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How are patient-related characteristics associated with shared decision-making about treatment? A scoping review of quantitative studies

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ABSTRACT

Objectives To identify what patient-related characteristics have been reported to be associated with the occurrence of shared decision-making (SDM) about treatment.

Design Scoping review.

Eligibility criteria Peer-reviewed articles in English or Dutch reporting on associations between patient-related characteristics and the occurrence of SDM for actual treatment decisions.

Information sources COCHRANE Library, Embase, MEDLINE, PsycInfo, PubMed and Web of Science were systematically searched for articles published until 25 March 2019.

Results The search yielded 5289 hits of which 53 were retained. Multiple categories of patient characteristics were identified: (1) sociodemographic characteristics (eg, gender), (2) general health and clinical characteristics (eg, symptom severity), (3) psychological characteristics and coping with illness (eg, self-efficacy) and (4) SDM style or preference. Many characteristics showed no association or unclear relationships with SDM occurrence. For example, for female gender positive, negative and, most frequently, non-significant associations were seen.

Conclusions A large variety of patient-related characteristics have been studied, but for many the association with SDM occurrence remains unclear. The results will caution often-made assumptions about associations and provide an important step to target effective interventions to foster SDM with all patients.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ We looked at a wide variety of treatment decisions, any patient-related characteristic that had been assessed, any year of publication and any measure of shared decision-making (SDM), and were therefore able to provide an overview that cuts across clinical settings, study foci and study measures.
⇒ We aimed to include studies that looked at a specific decision, not decision-making experience in general, and decided to err on the side of inclusion in order to be comprehensive, but may have been too lenient in some cases.
⇒ We did not put any restriction on how SDM should have been measured, allowing for constructs underlying the different SDM measures to differ and including studies that had used self-developed and unvalidated items, both making it more difficult to compare results across studies.

INTRODUCTION

Shared decision-making (SDM) is recommended when patients face preference-sensitive decisions about treatment.[1 2] In clinical practice, the occurrence of SDM remains low.[3 4] Being an active participant in SDM can be difficult for patients, and potentially even more challenging for some patients than for others.[5 6] Previous research has suggested that, for example, those with higher age or lower education[7 8] may be less likely to participate in SDM. This could be because they prefer to be less involved, because they struggle with certain aspects of SDM, such as understanding the information or expressing themselves,[6] or because clinicians may be less likely to involve patients in SDM whom they believe to have less desire or ability to participate.[8–10] Many decision aids have been developed to support patients in decision-making; however, their use in practice remains low.[11 12] Furthermore, decision aids alone are not sufficient for SDM to occur.[13 14] They tend to focus on clarifying options and explaining their harms and benefits, but less so on creating an empathic conversation.[15 16] Additional components, such as a focus on creating trusting relationships, may be needed.[17] Knowing about patient-related characteristics that are systematically associated with lower occurrence of SDM is an important step in further identifying support needs for patients, and educational or training needs for clinicians. This could involve promoting the use of existing materials, developing new materials or

training clinicians to better support patients during and outside of consultations.

To our knowledge, no evidence-based overview exists on associations between patient-related characteristics and the occurrence of SDM, either reported from an independent observer or from a participant perspective. A scoping review is germane, as it allows answering broad and heterogenous research questions.[18] With this scoping review, we aim to provide an overview of patient-related characteristics for which an association with the occurrence of SDM about treatment has been assessed in routine care. Our research question was: What has been reported in the quantitative literature about the empirical relationships between patient-related characteristics and the observed and/or experienced occurrence of SDM about treatment in routine care?

METHODS

We based this scoping review on established frameworks,[18 19] and the protocol was registered at Open Science Framework (osf.io/gbh5k/). The search strategy, developed with a librarian, included terms relating to SDM, patient-related characteristics and others (eg, distress, mental disorder) based on a simultaneous qualitative study on patient readiness for SDM about treatment.[6] The search was conducted on 25 March 2019 in: PubMed, MEDLINE, Embase, Web of Science, COCHRANE Library and Psychinfo, from their inception (the PubMed search strategy can be found in online supplemental file 1). Abstracts and full texts were screened independently and in duplicate. Disagreements were resolved in consensus meetings, consulting a third reviewer if necessary.

Peer-reviewed articles published in English or Dutch were included that reported on studies: (1) with an empirical, quantitative design, presenting new data or secondary analyses of existing data, in adult patients; that (2) involved a treatment decision for that patient (ie, a decision to start, stop, change, or forego a treatment for a somatic or mental health condition); and (3) measured SDM occurrence (independently observed or self-reported experience) in routine care and its association with patient-related characteristics. We defined patient-related characteristics as any characteristic of the person (eg, age, attitude toward treatment) or condition (eg, diagnosis). We excluded articles that (1) were case studies; (2) focused on decisions for children or about maternity care; (3) included patients with cognitive impairment prohibiting their participation in SDM or who were not able to speak the relevant language; (4) involved decisions about screening, diagnostic testing, clinical trial participation, advance care planning/end-of life care or general healthcare; or (5) only assessed SDM occurrence after an SDM intervention. One researcher performed data charting (see online supplemental file 2 for the full data extraction chart), a second researcher checked it. Disagreements were resolved in consensus, or with a third researcher if needed. In agreement with common practice for scoping reviews, we did not conduct a quality assessment.[19]

The results regarding a characteristic were categorised as mixed when it had been assessed in different ways (eg, variable analysed continuously vs categorically) and different results were found. The results were categorised as unclear when the direction or significance level was not clear from the article and the corresponding author did not respond to our request for clarification. In case both univariable and multivariable analyses had been conducted, we used the multivariable results for the categorisation. A thematic categorisation of the patient-related characteristics was made in consensus. The results are presented according to whether SDM was measured from the patient's, physician's or observer's perspective.

RESULTS

The search resulted in 5289 articles, of which we included 53 in this review (table 1). The full data extraction chart can be found in online supplemental file 2. Figure 1 depicts the inclusion process.

Article characteristics

The included articles were all written in English and published between 1989 and 2019, with the majority between 2010 and 2019 (n=44/53, table 1; online supplemental file 2). Sample sizes ranged from N=19 to N=5383. The majority of included articles focused on patients with a somatic condition (n=42), mostly cancer (n=29). Ten focused on patients with a mental health condition, and one on a wider population including both somatic and mental health conditions. Most studies were conducted in the USA (n=21) followed by the Netherlands (n=7). Studies measured SDM from the perspective of the patient (n=42), an observer (n=8), both the patient and an observer (n=2), or the physician (n=1).

Sociodemographic characteristics

The most frequently studied sociodemographic characteristics were age (n=46), gender (n=30), education level (n=34) and being in a committed relationship (n=16) (table 2). For each characteristic, no significant associations with SDM occurrence were found in more than half of the studies (age: 31/46, gender: 21/30, education level: 27/34, being in a committed relationship: 11/16). In the remaining studies, more SDM was associated with lower age (9/45), female gender (4/30), male gender (4/30) and being committed in a relationship (3/16).

Region and insurance status are not included in table 2. Region was studied in six studies. Two studies (in Sweden and Spain) found more SDM in patients who were from a more urban compared with a more rural area.[20 21] Three studies (Japan, Taiwan and the USA) found no associations between region and SDM occurrence.[22–24] In one other study from the USA, the specific study site was associated with SDM occurrence, but the results did not reveal a clear pattern for type of region.[25]

Table 1 Study characteristics

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Barr, 2016, USA[27]	Cross-sectional Questionnaire	Depression Depression treatment	N=972, Female: 69.0%, Age: M=43.2, SD=13.4	Patient	CollaboRATE
Barton, 2014, USA[52]	Cross-sectional Interview	Rheumatoid arthritis Rheumatoid arthritis treatment	N=509 - Rheumatoid Arthritis Panel (N=275): Female: 85.8%, Age: M=64, SD=11 - University of California, San Francisco (UCSF) Rheumatoid Arthritis (RA) Cohort (N=234): Female: 84%, Age: M=55, SD=14	Patient	Decision-making subscale of the Interpersonal Processes of Care survey, consisting of two items: "How often did you and your doctors work out a treatment plan together?" and "If there were treatment choices, how often did doctors ask if you would like to help decide your treatment?" (Never to Always)
Berger, 2017, USA[53]	Retrospective Questionnaire	Breast cancer Breast cancer treatment	N=873, Female: 100%, Age: M=59.1, SD=12.1	Patient	CPS (actual)
Broström, 2018, Sweden[35]	Cross-sectional Questionnaire, clinical examination	Obstructive sleep apnea Start of continuous positive airway pressure treatment	N=193, Female: 32.1%, Age: M=59.7, SD=11.5	Patient	CollaboRATE
De las Cuevas, 2013, Spain[54]	Cross-sectional Questionnaire	Psychiatric diagnosis Prescription of a new treatment or maintenance or change in dosage of current drug treatment	N=1111 Female: 67.4% Age: Psychiatric outpatient (n=571): M=49.5, SD=16.4; Primary care (n=540): M=44.7, SD=16.4	Patient	SDM-Q-9
De las Cuevas, 2014, Spain [41]	Cross-sectional Questionnaire, interview	Psychiatric diagnosis Psychiatric treatment	N=507, Female: 62.1%, Age: M=48.4, SD=13.6	Patient	CPS (actual)
De las Cuevas, 2014, Spain[45]	Cross-sectional Questionnaire	Psychiatric diagnosis Psychiatric treatment	N=846, Female: 64.4%, Age: M=49.9, SD=13.6, range=18–87	Patient	SDM-Q-9
Ekdahl, 2011, Sweden[55]	Cross-sectional Interview	Older patients with comorbidities according to ICD-10 Acute admittance/hospitalisation	N=156, Female: 50.6%, Age: range=76–98	Patient	CPS (actual)

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Ellis, 2016, USA [26]	Cross-sectional Interview	Colorectal cancer Surgery, radiation therapy and/or chemotherapy	N=154, Female: 42.2%, Age: ≤65 years: n=79 ≥65 years: n=75	Patient	CPS (actual)
Ernst, 2011, Germany [39]	Cross-sectional Questionnaire	Haemato-oncological Chemotherapy, stem cell transplantation, other	N=108 (patients who completed CPS; total sample N=117), Female (n=117): 43.6%, Age (n=117): M=57, Md=59; range 21–84	Patient	CPS (actual)
Fischer, 2006, The Netherlands [56]	Cross-sectional Questionnaire	Prostate cancer Prostate cancer treatment	N=126, Female: 0.0%, Age: M=67, range 48–82	Patient	One question, to what degree they felt they had had the opportunity to decide about their treatment, three response options (eg, “I had no say in the decision, the doctor made the decision”)
Fowler, 2013, USA [57]	Cross-sectional Questionnaire	Patients with hypertension or high cholesterol Blood pressure medication and cholesterol medication	N=2718 Hypertension (n=1027): Female: 50.6%, Age: >65: n=435 High cholesterol (n=822): Female: 49.1%, Age: >65 years: n=322	Patient	Four questions to assess the extent to which the healthcare provider informed and involved patients in decisions (eg, “Did the healthcare provider(s) explain that you could choose whether or not to have ___?” Yes/No).
Frisell, 2016, Sweden [20]	Retrospective Questionnaire, registry data	Breast cancer Immediate breast reconstruction after mastectomy	N=2217 (subsample of patients who completed questionnaire; total sample N=2929) Female: 100% Age (n=2217): - No immediate reconstruction (N=2726): Md=66, range 21–97 - Immediate reconstruction (N=270): Md=49, range 21–80	Patient	One item: “Did you feel involved in the decision-making process whether or not to perform breast reconstruction?” (Yes, Yes but not enough, No)

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Fukui, 2014, USA [42]	Cross-sectional Audio-recorded consultations, information provided by clinician	Psychiatric diagnosis Decisions during psychiatric visits	N=128, Female: 50.8%, Age: M=43.4, SD=10.63	Observer	SDM scale
Geessink, 2018, The Netherlands [32]	Cross-sectional Observations, questionnaire	Colorectal or pancreatic cancer Cancer treatment	N=80, Female: 45.0%, Age: M=71.8, SD=5.2	Patient Observer	SDM-Q-9 and VAS-I OPTION-5, OPTION-12 and MAPPIN'SDM
Gong, 2011, South Korea [31]	Prospective Information obtained during consultations, questionnaire	Carpal tunnel syndrome Surgery	N=78, Female: 91.0%, Age: Md=57, range=27–81	Patient	CPS (actual)
Goss, 2008, Italy [43]	Cross-sectional Audio-recorded consultations, questionnaire	Psychiatric diagnosis Treatment of main problem (most often anxiety or depression)	N=80, Female: 61.0%, Age: M=43.6, SD=13, range=23–76	Observer	OPTION-12
Hämäläinen, 2003, Finland[58]	Cross-sectional Questionnaire	Respiratory care Start of respiratory care therapy	N=3153, Female: 29.0%, Age: M=61, range=16–95	Patient	One item: “Were you allowed to participate in decision-making when the home respiratory care was started?” (Not at all, Somewhat, A great deal, Can’t say)
Hamann, 2010, Germany [48]	Cross-sectional Questionnaire	Schizophrenia Antipsychotic medication	N=300, Female: 41.7%, Age: M=39.7, SD=12.3	Physician	Physicians were asked whether the choice of medication was: 1. the doctor's preference; 2. the patient's preference; or 3. the result of a decision shared between doctor and patient.
Hamelinck, 2018, The Netherlands [59]	Cross-sectional Questionnaire	Breast cancer Type of surgery (breast-conserving or mastectomy), and for patients with invasive disease also adjuvant chemotherapy and/or adjuvant hormonal therapy	N=74, Female: 100%, Age: Surgery (n=74): Md=60, range=42–80; Adjuvant chemotherapy (n=43): Md=60, range=42–76; Adjuvant hormonal therapy (n=39): Md=60, range=42–86	Patient	CPS (actual)
Hawley, 2007, USA [60]	Cross-sectional Questionnaire, Surveillance, Epidemiology, and End Results (SEER) record	Ductal carcinoma in situ (DCIS) or breast cancer Breast cancer surgery	N=1038, Female: 100%, Age: M=59, range=29–79	Patient	CPS (actual)
Hawley, 2008, USA [61]	Cross-sectional Questionnaire	Breast cancer Breast cancer surgery	N=877, Female: 100%, Age: M=59, range=29–79	Patient	CPS (actual)

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Hou, 2014, China [36]	Cross-sectional Questionnaire, medical record	Colorectal cancer Surgery	N=113, Female: 42.5%, Age: M=62.8, SD=15.3, range=22–91	Patient	CPS (actual)
Kadmon, 2016, Israel [62]	Cross-sectional Questionnaire	Breast cancer Breast reconstruction surgery	N=70, Female: 100%, Age: M=52.7, SD=10.2, Md=52	Patient	Two questions about level of involvement in decision-making: 1. "What was the extent of your involvement in the decision-making process?" (Not involved, Slightly involved, Highly involved) 2. "How were decisions made about your breast reconstruction?" (The physician decided, The physician and I decided together, The physician decided after hearing my opinion, I decided after hearing the physician's opinion)
Keating, 2010, USA [25]	Cross-sectional Computer-assisted telephone interview, registry data, medical record	Lung or colorectal cancer Surgery, radiation therapy and/or chemotherapy	N=5383, Female: 46.6%, Age: 21–55: n=618; 56–70: n=1963; 71–80: n=1585; ≥81 years: n=1217	Patient	CPS (actual)
Krok-Schoen, 2016, USA [28]	Cross-sectional Questionnaire	Cancer Cancer treatment	N=606, Female: 63.2%, Age: 18–39 (n=227): M=30.8, SD=5.06; 40–59 (n=183): M=49.6, SD=5.75; ≥60 (n=169): M=68.6, SD=6.4	Patient	Six five-point Likert-type scale statements that measure the extent to which patients were involved. Categorised as Independent/isolated, Collaborative, Delegated, or Demanding roles.
Kunneman, 2014, The Netherlands [63]	Cross-sectional Questionnaire	Endometrial cancer Vaginal brachytherapy	N=53 (relevant subsample patients who faced a decision; total sample: N=95), Female: 100%, Age (N=95): Md=68; range=46–90	Patient	One question: "Do you feel you had a choice in the decision about whether or not to undergo VBT?" (No, Yes, I don't know)
Langseth, 2012, UK [64]	Cross-sectional Audio-recorded consultation, referral letter	Cardiac patients Ablation, implantable device, or pharmacological treatment	N=49, Female: 47.0%, Age: M=61	Observer	OPTION-12

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Larsson, 1989, Sweden [65]	Cross-sectional Questionnaire	Orthopaedic patients Surgery	N=666, Female: not reported, Age: M=56.6, range=15–94	Patient	One question to indicate who they believed made the decision (Joint patient-doctor, Doctor, Patient, Others)
Lofland, 2017, USA [23]	Cross-sectional Questionnaire, pharmacy and medical claims	Inflammatory bowel disease, rheumatoid arthritis or psoriatic arthritis Biologic therapy	N=306, Female: 77.8%, Age: SDM (n=120): M=47.9, SD=11.6; Non-SDM (n=237): M=48.0, SD=12.4	Patient	SDM-Q-9
Mandelblatt, 2006, USA [29]	Cross-sectional Patient interview, medical records	Breast cancer Surgery and/or adjuvant treatment	N=718, Female: 100%, Age: M=75	Patient	Four five-point Likert scale items to measure domains of SDM (eg, "I asked my surgeon to explain breast cancer treatments and/or procedure(s) to me in greater detail" (Strongly agree to Strongly disagree)
Matthias, 2014, USA [44]	Cross-sectional Audio-recorded consultations, questionnaire	Posttraumatic stress disorder (PTSD) Decisions during psychiatric appointments	N=63 (relevant subsample of patients who had faced a decision; total sample: N=79), Female (N=79): 14.0%, Age (N=79): M=53, SD=10, range=23–71	Observer	SDM scale SDM-Min
Moral, 2014, Spain [21]	Cross-sectional Videotaped consultation, patient interview	Various (primary care), either psychological or somatic problem Specific treatment decision not reported	N=368 (relevant subsample; total sample: N=658), Female (N=658): 60.9%, Age (n=658): M=52, range 18–88	Observer	CICAA-D
Morgan, 2015, UK [66]	Cross-sectional Questionnaire	Breast cancer Surgery or primary endocrine therapy	N=729, Female: 100%, Age: Md=77, range=70–96	Patient	CPS (actual)
Mueck, 2018, USA [46]	Cross-sectional Questionnaire	Gallstone disease Cholecystectomy	N=30, Female: 90.0%, Age: M=46, SD=16	Patient	SDM-Q-9
Nguyen, 2014, France [67]	Cross-sectional Questionnaire	Breast cancer Treatment for early stage breast cancer	N=238, Female: 100%, Age: M=56.3, SD=10.3, range=37–84	Patient	One question: "To what extent did you actually participate in deciding on your treatment?" (Not at all to To a great extent)

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Ommen, 2011, Germany [68]	Cross-sectional, retrospective Questionnaire	Inpatients of internal medicine or surgery wards Specific decision not reported	N=2197, Female: 26.3%, Age: 18–30 (n=454): 21.2%; 31–65 (n=1177): 55.0%; 66–97 (n=509): 23.8%; range=18–97	Patient	Cologne Patient Questionnaire scale 'co-therapy' consisting of four items: for example, "The doctors wanted me to be actively involved in the treatment process" (Strongly disagree to Strongly agree)
Palmer, 2013, USA [69]	Cross-sectional, secondary analyses Questionnaire	Prostate cancer Surgery, radiation, watchful waiting, other	N=181, Female: 0.0%, Age: M=61.3, SD=7.0, range=43–70	Patient	CPS (actual)
Phipps, 2008, USA [34]	Cross-sectional Questionnaire	Cancer Second-line chemotherapy	N=26, Female: 50.0%, Age: M=61, range=22–79	Patient	One question assessing participants' perception of involvement in decision-making (I made final decision about which treatment I would receive to My doctor made all the decisions regarding my treatment)
Sainio, 2003, Finland [33]	Cross-sectional Questionnaire	Cancer Cancer treatment	N=273, Female: 60.4%, Age: M=49.7, SD=10.5, range=18–65	Patient	12 items (To a great extent, To some extent, Not at all)
Santema, 2016, The Netherlands [47]	Cross-sectional Audio-recorded consultations	Vascular condition Vascular surgery	N=54, Female: 42.6%, Age: M=69.1, SD=15.2	Observer	OPTION-12
Seror, 2013, France [49]	Prospective Questionnaire, interview	Breast cancer Surgery, chemotherapy and/or adjuvant endocrine therapy	N=415, Female: 100%, Age: M=36.8, SD=3.8	Patient	CPS (actual)
Shabason, 2014, USA [40]	Cross-sectional Questionnaire	Cancer Radiation therapy	N=305, Female: 47.5%, Age: M=59.8, SD=12.0, range=18–87	Patient	Three 5-point scale items to assess physicians' participatory decision style: for example, "If there were a choice between treatments, would your radiation oncologist ask you to help him/her make the decision?" (Definitely yes to Definitely no)

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Shen, 2019, Taiwan [24]	Cross-sectional Questionnaire, medical chart review	Breast cancer Breast cancer treatment (type of surgery and/or neo-adjuvant chemotherapy) or treatment of complications after breast cancer treatment (eg, compression garments or massage for lymphedema)	N=511, Female: 100%, Age: M=57.9, SD=11.1	Patient	SDM-Q-9
Singh, 2010, Australia [37]	Prospective, observational Audio recording, questionnaire	Cancer Adjuvant treatment (chemotherapy and/or radiation	N=63, Female: 63.5%, Age: M=54.9, SD=13.1, range=24–84	Observer	Self-developed coding system consisting of 20 behaviours: for example, "Reason for consultation established" or "Multiple options presented" (Present or Not applicable, Absent)
Singh, 2010, USA and Canada [50]	Pooled analysis Questionnaire, interview, medical chart review	Cancer Cancer treatment	N=2742 (relevant subsample of patients who reported actual decisional role, total sample N=3489), Female (N=3489): 67.7%, Age (n=2144): <50: n=809 (37.7%); 50–64: n=35 (1.6%); >64: n=1300 (60.6%)	Patient	CPS (actual)
Solberg, 2014, USA [30]	Cross-sectional Questionnaire	Patients with a fill for antidepressant medication Depression treatment	N=1168, Female: 72.9%, Age: M=44.2, 18–34: n=344 (29.5%); 35–49: n=391 (33.5%); 50–64: n=347 (39.7%); ≥65: n=86 (7.4%)	Patient	Six questions about SDM aspects of care: for example, "During the past 6 months of depression treatment, were you asked for your ideas and preferences regarding your depression treatment?" (Yes/No)
Song, 2013, USA [70]	Cross-sectional Questionnaire, medical record	Prostate cancer Prostate cancer treatment	N=788, Female: 0.0%, Age: <65 years: N=483 (63.3%); ≥65 years: n=280 (36.7%)	Patient	One question: "Who was mostly responsible for deciding what to do about prostate cancer when you were first diagnosed?" (Patient only, Shared, Physician only)
Suzuki, 2012, USA [71]	Prospective Questionnaire, medical record	Head and neck cancer Head and neck cancer treatment	N=52, Female: 28.8%, Age: M=58.3, SD=12.4	Patient	PICS

Continued

Table 1 Continued

First author, year of publication, country, reference	Design, data collection method*	Health condition and decision specification	Sample characteristics: N, gender, age (in years)†	Measurement perspective	SDM measurement
Vaillancourt, 2014, Canada [72]	Cross-sectional, observational Audio-recorded consultation, patient questionnaire	Diet-related health condition Nutritional treatment	N=19, Female: 57.9%, Age: M=40.2, SD=25.2	Observer	OPTION-12
Van Stam, 2018, The Netherlands [73]	Prospective observational Questionnaire, medical record	Prostate cancer Prostate cancer treatment (active surveillance, radical prostatectomy, external beam radiotherapy, brachytherapy)	N=454 (relevant subsample of patients who completed the CPS for the actual decisional role, total sample N=474), Female: 0.0%, Age: M=66.5, SD=6.1, range=48–87	Patient	CPS (actual)
Verwijmeren, 2018, The Netherlands [38]	Cross-sectional, real-time observation of consultation Questionnaire	Bipolar disorder Pharmacotherapy treatment	N=81, Female: 64.2%, Age: M=52.0, SD=13.6	Patient Observer	SDM-Q-9 OPTION-12
Yamauchi, 2017, Japan[22]	Cross-sectional Questionnaire	Breast cancer Breast cancer treatment	N=650, Female: 100%, Age: <50: N=202 (31.1%); ≥50: N=448 (68.9%)	Patient	CPS (actual)

References for the SDM measures in the table: CICAA-D[21]; CollaboRATE[74]; CPS (Control Preferences Scale) actual[75–77] MAPPIN'SDM[78]; OPTION-5[79]; OPTION-12,[80] PICS[81]; SDM-scale[82 83]; SDM-Q-9.[84 85]

*The study design and data collection as is relevant for our research question, study design was marked as prospective when a time-sensitive characteristic was measured prior to the consultation.

†Rounded to one decimal place where possible

SDM, shared decision-making.

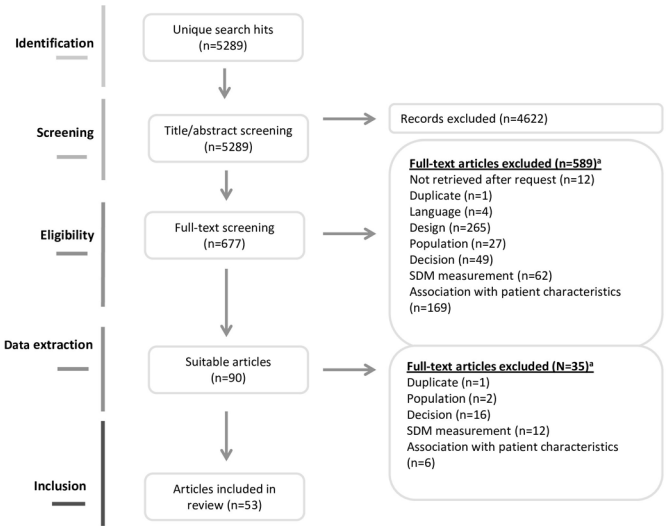

Figure 1 Flowchart of included articles. SDM, shared decision-making. [a]Reasons for exclusion are in hierarchical order.

Insurance status was assessed in six studies. Of the five studies conducted in the USA, four found no significant associations (comparisons: insured vs uninsured[26]; private vs public vs none[27 28]; private+Medicare vs Medicare vs Medicare+Medicaid[29]). One study found that patients with Medicare insurance were less involved in SDM than patients who were insured privately, through state programmes, or other (controlling for age).[30] Insurance was also assessed in one study in South Korea, in which patients with private insurance were more involved in SDM than patients without private insurance.[31]

General health and clinical characteristics

Ten studies assessed whether having (multiple) comorbidities compared with having no (or fewer) comorbidities was associated with SDM occurrence, and eight found no significant associations (table 3). One study found a positive association between number of comorbidities and more SDM, in patients with inflammatory bowel disease or arthritis.[23] One study in patients with cancer[32] found a positive association between having more (severe) comorbidities and more SDM. This association was only found when SDM was measured from the perspective of the observer, and not when measured from the perspective of patients.

Having a better general health status was positively associated with more SDM in three out of five studies among patients with cancer[25 33] or patients who take antidepressants.[30] Conversely, a study among patients with inflammatory bowel disease or arthritis found a negative association.[23] One study among patients with cancer found no significant association.[24]

Three studies assessed depressive symptoms, of which two found no significant associations.[30 34] In a study on sleep apnea treatment, having lower compared with higher levels of depressive symptoms was associated with more SDM, but when depressive symptoms were analysed as a continuous variable the association was non-significant.[35]

Sixteen studies assessed the association between diagnosis and SDM occurrence, of which seven focused on cancer (assessing either cancer type or primary cancer site), six on mental health conditions and three on somatic conditions other than cancer. Six of the seven studies that looked at cancer found no significant associations.[25 28 36–39] One study found that more SDM occurred in patients with head and neck cancer compared with other cancer sites.[40] One study, using multiple SDM measures (from the perspective of the patient or observer), assessed whether there was a difference between patients with pancreatic compared with colorectal cancer. In the analyses of two of these measures, more SDM occurred among patients with pancreatic compared with colorectal cancer; this association was non-significant using any of the other measures.[32] In the same study, it was also reported that SDM occurred less with patients with benign compared with malignant tumours when measured with the SDM-Q-9; no associations were found using other measures of SDM.

Of the six studies that looked at mental health diagnoses, five studies found no significant associations.[38 41–44] One study found that more SDM was reported among patients with depression than patients with schizophrenia.[45]

Of the three studies looking at somatic conditions other than cancer, one found a significant association: SDM occurred less with patients with ulcerative colitis, Crohn's disease and/or psoriatic arthritis compared with rheumatoid arthritis.[23] The two other studies (patients with gallstones[46] or vascular conditions[47]) found no significant associations.

Eleven studies assessed the association between SDM occurrence and cancer severity (table 3); six studies found no association. Four studies found that more severe cancer was associated with less SDM. One found that overall, more severe cancer was associated with more SDM, except for patients with the highest stage of severity; for them, the greatest severity of cancer was associated with lower SDM.[24]

Psychological characteristics and coping with illness

Having a positive attitude towards treatment was associated with more SDM in one study about sleep apnea treatment[35] and two studies about mental health treatment[45 48] (table 4). All other factors were only studied once (table 4).

Higher general perceived self-efficacy was found associated with more SDM in two studies (with seemingly partly overlapping samples) in mental health.[41 45] In the same studies, health locus of control was not significantly associated with SDM occurrence.

SDM style or preference

Having a preference for involvement in decision-making, prior to making the decision, was assessed in two studies about cancer (table 5). One study found a positive association with more SDM for decisions about surgery, but not for decisions about chemotherapy and adjuvant endocrine therapy.[49] The second study (adjuvant therapy after surgery[50]) found no significant association.

Table 2 Associations between sociodemographic characteristics and occurrence of shared decision-making (SDM), by measurement perspective

		Patient reported					Observer reported				Physician reported			
Characteristic	**n**	**Positive**	**Negative**	**Mixed**	**Unclear**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**
Age, gender, ethnicity/nationality														
Older age	46*	2[66 68]	8[29 30 35 41 45 50 56 73]	4[49 52 60 86]	–	23[22–26 28 31–33 36 38 40 46 53 55 58 59 62 63 67 69–71]	1[32]	1[37]	–	8[21 38 42–44 47 64 72]	–	–	–	1[48]
Female	30*	4[23 27 36 41]	4[34 50 58 68]	1[32]	–	13[25 26 28 30 31 33 35 38 40 45 46 52 55]	–	–	1[32]	8[21 37 38 42–44 47 72]	–	–	–	1[48]
Ethnicity (white)	16	–	–	1[52]	–	13[23 25 26 28–30 40 46 60 61 69 70 73]	–	–	–	2[42 44]	–	–	–	–
Minority status	1	–	–	–	–	1[53]	–	–	–	–	–	–	–	–
Country of birth	1	–	–	–	–	1[65]	–	–	–	–	–	–	–	–
Nationality (American compared with Canadian)	1	1[50]	–	–	–	–	–	–	–	–	–	–	–	–
Education and work														
Higher educated	34*	3[30 50 73]	1[58]	1[52]	1[69]	24[24–29 31–36 40 41 45 49 53 55 56 60 63 67 70 71]	–	–	1[32]	3[21 37 72]	–	–	–	1[48]
Higher health literacy	2	1[52]	–	1[24]	–	–	–	–	–	–	–	–	–	–
English language proficiency	1	1[52]	–	–	–	–	–	–	–	–	–	–	–	–
English as first language	2	–	–	–	–	1[46]	–	–	–	1[37]	–	–	–	–
Employed	8	1[30]	–	–	–	6[22 24 33 40 58 67]	–	–	–	1[72]	–	–	–	–
Higher income	8	2[28 58]	–	1[30]	–	5[25 34 53 67 71]	–	–	–	–	–	–	–	–
Socioeconomic status	1	–	–	–		1[68]	–	–	–	–	–	–	–	–
Involved in extra professional activities	1	–	–	–	–	1[67]	–	–	–	–	–	–	–	–
Involved in leisure activities	1	1[67]	–	–	–	–	–	–	–	–	–	–	–	–
Social situation						–								
Relationship status: married or in committed relationship	16	3[25 33 67]	–	–	1[69]	11[24 28–30 40 49 53 56 63 70 73]	–	–	–	1[21]	–	–	–	–
Having children	3	–	–	–	–	3[33 49 63]	–	–	–	–	–	–	–	–
Living alone	2	–	1[33]	–	–	1[26]	–	–	–	–	–	–	–	–
Having a caregiver	1	1[31]	–	–	–	–	–	–	–	–	–	–	–	–

*One or more of these studies used both a patient-based and observer-based SDM measurement; Not included in table: Insurance status and region.

Table 3 Associations between general health and clinical characteristics of condition or decision of interest and occurrence of shared decision-making (SDM), by measurement perspective

		Patient reported					Observer reported				Physician reported			
Characteristic	**n**	**Positive**	**Negative**	**Mixed**	**Unclear**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**	**Positive**	**Negative**	**Mixed**	**N.S.**
General health														
Comorbidities	10*	1[23]	–	–	–	9[25 26 29 31 32 49 53 63 73]	1[32]	–	–	–	–	–	–	–
Better general health status	5	3[25 30 33]	1[23]	–	–	1[24]	–	–	–	–	–	–	–	–
Better physical functioning	1	–	–	–	–	1[29]	–	–	–	–	–	–	–	–
Quality of life	2*	–	–	1[32]	–	1[71]	–	–	–	1[32]	–	–	–	–
Health related quality of life	1	–	–	–	–	1[73]	–	–	–		–	–	–	–
Frailty	1*	–	1[32]	–	–	–	–	–	–	1[32]	–	–	–	–
Body mass index/weight	3	–	–	–	–	3[26 40 53]	–	–	–	–	–	–	–	–
Smoking	2	–	–	–	–	2[53 58]	–	–	–	–	–	–	–	–
Depressive symptoms	3	–	–	1[35]	–	2[30 34]	–	–	–	–	–	–	–	–
History of depression	1	–	–	–	–	1[73]	–	–	–	–	–	–	–	–
Anxiety	1	–	–	–	–	1[35]	–	–	–	–	–	–	–	–
Clinical characteristics of condition or decision of interest														
Cancer severity	11	–	4[22 50 56 70]	1[24]	–	6[29 40 49 53 60 73]	–	–	–	–	–	–	–	–
Symptom severity	4*	–	–	1[35]	1[38]	1[30]	–	–	–	1[38]	–	1[48]	–	–
Longer illness duration	2	–	–	–	–	1[52]	–	–	–	–	-	–	–	1[48]
Longer time since diagnosis	1	1[24]	–	–	–	–	–	–	–	–	–	–	–	–
Higher number of drugs	2*	–	–	–	–	2[32 45]	–	–	–	1[32]	–	–	–	–
Prior treatment	2	1[30]	–	–	–	1[31]	–	–	–	–	–	–	–	–
Longer duration of total treatment by same mental health specialist	2*	–	–	–	–	1[38]	–	–	–	2[38 44]	–	–	–	–

Continued

Table 3 Continued

Characteristic	n	Patient reported					Observer reported				Physician reported			
		Positive	Negative	Mixed	Unclear	N.S.	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.
Positive family history of the disease	1	–	–	-	–	1[49]	–	–	–	–	–	–	–	–
Regular cancer screening prior to cancer diagnosis	1	–	–	–	–	1[49]	–	–	–	–	–	–	–	–
Risk of developing heart disease	1	–	–	–	–	1[57]	–	–	–	–	–	–	–	–

*One or more of these studies used both a patient-based and observer-based SDM measurement; Not in table: Diagnosis.

DISCUSSION

When a patient faces a decision between multiple treatment options, SDM is recommended.[1 2] Some patients may be less involved than others in decision-making. We aimed to identify which patient-related characteristics have been studied in relation to the occurrence of SDM about treatment as reported by an independent observer or a participant in the process, and summarise the findings.

Overall, the present review demonstrates many non-significant and mixed results regarding the association between patient-related characteristics and the occurrence of SDM. Importantly, the lack of evidence of associations between the characteristics studied and the occurrence of SDM is not evidence for no association. The heterogeneous nature of the studies (due to, eg, how the studied characteristics and occurrence of SDM were measured), and the sometimes small number of studies relating to a particular characteristic, provide insight into what has been studied and how often it has been studied. It does not provide conclusive evidence on associations that may exist with the occurrence of SDM. Focused systematic reviews and meta-analyses should provide additional information in this regard. Also, we have no indication of how often studies that showed null results were not published, so we should be mindful that possibly evidence on lack of association between patient-related characteristic and the occurrence of SDM may be under-reported.

We identified over 70 different patient-related characteristics of which the association with the occurrence of SDM had been assessed. SDM was assessed using 29 different measures (including self-developed items; online supplemental file 2), and most often from the patients' perspective. This perspective provides a relevant but incomplete view on the extent to which SDM occurred.[51] We categorised the characteristics into sociodemographic, health-related, or psychological characteristics, or SDM style or preference. Most studies were conducted in relation to somatic conditions, which often was cancer, and a minority in relation to mental health conditions. How frequently a particular patient-related characteristic had been studied differs greatly by characteristic—with sociodemographic characteristics having been studied most often and psychological characteristics and preference for involvement, least often. Of note, the latter has repeatedly been assessed but seldom such that preference for involvement was measured before engaging in the decision-making process. Overall, we found few clear determinants of SDM occurrence, even for characteristics that are commonly believed to be associated with less SDM, such as higher age, lower education or ethnic minority background.

The most frequently studied characteristics were age, gender and education. For all three, more than two-third of the studies found no significant association, the associations that were found were in either direction or studies showed mixed results. The same holds true for other sociodemographic characteristics, such as being

Table 4 Associations between psychological characteristics and coping with illness and occurrence of shared decision-making, by measurement perspective

		Patient reported				Observer reported				Physician reported			
Characteristic	n	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.
Decision-related													
Knowledge about the condition	1	–	–	–	1[31]	–	–	–	–	–	–	–	–
Accompanied to visit	1	1[29]	–	–	–	–	–	–	–	–	–	–	–
Preconsultation anxiety	1	–	–	–	–	–	–	–	1[37]	–	–	–	–
Fear of financial burden	1	–	–	–	1[31]	–	–	–	–	–	–	–	–
Positive attitude towards treatment	3	2[35 45]	–	–	–	–	–	–	–	1[48]	–	–	–
Medication adherence	1	–	–	–	–	–	–	1[44]	–	–	–	–	–
Positive patient assessment of disease	1	–	–	–	1[52]	–	–	–	–	–	–	–	–
Illness insight	1	–	–	–	–	–	–	–	–	1[48]	–	–	–
Illness uncertainty	1	–	–	–	1[71]	–	–	–	–	–	–	–	–
Illness self-management	1	–	–	–	–	–	–	–	1[44]	–	–	–	–
Patient activation	1	–	–	–	–	–	–	–	1[44]	–	–	–	–
General													
General perceived self-efficacy	2	2[41 45]	–	–		–	–	–	–	–	–	–	–
Internal health locus of control	2	–	–	–	2[41 45]	–	–	–	–	–	–	–	–
Active coping	1	–	–	–	1[73]	–	–	–	–	–	–	–	–
Ability to cope with daily life	1	1[58]	–	–	–	–	–	–	–	–	–	–	–
Reactance proneness	1	–	–	–	1[45]	–	–	–	–	–	–	–	–
Tendency to excuse	1	–	–	–	1[68]	–	–	–	–	–	–	–	–
Religiosity*	1	–	1[34]	–	–	–	–	–	–	–	–	–	–

*Definition: The extent to which someone believes that their religion is part of all aspects of their life.

in a committed relationship and ethnicity, and for clinical characteristics such as diagnosis or comorbidity. For some of the most frequently assessed characteristics (age, education, cancer severity, comorbidities and general health status) for which studies showed different results, we have looked at whether we could see a clear pattern in the results by diagnosis, SDM measure, age group or sample size (eg, whether positive associations were mainly found for a certain diagnosis, whereas non-significant associations were mainly found for other diagnoses). We were, however, not able to identify any clear patterns.

Table 5 Associations between shared decision-making (SDM) style or preference and occurrence of SDM, by measurement perspective

		Patient reported				Observer reported				Physician reported			
Characteristic	n	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.	Positive	Negative	Mixed	N.S.
Involved in previous decision about cancer treatment	1	1[49]	–	–	–	–	–	–	–	–	–	–	–
Preference for involvement	2	–	–	1[49]	–	–	–	–	1[37]	–	–	–	–
Desire for autonomy	1	–	–	–	1[46]	–	–	–	–	–	–	–	–
Avoiding or deferring decision-making style	1	–	1[62]	–	–	–	–	–	–	–	–	–	–

Clearly, if characteristics such as, for example, age, ethnicity or diagnosis were associated with SDM, this would allow for relatively practical ways for clinicians to identify patients who are likely to need additional support in order to become involved in treatment decision-making. With clear associations lacking, on the contrary, caution should be taken to assume that SDM with patients of certain ages, gender or education levels is more or less likely. Particularly for age, there are beliefs that elderly patients are less willing to be involved while many decisions elderly face are of a preference-sensitive nature and call for more SDM.

Fewer studies assessed psychological factors or preferences for involvement, in relation to SDM occurrence. Many of these characteristics can be considered to be states rather than traits and may change over time, in particular over the course of decision-making. We excluded studies that had measured state-like characteristics after the decision had been made, and/or at the same time as when self-reported levels of SDM were assessed, because the participants' experiences with the decision-making process of interest could have influenced their responses to such questions. Still, these characteristics may be highly relevant in better understanding what makes one individual more likely than another to become involved in treatment decision-making, or the same individual more 'ready' to engage in SDM at a particular time than at other times. In order to be ready, patients need, among others, to understand and apply the relevant information and communicate effectively with their clinicians.[6] This could be more difficult for patients who experience emotional distress or have difficulties accepting their diagnosis. In our review, two articles reported a positive association between higher general self-efficacy and more SDM, though these articles reported on seemingly partly overlapping samples. If further research supports this finding, fostering general self-efficacy may be a factor that could benefit patients. To date, the number of studies is too small to draw conclusions about relevant psychological characteristics with regard to the occurrence of SDM. One exception may be that having a favourable attitude towards treatment seems associated with higher SDM occurrence. This could be due to clinicians generally tending towards treatment, and preference congruence facilitating a shared decision-making process.

Strengths and limitations

The major strength of this review is that we looked at any patient-related characteristic that has been assessed in relation to a wide variety of treatment decisions, regardless of year of publication or SDM measure, allowing us to give an overview that cuts across clinical settings, study foci and study measures. Not putting any restrictions on how SDM was measured is, however, also a limitation. Most studies used validated SDM measures, but underlying constructs may differ and self-developed, unvalidated items were also included. This makes it more difficult to compare results across studies.

We aimed to include studies that have looked at a specific decision, rather than to what extent patients feel involved in treatment decision-making in general. This was, however, not always fully clear in the article. It is a strength that we decided to err on the side of inclusion to be comprehensive and not miss any relevant articles. It is, however, also a limitation, as we may have been too lenient in some cases. This means that it is possible that we have included some results that are less comparable to the rest, as patients' perceptions of involvement in general may differ from their perceived or observed involvement in a particular decision.

CONCLUSION

This review offers a comprehensive summary of studies that have assessed associations between one or more patient-related characteristics and the occurrence of SDM. From a practical standpoint, the results call for caution in making assumptions about whether SDM can or will occur with patients with particular characteristics. In fact, most if not all, patient-related characteristics studied do not point towards a clear association with the occurrence of SDM. In other words, SDM, if truly attempted, may occur with any patient with any of these characteristics. The review points out to the need for further research to clarify which patient-related characteristics may be associated with the occurrence of SDM, and how, to inform effective interventions to foster SDM. Importantly, such characteristics may not be those that are readily determined (eg, age, education), but rather less obvious psychological features. With the reliable identification of patients' specific support needs and the offer of adapted support, all patients could then have the best possible opportunity to contribute to the planning of their treatment.

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