study) | F | Health professionals | 1 patient | n.a. |
| Légard | 2013 | primary care | Canada | Mixed methods | B&F | Health professionals | Participants: a) 276 home care providers b) 7 members health care team c) 8 managers | n.a. |
| Lindhardt | 2008 | hospital | Sweden | Qualitative | B&F | Health professionals | 8 nurses | 100 n.a. |

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

*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)\(^43, 45, 64\) and to participate in decision making (PP)\(^49, 64\). Patients suffering from MCC are less likely to participate in SDM and worry about the burden of a treatment regime (PP/IP/HP)\(^47, 56, 57, 63\). 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)\(^44, 45, 50, 60, 64\), not being able to express preferences (HP)\(^44\), and not wanting (HP)\(^61\) or not being able (PP)\(^45\) to partake in decision making. Physical impairments can influence compliance (HP)\(^47\), whereas severe illness (PP)\(^49\) 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)\(^47, 53, 56\). 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)\(^41, 43, 48\). Additionally, having personal values, such as religion, views on survival and suffering, and self-sufficiency facilitates the SDM process (PP/IP)\(^58\). 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/HP)\(^41, 45, 50\). 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)\(^41, 48\). On the other hand, some patients reported feeling that health professionals undervalue the expertise of patients (P)\(^55\). 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)\(^42, 43\). 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)\(^42, 43, 45, 55\).

**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)\(^44, 50\). 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/HP)\(^41, 43, 61\).
| Factor                        | Barriers (number of studies in which this factor was identified as a barrier)                                                                 | Facilitators (number of studies in which this factor was identified as a facilitator)                                                                 |
|------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|
| Predisposing factors         | Patient characteristics                                                                                                                  |                                                                                                                                                |
|                              | Being in poor health: 13                                                                                                                  | Prior exposure to illness/decision making point: 4                                                                                              |
|                              | Cognitive/physical impairments: 13                                                                                                        | Personal values: 1                                                                                                                             |
|                              | Lower level of education: 5                                                                                                               | Being in good health: 1                                                                                                                        |
|                              | Age: 4                                                                                                                                     | Long term patient: None*                                                                                                                        |
|                              | Poor articulation: 4                                                                                                                       |                                                                                                                                                |
|                              | Difference in personal characteristics: None                                                                                               |                                                                                                                                                |
|                              | Health condition - stigma/discrimination: 2                                                                                               |                                                                                                                                                |
|                              | Ethnicity: 1                                                                                                                               |                                                                                                                                                |
|                              | Long term patient: 1                                                                                                                        |                                                                                                                                                |
|                              | Prior exposure to illness/decision making point: 4                                                                                          |                                                                                                                                                |
|                              | Personal values: 1                                                                                                                          |                                                                                                                                                |
|                              | Being in good health: 1                                                                                                                     |                                                                                                                                                |
|                              | Long term patient: None*                                                                                                                    |                                                                                                                                                |
| Decision characteristics     | Disease-based decision models (guidelines): 3                                                                                             | When decisions are allowed that are inconsistent with guidelines: 1                                                                            |
|                              | Burden of treatment regimen: 2                                                                                                             | Major decision: 1                                                                                                                             |
|                              | Shock of receiving diagnosis: 2                                                                                                            | Timing along the illness trajectory: None                                                                                                |
|                              | Minor decision: 1                                                                                                                          | Minor decision: None                                                                                                                           |
|                              | Timing along the illness trajectory: None                                                                                                  | Time to come to terms with diagnosis: None                                                                                                    |
|                              | Major decision: None                                                                                                                        |                                                                                                                                                |
|                              | Embarrassing or sensitive topics: None                                                                                                     |                                                                                                                                                |
| Interactional context factors| Power (im)balance in the patient-clinician relationship                                                                                      | Presumptions about the patient role                                                                                                             |
|                              | Presumptions about the patient role                                                                                                       | Having explicit ‘permission’ to participate in SDM: 4                                                                                           |
|                              | Not having explicit ‘permission’ to participate in SDM: 6                                                                                   | Perceived acceptability of asking the clinician questions: None                                                                               |
|                              | Expectation of the clinician making the decisions: 2                                                                                       |                                                                                                                                                |
|                              | Desire to act as a ‘good’ patient (driven by fear of consequences): 1                                                                         |                                                                                                                                                |
|                              | Belief that clinicians do not want patients involved: 1                                                                                     |                                                                                                                                                |
|                              | Perceived acceptability of asking the clinician questions: 1                                                                               |                                                                                                                                                |
|                              | Clinicians reinforces passivity by rewarding the behaviour: None                                                                            |                                                                                                                                                |
Table 2. Continued

| Characteristics | Barriers/Facilitators                                                                 |
|-----------------|-------------------------------------------------------------------------------------|
| **Interpersonal characteristics of the clinician** | Patients undervalue their expertise relative to clinicians: 3 ‘Doctor knows best’ and patients have ‘inferior’ knowledge: 2 Patients are not capable of understanding medical/technical information: 2 |
|                 | Clinicians with poor interpersonal skills: 5 Authoritarian HCPs: 4 Clinician does not listen to patients concerns: 2 Perceptions that clinicians are already doing SDM: 1 Lack of individualized approach and not asked about preferences: 1 Clinician does not address patient directly: 1 Poor relationship with clinician: None |

| **Trust** | Patients undervalue their expertise relative to clinicians: Recognizing there are two experts in the medical encounter: 5 |
|-----------|-------------------------------------------------------------------------------------------------------------------|
|           | Individualized approach where clinician seeks patient’s preferences: 4 Clinicians with positive interpersonal skills: 2 Equal relationship: 1 Clinician listens to patients concerns: 1 Good relationship with clinician: None |

| **Preparation for an SDM encounter** | Patients undervalue their expertise relative to clinicians: Recognizing there are two experts in the medical encounter: 5 |
|-------------------------------------|-------------------------------------------------------------------------------------------------------------------|
| **Preparation for SDM process**     | Patient focus on treatment burden versus clinicians concerns about morbidity and mortality: 2 Not wanting responsibility for wrong decision: 1 Fear of accepting reality of diagnosis: None |

| **Expectation of SDM outcomes**     | Accepting responsibility to be involved in decision-making: 5 Setting an agenda: 1 |
|-------------------------------------|-------------------------------------------------------------------------------------------------------------------|
| **Providing information about options** | Insufficient information about condition, options and outcomes: 3 Clinician does not explain the options and outcomes: 2 Clinician in repair-reflex mode (solutions without listening |

| **Preparation for the SDM process** | Sufficient information about condition, options and outcomes: 5 Clinician explains the options and outcomes: 2 Clinician knows patient’s and informal caregivers’ |
| **Table 2.** Continued |
|----------------------|
| Terminology used by HCPs |
| Clinician uses medical terminology: 1  |
| Clinician uses simple terminology: 1  |
| Decision support |
| Decision support from informal caregivers: 4  |
| Lack of written decision support: 1  |
| Purpose of decision support tool is unclear: None  |
| Decision support from others (e.g., family, other professionals): 15  |
| Written decision support: None  |
| **Social context** |
| **View of colleagues** |
| Disagreement between colleagues: 3  |
| Degree of contact between colleagues: 1  |
| Hierarchical structure of professionals: 1  |
| Culture of network |
| Social norms and values: None  |
| Collaboration |
| Degree of cooperation and response between colleagues: 10  |
| Degree of cooperation and response between colleagues: 6  |
| Leadership and social learning |
| Lack of support from management (incentive, feedback, role models): 3  |
| Support from management (incentive, feedback, role models): None  |
| **Organizational context** |
| **Organizational characteristics** |
| Complexity of the organization: 4  |
| Complexity of the organization: 1  |
| Capacities |
| No arrangements for continuous learning: 1  |
| Continuous learning opportunities: None  |
| Organizational constraints |
| Lack of resources (time): 11  |
| Lack of resources (time): 3  |
| Lack of support services: 2  |
| Lack of support services: None  |
| Lack of resources (staff): 4  |
| Lack of resources (staff): None  |
| **Economic and political context** |
| Policy |
| Unattractiveness of innovation by means of financial arrangements: 2  |
| Attractiveness of innovation by means of financial arrangements: 1  |
| **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).41

Preparation for an SDM encounter

**Perceived barriers:** Not all patients want or need to participate in SDM (HP/PP).44, 45, 48. A segment of the older patients preferred a more passive role in SDM (HP/PP).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).44, 45. Different views may complicate SDM, e.g., patients focus on treatment burden versus clinicians concerns about morbidity and mortality (HP).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).41, 45. Also, patients suggested that motivation, self-confidence, preparing themselves and family support could enable them to participate in SDM (PP/HP).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).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).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).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).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).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).41, 43, 44, 49, 51, 61. In addition, supportive informal caregivers ensured that patient preferences were recognized.59. Furthermore, personal experiences of family and friends are important in balancing options (PP/IP/HP).58, 67. Tailored information about conditions, options and outcomes was experienced as a facilitator to SDM (PP/IP/HP).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).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 diseased-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, however, there are several ways in which decision support from informal caregivers may also pose a burden on SDM.

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 patients preferences and priorities. Although older adults vary in whether they want and are able to participate in SDM, considering preferences is relevant for all patients. Tinetti (2019) found that working according to patients priorities led to less treatment burden and less unwanted healthcare. They also reported that initial fear among physicians that patients would formulate unrealistic goals was unjustified; if patient 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.

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.
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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

| #  | Searches                                                                 |
|----|--------------------------------------------------------------------------|
| 1  | 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. |
| 2  | 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 aging or senior*).ti,ab,kw. |
| 3  | 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. |
| 4  | communication barriers/ or (barrier* or facilitator* or obstacle* or hurdle* or hindrance* or limitat* or enabl* or implement* or perceiv* or involv* or challeng* or opportunit* or expectation* or interference*).ti,ab,kw. or (lack* adj3 (knowledge or time)).ti,ab,kw. |
| 5  | 1 and 2 and 3 and 4                                                      |
| 6  | comment/ or editorial/ or letter/ or news/ or (editorial* or comment* or letter* or systematic review*).ti,ab,kw. |
| 7  | 5 not 6                                                                 |
| 8  | limit 7 to ((dutch or english or german) and yr=”1980 -Current”)         |

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

1. Frosch DL, Singer KJ, Timmermans S: Conducting implementation research in community-based primary care: a qualitative study on integrating patient decision support interventions for cancer screening into routine practice. Health Expect 2011, 14(Suppl 1):73-84.
2. Uy V, May SG, Tietbohl C, Frosch DL: Barriers and facilitators to routine distribution of patient decision support interventions: a preliminary study in community-based primary care settings. Health Expect 2012, 1-12, Epub ahead of print
3. Stacey D, Graham I, O’Connor A, Pomey M: Barriers and facilitators influencing call center nurses’ decision support for callers facing values sensitive decisions: a mixed methods study. World Evid-Based Nu 2005, 2:184-195.
4. Holmes-Rovner MV, Valade D, Orlowski C, Draus C, Nabozny-Valerio B,
Keiser S: Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect 2000, 3:182-191.

5. Frosch DL, Legare F, Mangione CM: Using decision aids in community based primary care: An evaluation with ethnically diverse patients. Patient Educ Couns 2008, 73(3):490-496

6. Cabana MD, Rand CS, Powe NR, Wu AW, Wilson MH, Abboud F P-A.C.. et al. Why don’t physicians follow clinical practice guidelines? A framework for improvement. J Am Med Assoc 1999;282:1458–65.

7. Holmes-Rovner M, Valade D, Orlowski C, Draus C, Nabozny-Valerio B, Keiser S. Implementing shared decision-making in routine practice: barriers and opportunities. Health Expect 2000;3:182–91.

8. Edwards A, Elwyn G, Wood F, Atwell C, Prior L, Houston H. Shared decision making and risk communication in practice: a qualitative study of GPs’ experiences. Brit J Gen Pract 2005;55:6–13.

9. Wetzels R, Geest TA, Wensing M, Ferreira PL, Grol R, Baker R. GPs’ views on involvement of older patients: an European qualitative study. Patient Educ Couns 2004;53:183–8.

10. Schulman-Green DJ, Naik AD, Bradley EH, McCorkle R, Bogardus ST. Goal setting as a shared decision-making strategy among clinicians and their older patients. Patient Educ Couns 2006;63:145–51

11. Legare F, O’Connor AM, Graham ID, Saucier D, Cote L, Blais J, et al. Primary health care professionals’ views on barriers and facilitators to the implementation of the Ottawa Decision Support Framework in practice. Patient Educ Couns 2006;63:380–90

12. Aasen EM, Kvangarsnes M, Heggen Kr. Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. Scand J Caring Sci 2012;26:61–9.

13. Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people’s preferences for involvement in their own care: a qualitative study in primary health care in 11 European countries. Patient Educ Couns 2007;68:33–42.

14. Belcher VN, Fried TR, Agostini JV, Tinetti ME. Views of older adults on patient participation in medication-related decision making. J Gen Intern Med 2006;21:298–303.

15. Ekdahl AW, Andersson L, Friedrichsen M. ‘They do what they think is the best for me.’ Frail elderly patients’ preferences for participation in their care during hospitalization. Patient Educ Couns 2010;80:233–40. [46] Ekdahl AW, Andersson L, Wire ’hn AB, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. BMC Geriatr 2011;11.

16. Ruan J, Lambert V. Differences in perceived communication barriers among nurses and elderly patients in China. Nurs Health Sci 2008;10:110–6.

17. Fried, T. R., Tinetti, M. E., & Iannone, L. (2011). Primary care clinicians’ experiences with treatment decision making for older persons with multiple conditions. Archives of internal medicine, 171(1), 75-80.

18. Schuling, J., Gebben, H., Veehof, L. J. G., & Haaijer-Ruskamp, F. M. (2012). Deprescribing medication in very elderly patients with multimorbidity: the view of Dutch GPs. A qualitative study. BMC family practice, 13(1).

19. Reuben, D. B., & Tinetti, M. E. (2012). Goal-oriented patient care—
an alternative health outcomes paradigm. New England Journal of Medicine, 366(9), 777-779.

20. Ekdahl AW, Andersson L, Wire´hn AB, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. BMC Geriatr 2011;11.
Supplementary Table S2: Original taxonomy of barriers and facilitators

| Predisposing factors | Barriers                                                                 | Facilitators                                                                 |
|----------------------|---------------------------------------------------------------------------|------------------------------------------------------------------------------|
| Patient characteristics | Being in poor health, Cognitive/physical impairments, Age, Ethnicity, Lower level of education, Poor articulation, Difference in personal characteristics, Health condition - stigma/discrimination, Long term patient | Being in good health, Prior exposure to illness/decision making point, Long term patient |
| Decision characteristics | Timing along the illness trajectory, Minor decision, Major decision, Embarrassing or sensitive topics, Shock of receiving diagnosis | Timing along the illness trajectory, Minor decision, Major decision, Time to come to terms with diagnosis |

| Interactional context factors | Barriers                                                                 | Facilitators                                                                 |
|-------------------------------|---------------------------------------------------------------------------|------------------------------------------------------------------------------|
| Power (im) balance in the patient - clinician relationship | Presumptions about the patient role, Expectation of the clinician making the decisions, Desire to act like 'good' patient driven by fear of consequences, Perceived acceptability of asking the clinician questions, Belief that health professionals do not want patients involved, Health professionals reinforces passivity by rewarding the behavior, Not having explicit 'permission' to participate in SDM, Patients undervalue their expertise relative to health professionals, 'Doctor knows best' and patients have 'inferior' knowledge, Patients are not capable of understanding medical/technical information | Presumptions about the patient role, Perceived acceptability of asking the clinician questions, Having explicit 'permission' to participate in SDM, Patients undervalue their expertise relative to health professionals, Recognizing there a two experts in medical encounter |
| Interpersonal characteristics of the clinician | Authoritarian HCP’s | Equal relationship |
|-----------------------------------------------|--------------------|-------------------|
| Clinician does not listen to patients concerns | Health professionals with poor interpersonal skills | Clinician listens to patients concerns |
| Health professionals with poor interpersonal skills | Good relationship with clinician | Health professionals with positive interpersonal skills |
| Poor relationship with clinician | Individualized approach where clinician seeks patient’s preferences | |
| Lack of individualized approach and not asked about preferences | | |
| Clinician does not address patient directly | | |
| **Trust** | Trust in clinician | Trust in clinician |
| | Lack of trust in clinician | Lack of trust in clinician |

| Preparation for a SDM encounter | Perceived need for preparation | Accepting responsibility to be involved in decision-making |
|---------------------------------|--------------------------------|------------------------------------------------------|
| Patient is not entitled to a choice | Patient is not explicitly offered a choice/or it is presented in a biased way | |
| ‘Doing nothing’ is not an option | Patient does not want to or need to participate in SDM | |
| Patient does not want to or need to participate in SDM | Not knowing what to expect from the SDM consultation | |
| Not knowing what to expect from the SDM consultation | | |

| Preparation for the SDM process | Providing information about options | Sufficient information about condition, options and outcomes |
|---------------------------------|-----------------------------------|----------------------------------------------------------|
| Insufficient information about condition, options and outcomes | Clinician does not explain the options and outcomes | Clinician explains the options and outcomes |
| | Clinician uses medical terminology | Clinician uses simple terminology |
| Terminology used by HCP’s | | |
| Decision support | Lack of written decision support | Written decision support Decision support from others (e.g. family, other pros) |
| Purpose of decision support tool is unclear | | |

| Social context | View of colleagues | Disagreement between colleagues |
|----------------|--------------------|--------------------------------|
| Degree of contact between colleagues | | |
| Hierarchical structure of professionals | | |
| Culture of network | Social norms and values | Social norms and values |
| Collaboration | Leadership and social learning | Organizational context | Economic and political context |
|---------------|-----------------------------|------------------------|-------------------------------|
| Degree of cooperation and response between colleagues | Lack of support from management (incentive, feedback, role models) | Complexity of the organization | Attractiveness of innovation by means of financial arrangements |
| Degree of cooperation and response between colleagues | Support from management (incentive, feedback, role models) | No arrangements for continuous learning | |
| | | Lack of support services | Support services |
| | | Lack of resources: time | Resources: time |
| | | Lack of resources: staff | Resources: staff |
Supplementary Table S3: Quality assessment of included studies (according to the Standard Quality Assessment Criteria (Kmet, Lee, & Cook, 2004))

| Study identification | (Belcher et al., 2006) | (Bragstad et al., 2014) | (Dyrstad et al., 2015) | (Ekdahl et al., 2012) | (Ekdahl et al., 2011) | (Ekdahl et al., 2010) | (Fried et al., 2011) | (Gauthier, 2005) | (Lindhardt et al., 2008) |
|----------------------|------------------------|-------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|------------------------|
| Question / objective sufficiently described | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Study design evident and appropriate? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Context for the study clear? | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 1 |
| Connection to a theoretical framework / wider body of knowledge? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Sampling strategy described, relevant and justified? | 1 | 2 | 1 | 1 | 2 | 1 | 2 | 1 | 2 |
| Data collection methods clearly described and systematic? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 1 | 2 |
| Data analysis clearly described and systematic? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Use of verification procedure(s) to establish credibility? | 2 | 2 | 2 | 2 | 2 | 0 | 2 | 2 | 0 |
| Conclusions supported by the results? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Reflexivity of the account? | 0 | 0 | 2 | 1 | 0 | 2 | 0 | 0 | 2 |
| Total score /possible maximum score | 17/20 | 17/20 | 19/20 | 18/20 | 16/20 | 19/20 | 18/20 | 13/20 | 20/20 |
| Summary score (0-1) | 0.85 | 0.85 | 0.95 | 0.90 | 0.80 | 0.95 | 0.90 | 0.65 | 1.00 |
| Qualitative studies (part 2) | (Schuling et al., 2012) | (Funk, 2004) | (Blaum et al, 2018) | (Puts et al, 2017) | (Doekhie et al. 2018) | (Ferris et al. 2018) | (Riffin et al. 2018) | (Peacock et al, 2017) | (Petrillo et al. 2018) |
|----------------------------|------------------------|--------------|--------------------|-------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Question / objective sufficiently described | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Study design evident and appropriate? | 2 | 2 | 1 | 2 | 2 | 2 | 2 | 2 | 2 |
| Context for the study clear? | 1 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Connection to a theoretical framework / wider body of knowledge? | 2 | 2 | 2 | 1 | 2 | 2 | 1 | 2 | 2 |
| Sampling strategy described, relevant and justified? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Data collection methods clearly described and systematic? | 2 | 2 | 0 | 2 | 2 | 2 | 2 | 2 | 2 |
| Data analysis clearly described and systematic? | 2 | 2 | 0 | 2 | 2 | 2 | 2 | 2 | 2 |
| Use of verification procedure(s) to establish credibility? | 2 | 0 | 0 | 2 | 1 | 2 | 1 | 2 | 2 |
| Conclusions supported by the results? | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 | 2 |
| Reflexivity of the account? | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 |
| Total score / possible maximum score | 17/20 | 16/20 | 11/20 | 17/20 | 19/20 | 18/20 | 16/20 | 18/20 | 18/20 |
| Summary score (0-1) | 0.85 | 0.80 | 0.55 | .85 | 0.95 | 0.90 | 0.80 | 0.90 | 0.90 |
### Quantitative studies

| Question/ objective sufficiently described? | (Menne & Whitlatch, 2007) | (Milde et al., 2015) | (Naik et al., 2011) | (Chi et al. 2017) |
|--------------------------------------------|---------------------------|----------------------|---------------------|------------------|
| Study design evident and appropriate?      | 2                         | 2                    | 2                   | 2                |
| Method of subject/comparison group selection or source of information/input variables described and appropriate? | 2                         | 2                    | 1                   | 2                |
| Subject (and comparison group, if applicable) characteristics sufficiently described? | 2                         | 2                    | 2                   | 2                |
| If interventional and random allocation was possible, was it described? | n/a                       | 2                    | n/a                 | n/a              |
| If interventional and blinding of investigators was possible, was it reported? | n/a                       | 2                    | n/a                 | n/a              |
| If interventional and blinding of subjects was possible, was it reported? | n/a                       | n/a                  | n/a                 | n/a              |
| Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? | 2                         | 2                    | 2                   | 2                |
| Sample size appropriate?                   | 2                         | 2                    | 2                   | 2                |
| Analytic methods described/justified and appropriate? | 2                         | 2                    | 2                   | 2                |
| Some estimate of variance is reported for the main results? | 2                         | 2                    | 2                   | 0                |
| Controlled for confounding?                | 0                         | 0                    | 0                   | 0                |
| Results reported in sufficient detail?      | 2                         | 1                    | 1                   | 2                |
| Conclusions supported by the results?      | 2                         | 2                    | 2                   | 2                |
| Total score /possible maximum score         | 20/22                     | 23/26                | 17/22               | 18/22            |
| Summary score (0-1)                        | 0.91                      | 0.88                 | 0.77                | 0.80             |
### Mixed Method Studies

#### Qualitative part

| Study identification                                                                 | (Legare et al., 2013)* | (Kiselev et al. 2017) | (Rose et al. 2018) |
|---------------------------------------------------------------------------------------|-------------------------|------------------------|-------------------|
| Question / objective sufficiently described                                           | 2                       | 2                      | 2                 |
| Study design evident and appropriate?                                                | 2                       | 2                      | 2                 |
| Context for the study clear?                                                         | 2                       | 2                      | 2                 |
| Connection to a theoretical framework / wider body of knowledge?                     | 2                       | 2                      | 1                 |
| Sampling strategy described, relevant and justified?                                 | 2                       | 2                      | 2                 |
| Data collection methods clearly described and systematic?                            | 2                       | 2                      | 2                 |
| Data analysis clearly described and systematic?                                      | 2                       | 2                      | 2                 |
| Use of verification procedure(s) to establish credibility?                            | 2                       | 2                      | 1                 |
| Conclusions supported by the results?                                                | 2                       | 2                      | 2                 |
| Reflexivity of the account?                                                          | 2                       | 0                      | 0                 |
| **Total score /possible maximum score**                                              | **20/20**               | **18/20**              | **16/20**         |
| Summary score (0-1)                                                                  | **1.00**                | **0.90**               | **0.80**          |
### Mixed Method Studies

#### Quantitative part

| Study identification | (Legare et al., 2013)* | (Kiselev et al. 2017) | (Rose et al. 2018) |
|----------------------|------------------------|-----------------------|-------------------|
| Question/ objective sufficiently described? | 2 | 2 | 2 |
| Study design evident and appropriate? | 2 | 2 | 2 |
| Method of subject/comparison group selection or source of information/input variables described and appropriate? | 2 | 2 | 2 |
| Subject (and comparison group, if applicable) characteristics sufficiently described? | 2 | 2 | 1 |
| If interventional and random allocation was possible, was it described? | n/a | n/a | n/a |
| If interventional and blinding of investigators was possible, was it reported? | n/a | n/a | n/a |
| If interventional and blinding of subjects was possible, was it reported? | n/a | n/a | n/a |
| Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported? | 2 | 2 | 2 |
| Sample size appropriate? | 2 | 2 | 2 |
| Analytic methods described/justified and appropriate? | 2 | 2 | 2 |
| Some estimate of variance is reported for the main results? | 2 | 2 | 2 |
| Controlled for confounding? | 0 | 0 | 0 |
| Results reported in sufficient detail? | 2 | 2 | 2 |
| Conclusions supported by the results? | 2 | 2 | 2 |
| **Total score /possible maximum score** | 20/22 | 20/22 | 19/22 |
| **Summary score (0-1)** | 0.90 | 0.90 | 0.86 |
| **Summary score mixed methods** | 0.95 | 0.90 | 0.83 |
## Supplementary Table S4: PRISMA checklist

| Section/topic                  | # | Checklist item                                                                 | Reported on page # |
|-------------------------------|---|-------------------------------------------------------------------------------|-------------------|
| **TITLE**                     |   |                                                                               |                   |
| Title                         | 1 | Identify the report as a systematic review, meta-analysis, or both.            | 31                |
| **ABSTRACT**                  |   |                                                                               |                   |
| Structured summary            | 2 | 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. | 32                |
| **INTRODUCTION**              |   |                                                                               |                   |
| Rationale                     | 3 | Describe the rationale for the review in the context of what is already known. | 33, 34            |
| Objectives                    | 4 | Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS). | 34                |
| **METHODS**                   |   |                                                                               |                   |
| Protocol and registration     | 5 | 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. | -                 |
| Eligibility criteria          | 6 | 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. | 35                |
| Information sources           | 7 | 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. | 34, 35            |
| Search                        | 8 | Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated. | Supp. table 1     |
| Study selection               | 9 | State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis). | 35                |
### 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]).
### DISCUSSION

| Step | Description |
|------|-------------|
| 24   | **Summary of evidence**: 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). |
| 25   | **Limitations**: 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). |
| 26   | **Conclusions**: Provide a general interpretation of the results in the context of other evidence, and implications for future research. |

### FUNDING

| Step | Description |
|------|-------------|
| 27   | **Funding**: Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review. |

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*From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi: 10.1371/journal.pmed1000097*

For more information, visit: [www.prisma-statement.org](http://www.prisma-statement.org).