Review Article

Minority patient preferences, barriers, and facilitators for shared decision-making with health care providers in the USA: A systematic review

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ABSTRACT

Objectives: This systematic review of contemporary literature sought to better understand racial and ethnic minority patients' shared decision-making (SDM) preferences, challenges and facilitators.
Methods: Data sources were PubMed, CINAHL, Embase, Google Scholar, PsycINFO, Sociological Abstracts, and Web of Science databases for publications between 2011 and 2016. Publications were included if they studied SDM during the clinical encounter for minority adults in clinical care in the United States. We conducted a narrative, descriptive synthesis of each study.
Results: From over 5000 publications identified through the search strategy, 18 met eligibility criteria following an abstract and full text (n = 685) review in Covidence. Studies focused on SDM in developing treatment plans (n = 10), and were conducted in primary care (n = 6) or hospital/health system settings (n = 6). Patients' decision preferences ranged from physician-driven altogether or initially, to patient-driven style. A comprehensive list of SDM facilitators and barriers was developed.
Conclusion: Despite strong policy and research SDM support to increase patient communication and a growing published literature, results suggest lack of representation of minority populations in contemporary literature.
Practice implications: Provider training may be needed to facilitate patient-provider transition from a passive toward a more active SDM engagement over time while confidence, trust and rapport is established.

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1. Introduction

Patient involvement in decision-making with service providers through shared decision-making (SDM) has been a key focus of health care policy seeking to improve communication between providers and patients as well as patient engagement in their own health care [1–3]. The goal of SDM is to promote patients' ability, in collaboration with providers, to make informed treatment decisions based on an understanding of available treatment options and on each patient's circumstances, beliefs, values, and preferences [4]. In this study, SDM refers to the collaborative process that takes place between service providers and patients including exchange of information and treatment options and taking into account patient and family needs, beliefs, values, and preferences [5]. SDM can happen at any point in the service delivery process: prevention, diagnosis, or intervention. We define SDM broadly to encompass the various definitions found in the literature.

The practice of SDM during the clinical encounter between the patient and/or family member and health care provider has been associated with higher patient satisfaction with services, adherence to the treatment plan, and positive health outcomes [6,7]. For example, SDM is associated with better patient health outcomes measured by physical and mental health status [8]. Among women with breast cancer, those who participate in SDM have higher odds of patient satisfaction [9]. For cancer survivors, a participatory physician style that promotes SDM is associated with patient trust, self-efficacy, perceived self-control, reduced sense of uncertainty, and improved mental health [10]. A 2015 meta-analysis of SDM in pediatrics found that SDM is associated with improved knowledge and reduced decisional conflict [11]. In addition, SDM is associated with youth report of positive surgical outcomes [12]. SDM is also associated with positive financial and service use outcomes such as decreased health care costs, rates of hospitalization, emergency department visits, and out-of-pocket costs for children with special health care needs [9,11,13].

Though benefits of SDM may be the same for minority and White patients, there are disparities in rates of patient participation. In a recent study, only 9.3% of White/Caucasian patients reported poor perceived SDM compared to 14.7% of Hispanic patients, 12.7% of Asian/Pacific Islander patients, and 11.3% of Black/African American patients [8]. Moreover, evidence shows that SDM is a particularly relevant strategy for giving voice to those who are historically disenfranchised, thereby increasing the quality of provider-patient communication and ultimately engagement and satisfaction with health services among racial and ethnic minority (minority thereafter) patients [14]. Despite this promise, there is also evidence that SDM may not be experienced in the same way among minority patients due to life experiences, individual and system-level challenges, and cultural differences among others [15,16]. Additional research is needed to identify and document these differences.

Previous comprehensive reviews have focused on the role of specific decision-aid interventions to address health disparities [17,18], on the impact of SDM on patient outcomes [19] and on patient preferences for SDM engagement in general [20]. Although these reviews address key aspects of SDM engagement, to our knowledge, no review of the literature has focused on summarizing contemporary literature on the SDM preferences and the barriers and facilitators that minority patients experience during the clinical encounter. In addition, some of these reviews excluded qualitative studies [19], which are important in the field of health disparities to understand nuanced interpretation of experiences. This paper contributes to the literature by conducting a systematic search and review of both qualitative and quantitative literature to understand SDM preferences, barriers, and facilitators among racial and ethnic minority patients at a time of strong policy support.

One prime example of policy support in the United States is the Affordable Care Act (ACA) legislation, enacted in 2009–2010. This legislation includes SDM as a formal patient education and communication model for health care system reform [4]. Although efforts to promote SDM in clinical settings have been promoted since early 1990s [21], the support provided by the 2009–2010 ACA legislation has contributed to increased attention among policy-makers, providers, and patients regarding the use of SDM as a communication model in health care settings [22,23]. This study focuses on exploring the state of the field on minority patients' SDM engagement preferences, as well as barriers and facilitators to their SDM in a climate of policy support in the United States.

We sought to answer the following questions: What are the preferences among minority patients (ages 18 and older receiving care in the United States) regarding SDM style (e.g., provider vs patient led) during the clinical encounter? What are the barriers and facilitators for SDM engagement among minority patients? Our research questions and study approach are framed by the expanded Andersen Model for Health Services [24]. This model was developed to increase relevance for racial/ethnic minority populations and their health care service use. In addition to the original emphasis on individual characteristics (e.g., age, gender) and contextual factors that contribute to health services use (e.g., enabling factors such as financial resources), the expanded model emphasizes patients' psychosocial factors of attitudes, knowledge, social norms, and perceived control as determinants of service engagement.

2. Methods

2.1. Data sources and search strategy

We developed a review protocol a priori and registered it in PROSPERO (CRD42016044091). In collaboration with an experienced academic librarian, we searched PubMed, CINAHL, Embase, Google Scholar, PsycINFO, Sociological Abstracts, and Web of Science databases for articles published between January 2011 and January 2016. We developed a list of Medical Subject Heading (MeSH) search terms, subject headings, and keywords as applicable to search each database based on our inclusion and exclusion

criteria (described below). Appendix 1 presents the complete search strategy.

2.2. Study selection and inclusion criteria

We used a PICOT format (patient, intervention, comparison, outcome and type of study) to structure the research questions, study selection, and inclusion criteria [25]. Eligibility criteria were defined as studies that included individuals 18 years of age or older engaged in clinical care for any health condition; data collection completed between 2010 and 2016 (after ACA implementation); and use of quantitative, qualitative, or mixed methods analyses. Based on guidance from previous systematic reviews exploring racial/ethnic disparities in decision-making [17,26], we included studies where at least 50% of the sample identified as a racial/ethnic minority or where a subgroup analysis by race/ethnicity was conducted. We selected articles that measured preferences for SDM during the clinical encounter between the provider and adult patients. In this work, we use preferences to indicate whether the patient prefers for the health provider to lead or have control over treatment decisions or whether the patient prefers to actively engage in that process with the provider to reach shared decisions. We also included studies addressing barriers and facilitators to SDM engagement among racial/ethnic minorities. A health provider is defined as an individual (e.g., primary care provider, nurse, psychiatrist, clinical social worker, psychologist, or physical therapist) who is authorized to practice by the State and is performing within the scope of their practice as defined by State law [27].

We excluded articles that did not present results from empirical studies (e.g., commentaries, study protocols, and theoretical frameworks), that focused on children or on developing a SDM measure, and where fewer than 50% of the identified sample was a racial or ethnic minority. We chose these exclusion criteria to perform a comprehensive literature search on published studies of minority SDM. In addition, given our interest in exploring minority patient preferences for SDM engagement since enactment of the ACA—a U.S. health policy—we excluded articles conducted outside the United States.

We addressed risk of bias in the overall review process by following Cochrane guidelines for systematic literature reviews [28], and by using Covidence software—a Cochrane technology web-based platform designed to help researchers produce timely, high-quality systematic reviews—to track each document through the inclusion and exclusion criteria process [29]. The Covidence database also allowed us to use multiple coders working independently, assess reliability, and identify conflicts for resolution through team discussion. Two trained researchers independently screened the title and abstract of each article for possible inclusion. We reviewed the full text of each screened article to make a final decision about whether these articles met inclusion and exclusion criteria.

2.3. Data extraction and synthesis

We used Microsoft Excel to review and extract details about each study included in the final sample. We extracted details about patient characteristics that the Andersen Behavioural Model specifies affect patient preferences. More specifically, we extracted details about patient characteristics (e.g., racial/ethnic group and gender), psychosocial factors related to minority patient preferences for SDM (e.g., attitudes toward SDM), and barriers and facilitators that may represent enabling factors related to SDM engagement.

We also extracted the following information from each study: study purpose, methods type (e.g., quantitative, qualitative, or mixed methods), study design type (e.g., cross-sectional), details about the percentage of racial and ethnic minorities in the sample, study location (e.g., city/state), number of total participants, data collection and analysis description, details about how SDM was measured (if at all), health care setting (e.g., primary care, cancer care, hospice), point where SDM occurred in study (e.g., in developing a treatment plan or end-of-life care) and references cited that may be relevant to the present review. From this comprehensive extraction, we report in Tables 1 and 2 only the results that align with the focus on this paper. We conducted a narrative, descriptive synthesis of the extracted information to answer our research questions [30].

3. Results

3.1. Overview of the reviewed studies

Our initial database search yielded 5158 unique articles. After excluding 4473 articles based on title and abstract review in Covidence, we reviewed the full text of 685 articles. From this group, we excluded 667 articles for various reasons described in Fig. 1. We identified a final sample of 18 articles that met all inclusion criteria. Fig. 1 presents the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram for this study and summarizes results from the article screening process.

Table 1 presents an overview and summary of the reviewed articles. Eight articles used quantitative methods alone, five used qualitative methods alone, and five used mixed methods. Two of the reviewed studies were randomized controlled trials. Most studies (n = 14) reported on a mixed sample that included racial and ethnic minorities and White participants [31–44]. A majority of studies measured SDM in the context of developing treatment plans (n = 10) and were conducted in primary care (n = 6) or hospital or health system settings (n = 6). Nine studies specifically reported SDM preferences. With the exception of one study that reported White vs non-White racial groups, studies (n = 17) included Black and/or Hispanic individuals in their analysis. Other racial groups included were Asian/Pacific Islander (n = 5), American Indian/Alaskan Native (n = 1), or 'other' (n = 5).

3.2. Decision-making preferences

Nine studies reported SDM preferences of patients during the clinical encounter. SDM preferences in these studies fell into four categories, described below. See Table 1 for a summary of each articles' purpose, data collection timeline, population, SDM style reported, and a comprehensive list of SDM barriers (denoted with a minus sign) and facilitators (denoted with a plus sign).

3.2.1. Provider-driven decision-making vs SDM

In four studies (n = 4) [32,33,39,42], the majority of patients preferred a provider-driven decision-making style. Some of the reasons provided for this preference were that the participant did not feel prepared to participate in decisions or preferred taking an active role only as time passed after their initial diagnosis. In three studies, participants reported feeling unprepared to participate in SDM or to advocate for their health service use because they lacked medical training, felt unqualified, and preferred to rely on the provider's knowledge to make decisions rather than on the information obtained on their own [32,33,39]. In an additional study, patient depression was associated with a preference for a more passive role in SDM [42].

Two studies reported SDM preferences by minority group and compared minority and non-minority preferences [32,39]. In one of these studies [32], African American and Latino participants expressed discomfort in taking an active role with their provider for their own health-related decisions, but they did recommend that their peers take an active role. More specifically, discomfort at

Table 1
Descriptive overview of the included SDM studies.

Study	Design	Purpose	Data Collection Timeline	N = Total sample	N = Minorities	Decision Making (DM) Preference	SDM Challenges (-) & Facilitators (+)
Alegría et al. [31]	Randomized Clinical Trial	To assess whether the DECIDE intervention, an educational strategy that teaches patients to ask questions and make collaborative decisions with their health care professional, improves patient activation, self-management, and engagement / retention in behavioral healthcare.	February 2009-October 2011	Intervention: n = 329 Usual Care: n = 318	Intervention: Latino: n = 215 (65.3%) Black: n = 33 (10%) Other: n = 27 (8.2%) Usual Care: Latinos: n = 213 (67%) Black: n = 36 (11.3%) Other: n = 19 (6%)	Not reported	• (+) Participation in a SDM intervention (DECIDE) was associated with patients' learning to ask questions and increased self-management.
Allen et al. [32]	Focus groups	To describe women's awareness of, attitudes toward, and intention to comply with the 2009 United States Preventive Services Task Force mammography guidelines recommending biennial screening starting at age 50.	February-April 2011	n = 77	Black (non-Hispanic): n = 27 (35%) Hispanic: n = 20 (26%)	Provider-driven	• (+) Understanding of health screening guidelines • (-) Mistrust or suspicion of health care provider and insurance company motives for changing mammography guidelines • (+/-) Provider willingness to consider patient preferences
Aysola et al. [33]	Interviews	To characterize patients' experiences with care after patient-centered medical home (PCMH) adoption and their understanding of the PCMH model.	November 2013-April 2014	n = 48	Black: n = 22 (46%) Hispanic: n = 2 (4%) Asian: n = 1 (2%)	Provider-driven	• (+) Good rapport with provider • (-) Feeling unqualified to participate in decisions
Chao et al. [34]	Cross-sectional	To identify sociodemographic and communication factors associated with disclosure of complementary health approaches to providers by low-income patients with diabetes.	2009-2011	Sample for majority of analyses (complementary health approach users): n = 132	Asian/Pacific Islander: n = 72 (54.6%) Latino: n = 35 (26.5%) Black, White, or other: n = 25 (18.9%) = 132.	Not reported	• (+) Patient disclosure to provider about using complementary health approaches (e.g., massage, acupuncture) • (+) English and language concordance
Christopoulos et al. [35]	Interviews	To understand important steps in the HIV care continuum.	February 2011-October 2012	n = 34	Hispanic: n = 9 (26%) African American: n = 9 (26%) Asian-American: n = 3 (8%)	Evolving DM preference overtime	• None reported
Danis et al. [36]	Focus groups and pre- and post-discussion questionnaire	To understand public attitudes about discussing out-of-pocket and insurer costs in the doctor-patient relationship and whether communication strategies may enhance patient receptivity to discussing costs with doctors.	July–August 2011	n = 211	Black: n = 72 (41%) Other: n = 11 (6%) Hispanic: n = 62 (31%) Note: Race is reported for the 177 participants with no missing data. Ethnicity is reported for the 203 participants with no missing data.	Not reported	• (-) Health care access barriers • (-) Impersonal doctor visits and busy schedules • (-) Lack of provider knowledge about costs • (+) Long term doctor-patient relationship/ trust
Hagerty et al. [46]	Prospective	To assess differences in satisfaction with care and SDM between English and Spanish-speaking family members of patients in a neurological intensive care unit.	April 2013-February 2014	n = 73	English speakers: n = 50 (69%) Spanish speakers: n = 23 (n = 32%) Note: Participants were family members of Hispanic patients.	Not reported	• (+) Family members feel supported during SDM
Kaplan et al. [37]	Cross-sectional	To examine factors associated with decisional conflict in economically disadvantaged men diagnosed with prostate cancer before treatment choices were made.	January 2011–October 2013	n = 70	Black/African American: n = 34 (49%) Hispanic/Latino: n = 8 (11%) Other or mixed race/ ethnicity: n = 4 (6%)	Not reported	• (-) Poor prostate cancer knowledge
Moise et al. [42]	Cross-sectional	To assess whether elevated depressive symptoms are associated with decision-making preference in patients with comorbid chronic illness.	2011-2014	n = 195	Hispanic: n = 151 (77%) Black: n = 75 (39%)	Provider-led	• (+/-) Depressive symptoms were associated with a preferred clinician-led style

Noh [45]	Interviews	To identify the unique values and preferences of older African American hospice patients and facilitate the ability of hospice care professionals to honor these end of life preferences.	August 2011–January 2012	n = 28	African American: n = 28 (100%)	Patient-driven / Independent	• (+) Patient expression of concern and willingness to ask questions • (+) Providers take time to explain health conditions and make sure patients understand information • (+) "Caring and friendly" provider attitude
O'Leary et al. [38]	Cluster Randomized Controlled Trial	To evaluate the effect of patient centred bedside rounds (PCBRs) on measures of patient-centred care.	Interviews: May 2014-December 2014 Survey: May 2014–January 2015	Interviews: n = 236 Survey: n = 493	Interview patients: Non-white race: n = 133 (56%) Survey respondents: Non-white race: n = 157 (32%)	Shared decision-making	• (+) Concordance between patients' preferred and experienced role in decision making
Owens et al. [47]	Focus groups	To assess whether a computer-based informed decision making intervention for prostate cancer screening would be appropriate for African American men.	September-December 2011	n = 39	African American: n = 39 (100%)	Not reported	• (+) Patient knowledge about prostate cancer screening • (+) Doctors' disclosure about the benefits and harms of screening
Park et al. [39]	Cross-sectional	To evaluate preferences for SDM during mental health treatment in a sample of veterans diagnosed with mental illness.	March 2010–October 2011	n = 239	Black: n = 113 (47%) Multi-racial: n = 9 (4%) American Indian / Alaskan Native: n = 3 (1%) Native Hawaiian/ Pacific Islander: n = 1 (<1%)	Provider-driven	• (+) Patient preference for obtaining knowledge • (+) Strong therapeutic relationship with provider
Prakash et al. [40]	Interviews and survey	To examine the influence of behavioral stage of change on dialysis modality decision-making.	Surveys administered August 2012–June 2013. Interview timeline not given	Survey: n = 55 Interviews: n = 16	Survey: Black: 59.3% Hispanic/Latino: 3.6%; Other: 1.9% Interviews: Black: 56.3% Hispanic / Latino: 6.3% Note: Exact n of racial/ethnic minorities is not reported. Only percentages are reported for each category.	Patient DM ownership was important to monitor disease. A broad range of preferences reported, from not wanting to be involved to wanting to know all details.	• (+) Patient being in an acting vs thinking State of Change • (+) Doctors explaining treatment options • (+) Higher knowledge about the health condition • (-) Lifestyle barriers (e.g., fears about dialysis, distance to a dialysis center)
Rodríguez et al. [41]	Cross-sectional	To investigate the distribution of health literacy, numeracy, and graph literacy in African Americans and older veterans.	January–February 2012	n = 502	African American: 55% American Indian / Asian: 3% Hispanic: 19% Note: Exact n of racial/ethnic minorities is not reported for all categories. Only percentages are reported for each category.	Shared decision-making	• (+) Trust in physicians
Sandiford & D'Errico [48]	Quasi-experimental	To describe the development / implementation of a prostate cancer screening intervention and risk assessment decision tool.	Exact timeline not provided, but tools used during intervention display 2014 copyright date.	n = 50	African American: n = 50 (100%)	Not reported	• (+) Use of a formal prostate cancer screening decision aid
Song, et al. [43]	Interviews	To examine patient perspectives on how decisions to start dialysis were made, with emphasis on the decision-making context, the information they received and their perceptions of communication with physicians prior to the decision to undergo dialysis.	September 2011-September 2012	n = 99	African American/Black: n = 76 (76.8%) White: n = 23 (23.2%)	Not reported	• (+) Physician asks about patient values and treatment preferences • (+) Physician communicates treatment risks and burdens • (-) Patients feel rushed to make decisions • (+) Patients feel informed and prepared to make decisions • (-) Patient feelings of fatalism and lack of choices

Table 1 (Continued)

Study	Design	Purpose	Data Collection Timeline	N = Total sample	N = Minorities	Decision Making (DM) Preference	SDM Challenges (−) & Facilitators (+)
Tapp et al. [44]	Focus groups and process evaluation	To describe a participatory approach used to adapt and implement a shared decision-making intervention related to asthma into primary care.	April 2011–April 2012	Practices: n = 6 Providers: n = 148 Patients: n = 2,066	Patient demographics varied by clinic: African American: 51%-83% Hispanic: 3%-26% White: 11%-22%	Not reported	• (+) A non-physician provider assesses the patient's health needs, offers education, and helps the patient develop a treatment plan that includes their goals/preferences.

not being prepared for a discussion with the provider was more prevalent among African Americans than Latinas. Latinas were less likely than African Americans to advocate for their own preferences and to feel empowered to participate in SDM. Participants also felt that health providers would not react positively to a patient taking a more active role during the encounter. The second study [39] found no differences between White and minority patients receiving mental health services in preferences for SDM. However, White participants were more likely than minority patients to prefer relying on their provider's knowledge as a source of information.

3.2.2. Patient-driven decision-making vs SDM

In two studies (n = 2) [40,45], participants reported a preference for taking an active role in decisions related to their care. In a study of patients receiving hospice care, participants underscored the utility of providers allowing them enough time to make decisions based 'on their own judgement' and not feeling 'pushed' in their decisions so they could lead the process and make decisions based on patient needs and preferences [45]. The need for providers to respect patient-driven decisions and make the proper arrangements for these wishes to be followed was also important for patients. Patients also perceived provider support of a patient-driven decision-making style as a sign of respect from providers 45. One additional study reported that, although patients reported various SDM styles ranging from lack of SDM engagement to full engagement, their ownership of this process was important to monitor their disease and ongoing treatment [40].

3.2.3. Shared decision-making

This style referred to patient preference for collaborative decisions that included both the provider and the patient and often family members in the decision-making process as a team. Two studies [38,41] reported patient preference for a SDM style. One study of hospitalized patients [38] found that most patients preferred SDM between the patient and the provider. SDM was also the most frequently experienced style of decision-making by participants during the clinical encounter [38]. In another study, participants reported preference for a SDM approach with their providers, but noted that they often assume a more passive decision-making role in the actual clinical encounter [41].

3.2.4. Evolving decision-making style over time

One of the reviewed studies [35] suggested that some patients prefer a decision-making process where provider-driven decision-making gradually shifts to a patient-driven process. This study reported patients with HIV positive status expressing a preference for a decision-making style that evolves over time. Patients expressed a preference for a more passive SDM engagement when they are first diagnosed with the health condition and evolving to a more active role in their care over time. This process allows patients to become more familiar with options as treatment progresses and health routines are established [35].

3.3. SDM engagement barriers and facilitators

From all of the studies reviewed (n = 18) [31–48], all but one study [35] reported challenges and/or facilitators to SDM engagement among minorities (see Table 1). Most of these studies reported SDM engagement barriers and/or facilitators at the patient level (n = 11 [31–34,37,38,40,42,43,45,46]). Facilitators included developing confidence (e.g., though patient activation), rapport with providers, and a trusting and positive patient-provider relationship. Language concordance between the

Table 2
Summary of health-related topics/decisions, SDM definitions, and measurement of SDM preferences.

Paper by Author	Health-related topic/ decision	Definition of SDM	Measure used to assess SDM preferences
Alegría et al. [31]	Self-perceived activation and self-management in behavioral health care/mental health services	No formal definition provided. SDM was partly defined as part of patient activation: "Patient activation . . . involves the acquisition of knowledge, skills, and beliefs to enable thoughtful action and active participation in decisions about one's health care" (pg. 558).	SDM preferences not measured
Allen et al. [32]	Awareness of, attitude toward, and compliance with new mammography guidelines	No formal definition provided	Open ended focus groups with following questions about decision making: 1. Think about a time when you had to make a health decision for yourself or someone in your family. Did you want to talk about it with your health care provider? 2. What made you want to discuss it with your provider? 3.What did you want to know? 4. How did your provider respond? 5. How did you feel about that response? 6. What would have made that experience more successful for you?
Aysola et al. [33]	Experiences with care after patient-centered medical home (PCMH) adoption among patients with hypertension and/or diabetes	No formal definition provided. However, study "respondents often described shared decision-making by specifying who should be engaged in discussions around medical treatment and medication decisions" (pg. 1464).	Semi-structured interview guide including open-ended items and structured Likert-scaled survey questions. The interview guide aimed to assess respondents' experiences with delivery of care at their practices post-PCMH adoption and their perceptions and understanding of the overall PCMH model and key components. Interview questions focused on the following PCMH domains: patient–provider relationship, shared decision-making, team-based and coordinated care, electronic health records, and enhanced access to care. The exact questions/items were not presented in the article.
Chao et al. [34]	Disclosure of use of complementary health approaches to providers among low-income patients with diabetes	No formal definition provided	SDM preferences not measured
Christopoulos et al. [35]	HIV treatment continuum for HIV-infected individuals	No formal definition provided	In-depth interviews where patients discussed their role in decision making.
Danis et al. [36]	Attitudes toward discussing out-of-pocket and insurer costs with physicians	No formal definition provided	SDM preferences not measured
Hagerty et al. [46]	Differences in needs and care satisfaction between English and Spanish speaking family members of patients in a neurological Intensive Care Unit	No formal definition provided	SDM preferences not measured
Kaplan et al. [37]	Decisions before any treatment choices have been made among men with newly diagnosed prostate cancer	"Shared decision-making (SDM) is a process by which physicians share relevant risk and benefit information of all treatment options and patients share relevant personal information with the clinician. Thereby, a truly patient-centered decision is reached" (pg. 2721).	SDM preferences not measured
Moise et al. [42]	Decision making preference in adults with uncontrolled hypertension	"Shared decision-making (SDM) refers to a collaborative process whereby clinicians and patients make health decisions together by increasing awareness of options, exchanging information about best available evidence, exploring values and preferences, and finally making an informed decision" (pg. 63).	Preference for decision-making was assessed using the Control Preference Scale [49], which ranged from strong clinician-direction to little clinician-input.
Noh, 2014 [45]	Values important to terminally ill African Americans receiving hospice care	No formal definition provided	Open-ended interview questions about values participants believed were important in receiving health care services and experiences in having these values respected by hospice care workers. Preference for SDM was a value often mentioned by participants.
O'Leary et al. [38]	Evaluation of the effect of patient-centered bedside rounds on patient-centered care among hospitalized general medical patients	No formal definition provided. SDM definition described as part of patient-centered care: "Patient-centered care can be described as a partnership between patients and healthcare professionals with deliberate efforts to inform and engage patients so that they might share in decision-making" (pg. 921)	Preferred and experienced roles in medical decision-making were assessed using the Control Preferences Scale [49].

Table 2 (*Continued*)

Paper by Author	Health-related topic/ decision	Definition of SDM	Measure used to assess SDM preferences
Owens et al. [47]	Development of a decision aid for prostate cancer screening for African American men	Authors used the informed decision making definition as provided by the CDC and Prevention's Task Force on Community Preventive Services (pg. 208): "When an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time."	SDM preferences not measured
Park et al. [39]	Preferences for shared decision making in mental health treatment among veterans with serious mental illness	"Shared decision making is a collaborative process by which consumers and clinicians share information, provide expertise, and clarify preferences in order to reach agreement and make decisions regarding care and treatment" (pg. 1409).	Three-item scale developed by Levinson and colleagues [50] and adapted it for the context of mental health treatment decisions. The adapted scale assessed patient preferences for obtaining information on their own, being offered options for treatment, and making their own treatment decisions. Items were rated on a 6-point scale from 1, strongly agree, to 6, strongly disagree.
Prakash et al. [40]	Dialysis modality decision making among patients on dialysis	No formal definition provided	The authors developed and pilot tested 12 items related to dialysis decision making (e.g., "I want to be deeply involved in deciding about dialysis") and conducted in-depth qualitative interviews where one of the discussion topics included personal involvement in decision making.
Rodríguez et al. [41]	Health literacy, numeracy, graphical literacy, shared decision making, and trust in physicians among veterans receiving outpatient care	No formal definition provided	Two items based on work from Strull and colleagues [51]; one item assessed the usual role patients play in their interactions with physicians; the second item assessed the role patients believe they should play. Both items use a 5-point scale ranging from 1 "the doctor makes (should make) the decision" to 5 "I (should) make the decision".
Sandiford & D'Errico, [48]	Development and implementation of an intervention; risk assessment decision tool for prostate cancer screening among African American men.	No formal definition provided	SDM preferences not measured
Song, et al. [43]	Decision making surrounding dialysis initiation	No formal definition provided	SDM preferences not measured
Tapp et al. [44]	Adaption and implementation of an evidence-based asthma SDM intervention into primary care practices	"SDM is a process where patients and their health-care providers are jointly engaged in making decisions about medical tests and treatment" (pg. 381).	SDM preferences not measured

provider and patient was also included as a key facilitator in one publication [34]. Challenges included patient's sense of fatalism and perceived lack of choice. Barriers and facilitators at the provider level were the second most reported (n = 5) [32,36,40,43,45]. Facilitators included clinician willingness to consider patient preferences and disclosure about benefits and harms of health screenings. Challenges included impersonal doctor visits and busy schedules. Two publications focused on the quality of the relationship between the clinician-patient dyad [33,40] (e.g., trust, long-term relationship, and good rapport) as facilitators of SDM engagement. Last, two studies reported system level challenges (n = 2) [32,36] related to barriers to health care access and patient mistrust or suspicion of clinicians in general and of insurance company motives for changes in health guidelines.

Overall, SDM engagement challenges focused on the patient's perceived abilities such as feeling unqualified on the particular health condition or treatment to be part of the SDM process initially or altogether; perception of having limited service or treatment choices; having a provider merely conveying information about treatment options but not asking about the patient's values and preferences for those options; and not being able to communicate successfully with providers. One of these studies reported that patients were interested in learning more and making decisions regarding out-of-pocket costs to avoid doctors making "arbitrary decisions regarding costs when patients are unaware of costs [36]."

3.4. Summary of health-related topics and decisions, SDM definitions, and measurement of SDM preferences

The 18 studies included in this review focused on a wide range of health-related topics and decisions (e.g., attitudes toward updated mammography guidelines [32], SDM preferences in mental health treatment [39], and dialysis modality decision-making [40]). Four studies explicitly defined SDM [37,39,42,44]. In these studies, the authors generally defined SDM as a process by which patients and their physicians share and review relevant information and collaboratively make an informed decision. For example, Moise and colleagues [42] define SDM as "a collaborative process whereby clinicians and patients make health decisions together by increasing awareness of options, exchanging information about best available evidence, exploring values and
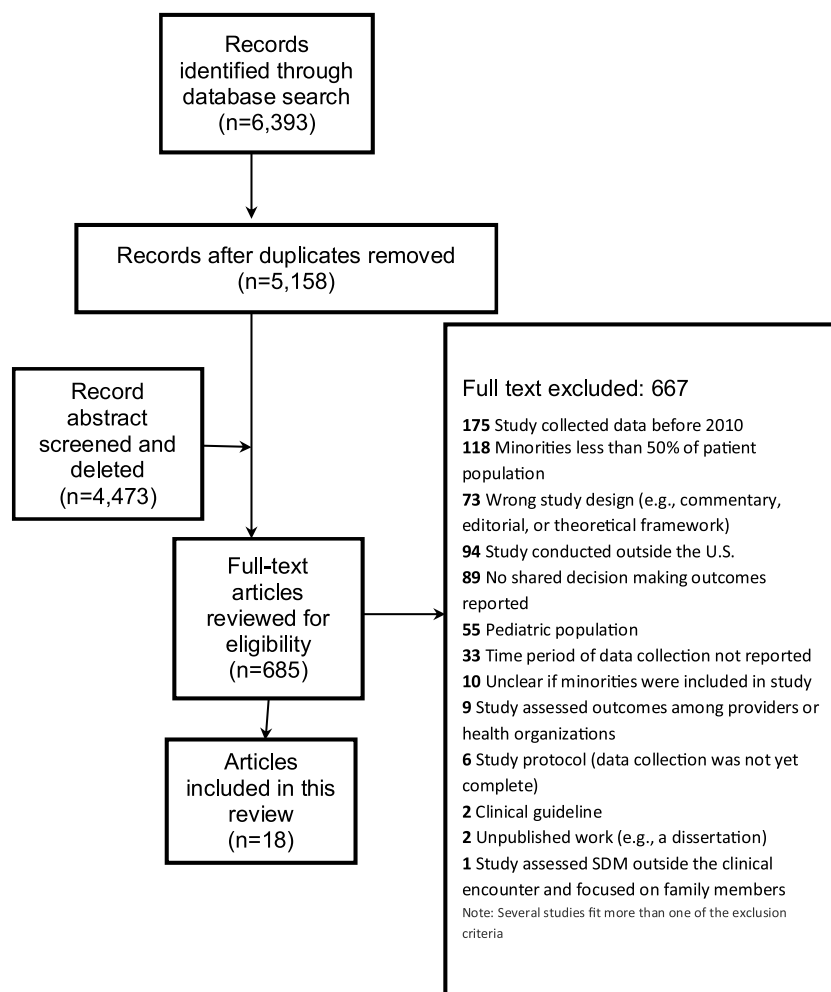
Fig. 1. PRISMA Flow Diagram.

preferences, and finally making an informed decision." Three studies presented definitions of related terms (i.e., patient activation [31], patient-centered care [38], and informed decision-making [47]). The remaining 11 studies did not provide a formal definition of SDM [32–36,40,41,43,45,46,48].

The nine studies that reported patient preferences for SDM used a wide variety of measures to assess these preferences. Two studies [38,42] used the Control Preferences Scale [49], which assesses the degree of control a person wants when making decisions about medical treatment. Two studies [39,41] used or adapted previously developed scale items [50,51] to assess SDM preferences. Four studies [32,33,35,45] qualitatively elicited patient SDM preferences through interviews or focus groups and/or found that these preferences emerged as themes. One study [40] used a mixed-methods approach to assess patient preferences by developing and pilot-testing survey items related to dialysis decision-making combined with qualitative interviews where one discussion topic was decision-making involvement. Table 2 provides detailed information regarding the health-related topics and decisions, SDM definitions, and measurement of SDM preferences included in sample studies.

4. Discussion and conclusion

This systematic search and review of the literature sought to understand minority patient SDM preferences as well as barriers to

and facilitators of their engagement in SDM since the implementation of national policy supporting this health care model to increase the quality of provider-patient communication and patient engagement in health decisions and treatment plans.

4.1. Discussion

This review of the literature illustrated that minority patients do not experience SDM uniformly. Patients reported a preference for a variety of SDM styles that ranged from provider-driven decision-making to a patient-driven process. These findings align with empirical studies showing that the promotion of shared decisions between providers and minority patients is not always the preferred communication model in health care settings [15]. We also found a higher number of studies reporting patient preference for a provider-driven decision-making approach. These patients preferred the provider to lead the decision-making process altogether or during the initial phase of the health care engagement process. For this evolving decision-making process, some minority groups with low English language proficiency and/or health literacy may prefer a more provider-driven communication process initially because they have a harder time interrupting the conversation to digest information and check-in to confirm understanding. A gradual process of increasing SDM may allow these patients time to confirm understanding, become more familiar with treatment options and the health care system, and

develop trust with the provider so they can increase their engagement in the decision-making process over time. Our results mirror another study that reported African American men and women undergoing cancer therapy had a preference for higher independence in information-seeking but higher reliance on provider recommendations for decision-making [52].

On the other hand, our results diverge from a previous review of decision-making patient preferences where most of the reviewed studies reported a preference for a SDM style [20]. However, this review did not focus on race and ethnicity and did not report on detailed preferences, such as the trajectory of preferred SDM style over the engagement process among racially and ethnically minority patients. It is possible subgroup differences were masked by this aggregated reporting approach.

In our study, the two main reasons provided by patients for not preferring an active role in the SDM process altogether or initially were individual in nature. First, patients often felt unschooled about their particular health condition (e.g., due to a lack of medical knowledge and unfamiliarity with a particular procedure). Second, they trusted the information provided by the provider more than the information accessed on their own. This sense of inadequacy among some patients may lead to what we found to be an initial deferment of decision-making to the provider and, to what we called an 'evolving SDM style over time'. Patients preferring this style may need more time for this sense of inadequacy to subside as they gain more health-related information and confidence and trust in the provider and health care system. This initial discomfort with SDM may also be accentuated by existing challenges at the provider and system level for this patient population. For example, our review showed challenges related to a lack of patient access to health care, providers using an impersonal approach to communication, and patients not having enough time with the provider during the medical encounter. Our results mirror those of the general literature reporting system-level barriers [53] and SDM miscommunication and mistrust between providers and minority patients due to barriers to cross-cultural communication, racism, and impersonal patient relationships with providers [54,55].

On the other hand, we found several facilitators to a more positive SDM experience for minority patients. Among health care provider actions, facilitators included explanations of changes in health screening guidelines, full disclosure not only about treatment options but also treatment harms and side effects, willingness to consider patient preferences, and fostering a warm and personal relationship with patients. Among patient factors, facilitators included their participation in effective activation interventions that increase confidence, assertiveness and self-efficacy to play an important role in treatment decision-making; feeling that family members are supported during the SDM process; disclosure of use of complementary health approaches; readiness to make decisions; and concordance on SDM approach with the provider. Evidence of the importance of racial concordance between provider and patient as a facilitator to SDM has been recently reported in the literature [56]. Additionally, some of our results align with the general literature reporting the importance of family members in decision-making among Latinas and African Americans and patient beliefs of self-efficacy [54].

Several study limitations are important to consider. We implemented detailed eligibility criteria for the selection of studies reviewed. As a result, a total of 33 studies examining the role of SDM among minorities were excluded because they did not include the specific date(s) when the study data were collected. We also excluded papers where the number or percentage of minorities included in the sample was not provided. These exclusions may have led us to miss potentially relevant research about minority patient SDM preferences. In addition, our search

was completed in January of 2016 and newer findings in this area of research were not captured. Last, we provided an overview of minority preferences in general because we were not able to analyse results across specific racial and ethnic groups (e.g., Hispanics vs Whites) due to a lack of reporting in the selected studies.

Policy legislation has been in place for almost a decade supporting the use of SDM as a collaborative strategy to promote higher minority patient engagement in their own health management and treatment plans. The results of these efforts are apparent through policy support, dedicated SDM research funding to improve quality of care for minorities through the National Institute of Health [57], through the Patient-Centered Outcomes Research Institute or PCORI where minorities are a priority population [58], and a meta-analysis study showing health and service benefits of SDM tools among underserved minority patients [17]. We also found growth in SDM literature since the implementation of national policy supporting this communication model in health care.

However, we identified only 18 studies that met the eligibility criteria for this study. Our results suggest growth in the SDM literature for this time period but seemingly without a focus on minority populations. For example, for the broader SDM literature, a systematic review on evidence of SDM impact included 39 articles, and systematic reviews of narrower SDM topics range from 5 to 102 publications included. We provide references for seven of these exemplars for additional reading [19,59–64]. Most of the studies evaluating patient preferences, barriers, and facilitators to SDM engagement that were not selected had methodological limitations for our purposes such as not reporting the percentage of minority patients included in the study and not including a timeline for data collection. Additionally, limited research on subgroup analyses in this body of work makes it difficult to ascertain whether our observations regarding minorities are different from the general population.

Future research should seek to assess the impacts of the various patient, provider, and concordance characteristics associated with the types of SDM used and their success fostering trust, satisfaction with care, and distal treatment outcomes. Of particular importance, preferences for SDM among minority populations may differ by condition or setting: for example, parents may be immediately ready to engage in SDM on behalf of their child, while adults who are sick may be less ready. In our study, we did not identify a clear pattern between a decision-making preference and a particular health condition. For example, provider-led preferences were reported among studies on mammography screening [32], hypertension and diabetes [33,42] and mental health treatment for veterans [39]. An evolving preference was reported in HIV treatment [35], and a patient-driven preference was reported for studies of hospice care [45] and dyalisis [40]. This work will require research to understand how minority patient preferences may differ across health conditions. It will also require significant samples of minority patients to explore variation in SDM styles and to allow exploration of nuanced preferences among subgroups of minority patients. As a first step, the SDM field could benefit from more accurate reporting on the percentage of minority populations included in empirical studies, and a clear timeline for data collection and reporting.

4.2. Conclusion

Our findings showed that policy and research funding support does not necessarily guarantee higher representation from minority communities in the SDM literature. It is unknown if this lack of literature is due to a lack of research on this population, lack of reporting, or both.

Future work on minority SDM should seek to disentangle issues of distrust and discomfort from preference for SDM. For example, qualitative analyses and mixed methods may serve better to understand stated preferences for SDM separate from a particular clinical relationship. Examination of SDM quality and outcomes among minority populations with variation in resources, such as education and income, may help to elucidate SDM preferences when minority patients have levels of education and income similar to that of their clinicians. While interest in cultural concordance between patient and clinician has faded somewhat as an overarching strategy to improve access, exploration of SDM by cultural concordance may bring to light different styles of communicating and sharing in decisions that are relevant for improving quality and satisfaction with care among minority patients.

4.3. Practice implications

Provider training may be needed to allow and facilitate patient transition from a passive toward a more active SDM engagement over time. Practitioners may also need to recognize that it takes time for this evolving process to emerge. We need to learn what strategies—for example, structures, protocols, and patient-provider alliance—are necessary for providers to facilitate the conditions needed for patients to feel at ease and competent to evolve in their decision-making role at any point throughout the treatment process. In fact, re-conceptualizing SDM as a dynamic process rather than a static state makes room for new ideas about how to measure and build SDM partnership over time. In addition to culturally relevant interventions and policies that facilitate SDM and address relevant barriers, providers may need to work first on establishing trust as a critical foundation of a more collaborative SDM engagement over time. For example, SDM may need to be delivered in two phases with a more directive approach at initial diagnosis, leading to more active patient involvement in SDM over time to allow for facilitators to be in place (e.g., trust, a sense of competence, and patient activation). Health care providers can also facilitate SDM engagement by balancing their own expectations for patient engagement with minority patients' actual preferences, and by modifying clinical practices to recognize the evolving role some patients may prefer over time.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.pec.2019.02.003.

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