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REVIEW ARTICLE

Barriers and facilitators to shared decision-making in oncology: a systematic review of the literature

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Abstract

Purpose Shared decision-making (SDM) is a strategy to facilitate patient-centered care and is increasingly important in oncology, where patients are faced with complicated treatment decisions that require them to weigh efficacy and safety, quality of life, and cost. Understanding the contributors to the use of SDM may provide insight to its further implementation. Therefore, the objective of the study was to examine the patient-related barriers/facilitators to SDM in oncology care.

Methods A systematic literature review using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was executed. A search strategy composed of cancer, decision-making, and patient-centered terms was conducted utilizing PubMed, EBSCO MEDLINE, Scopus, CINAHL, and the Cochrane Library databases between January 2007 and November 2017. Full-text, US-based, English language articles describing the patient perspective of SDM in oncology care were included. Relevant data from articles were reviewed in a qualitative synthesis.

Results From 3435 potential citations, a total of 35 articles were included. The most common cancers studied were breast ($n = 22$; 62.9%) and prostate ($n = 9$; 25.7%). The identified themes for barriers to SDM were uncertainty in the treatment decision, concern regarding adverse effects, and poor physician communication. Themes for facilitators for SDM included physician consideration of patient preferences, positive physician actions and behaviors, and use or encouragement of support systems.

Conclusion As SDM gains use within oncology practice, understanding key influences will allow for more effective implementation of strategies to increase patient engagement and improve care and value in the treatment process.

Keywords Neoplasms · Patient-centered care · Patient participation · Communication barriers

Introduction

Shared decision-making (SDM) is defined as "an approach where physicians and patients share the best available evidence when faced with the task of making treatment decisions, and where patients are supported to consider options, to achieve informed preferences" [1]. The concept of SDM is seen as a key component of patient-centered care and highlights the importance of the physician-patient relationship in optimizing health outcomes [2]. A 2013 report by the Institute of Medicine (IOM) noted that clinicians seek patients' treatment preferences only about half the time, though most doctors believe they do so routinely [3]. However, the benefits of employing SDM can be significant with regard to value to patients. A recent Cochrane review across a broad scope of treatment/screening decisions identified significant gains in knowledge, accuracy of risk perceptions, and alignment of values

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and healthcare decisions through the use of decision aids (DAs) compared to usual care [4].

Specifically in the field of oncology, the National Comprehensive Cancer Network (NCCN) also recently addressed the need for greater SDM by releasing their Evidence Blocks, which are intended to measure the value to patients of various cancer therapies. As stated by the NCCN, the purpose of the Evidence Blocks is to "provide the health care provider and the patient information to make informed choices when selecting systemic therapies based upon measures related to treatment, supporting data, and cost" and to serve as "a starting point for shared decision-making considering the patient's own value system" [5]. The Center for Medicare and Medicaid Innovation (CMMI) has also considered the role of SDM in oncology. In early draft versions of the oncology care model (OCM), "shared decision-making with beneficiaries to inform their recommendation about whether a beneficiary should receive chemotherapy treatment" was initially required by CMS, but when the program was fully implemented in mid-2016, that requirement was no longer included [6]. However, a new report published by the Urban Institute advocates for SDM by suggesting that the OCM could be "substantially improved by incorporating a formal framework for SDM between patients and oncologists" [7]. Another recently published article focusing specifically on the American Society of Clinical Oncology (ASCO) value framework provides specific recommendations on enhancing SDM by (i) including the importance of economic perspective, (ii) using absolute measures of risk and formal patient-preference methodology, and (iii) foregoing safety parameters for higher-order utility considerations [8].

A variety of literature exists across general medicine; however, SDM has been gaining prominence in oncology practice with the increasing use of evidence-based guidelines related to diagnosis, complex treatment options, the inherent challenges of the risk communication process, and the emergence of value assessment frameworks. Thus, there is a need to understand patient and physician perspectives on SDM in oncology care. Specifically, understanding the patient perspective in terms of their knowledge of treatment options, goals of treatment, value placed on various aspects of care, impact of coping mechanism, health literacy, and trust/confidence in their physician is a key. This also necessitates the assessment of physicians' attitudes toward SDM, their approach to eliciting patient preferences, their confidence in addressing patients' questions, and their implementation of SDM in routine care.

A preliminary survey of the literature specific to oncology reveals some viable evidence from the physician viewpoint. Most recently, Frerichs et al. [9] conducted focus groups with healthcare providers in Germany and identified an array of facilitators and barriers related to SDM in oncology. Positive attributes included working with informed patients with involved families and the development of a trusted therapeutic partnership, while negative attributes included restraints of time and communication across disciplines [9]. A further German study by Muller et al. [10] executed a needs assessment regarding implementation of SDM across healthcare providers, patients, and family members. Five broad areas of needs for implementing SDM were identified, including changes in communication, collaborative involvement, a trusted relationship, cultural changes, and structural changes [10].

Complimentary to these studies is the patient viewpoint associated with SDM in oncology care. Notably, no comprehensive systematic literature reviews exist across adult patients, although a recent Cochrane review did evaluate interventions regarding SDM among pediatric cancer patients and found no (randomized or controlled trial) evidence available for synthesis, despite significant interest in the area [11]. Since the patient viewpoint is paramount in the execution of SDM, it follows logically that evaluation of contributors to the process from their perspective is vital. Accordingly, the present study represents a systematic review of the literature examining the patient-related barriers and facilitators to SDM in oncology care. This review and analysis categorizes existing evidence, identifies gaps in knowledge, and can be used to guide the development of future SDM initiatives.

Methods

The systematic literature review is a multi-step process: identification of database, abstraction of articles, and tabulation of results. Due to the anticipated variety of study designs and outcomes stemming from the research objective, a meta-analysis was deemed inappropriate for either objective.

Literature search strategy

Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [12], a systematic literature review and evaluation of all relevant publications from January 2007 to November 2017 was conducted. The literature review and analysis was executed utilizing PubMed, EBSCO MEDLINE, Scopus, CINAHL, and the Cochrane Library databases. Furthermore, reference lists of identified articles were screened for additional citations. An overarching literature search strategy was devised to meet the two study objectives: (1) to identify barriers and facilitators to SDM in oncology and (2) to evaluate outcome measures (e.g., acceptability, feasibility, knowledge) of DAs in the process of SDM in oncology. This analysis focuses on the first objective. The search strategy was three pronged, using (1) terms related to cancer (e.g., *neoplasms*, *malignancy*, *metastases*), (2) terms related to decision-making (e.g., *decision support*, *shared treatment decision*, *decision aid*), and (3) patient-centered

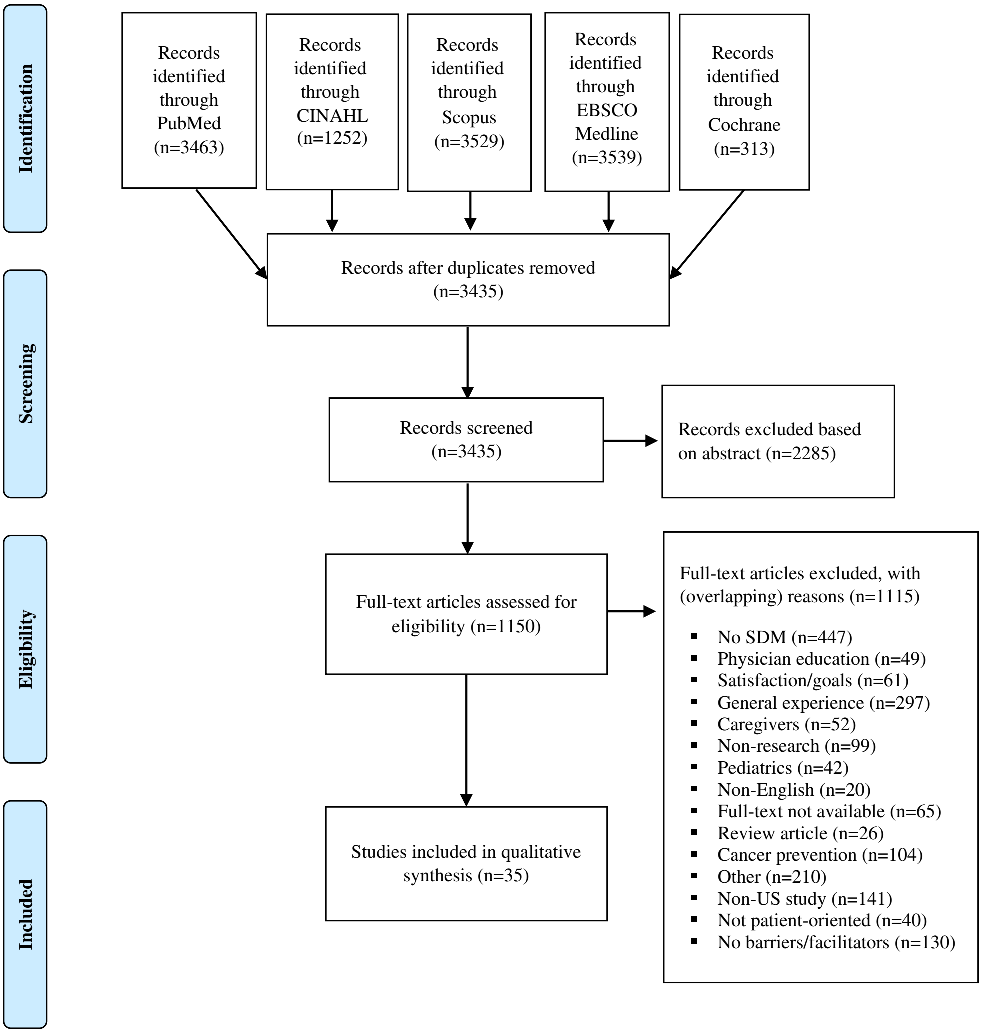
Table 1 List of search terms from PubMed

Cancer terms	Decision-making terms	Patient-centered terms
Brain neoplasms	Chemotherapy decisions	Patient-centered care
Breast neoplasms	Chemotherapy preference	Patient-centered communication
Colorectal neoplasms	Decision analysis	Nurse-patient relations
Endometrial neoplasms	Decision making	Physician-patient relations
Gallbladder neoplasms	Decision protocol	Professional-family relations
Head and neck neoplasms	Decision support technique	Professional-patent relations
Hematological neoplasms	Decision support	Doctor-patient communication
Kidney neoplasms	Shared decision	Oncologist-patient communication
Liver neoplasms	Shared decision making	Physician-patient communication
Lung neoplasms	Shared decision model	Health communication
Oropharyngeal neoplasms	Shared treatment decision	Patient empowerment
Ovarian neoplasms	Participatory decision making	Patient engagement
Pancreatic neoplasms	Patient care planning	Patient input
Pharyngeal neoplasms	Patient communication decision aid	Patient involvement
Prostate neoplasms	Patient decision aid	Patient participation
Stomach neoplasms	Control preferences scale	
Testicular neoplasms		
Urogenital neoplasms		
Urological neoplasms		
Uterine cervical neoplasms		
Vaginal neoplasms		
Cancer		
Cancroid		
Carcinoma		
Cyst		
Malignancy		
Metastatic		
Neoplasm		
Oncology		
Polyp		
Sarcoma		
Benign neoplasm		
Benign tumor		
Cancer education		
Carcinomatosis		
Malignant tumor		
Medical oncology		
Neoplasm metastases		
Radiation oncology		
Surgical oncology		

Variations of terms (metastatic, metastases; oncology, oncological) were incorporated into the search strategy

terms (e.g., *patient-centered care*, *patient involvement*, *physician-patient communication*). Citations isolated in the identification stage from the database searches were scanned for duplicates, which were subsequently removed. Remaining citations entered the screening stage, where titles and abstracts were assessed against the inclusion/exclusion criteria (described below) and their relation to the research objective. Finally, articles progressed through an eligibility assessment using a full-text review (again assessing inclusion/exclusion criteria and the research objective) to determine the final included result set.

Fig. 1 Flow chart of the publication selection process



Inclusion/exclusion criteria

English language articles were included in the review if they provided data regarding patient perspective, contributors, and challenges to their role in SDM during oncology care, including areas such as knowledge, satisfaction, preferences, and communication style. Only US-based studies were considered for inclusion as it was felt that barriers/facilitators to SDM would be unique to different healthcare structures globally. Physician-focused data, although not the focus of this study, was included if the article collected data on both patients and physicians. Review articles, theses/dissertations, conference abstracts, commentaries, editorials, or summary reports on the topic were excluded from the study.

Data extraction

Under the supervision and guidance of two faculty investigators (JRC and KMK), one industry liaison (CZ) and one medical librarian, four graduate students in pharmacy administration and six PharmD students compiled potential search terms of interest. The term list was utilized in trial searches to narrow the list to those terms rendering the most appropriate results. The original search strategy was created using Medical Subject Headings (MESH) terminology and associated terms in PubMed and subsequently translated for the other databases, with assistance of the medical librarian. Searches were then executed across all databases, and references were compiled into EndNote X7 (Clarivate Analytics, Philadelphia, PA, USA). Articles prior to 2007 and duplicates were removed, rendering a set of 3435 records for abstract review; these abstracts were uploaded to DistillerSR (Evidence Partners, Ontario, Canada).

The full student team executed the title-abstract review. Questionable abstracts were discussed and decisions rendered jointly as a research team with the faculty investigators. Graduate students located and downloaded full texts for the records that progressed through the screening phase ($n = 1150$), utilizing interlibrary loans when necessary.

Graduate students and faculty investigators executed the eligibility phase to render an interim final result set (n = 249), containing articles relevant to the two major objectives of the systematic review. Specific to the objectives of barriers/facilitators to SDM, the faculty investigators narrowed the final result set, specifying reasons for exclusion (of which articles may have had multiple). The faculty investigators extracted the following information from each article: author, year published, study aim/objective, study design, data collection methodology, setting, sample size, inclusion/exclusion criteria, cancer type/stage, treatment type, sample description, physician enrollment, major themes for barriers/facilitators, and key findings. Limitations were also assessed for each article as a measure of article quality, since the differing study designs made use of a formalized quality assessment tool non-feasible. Information was cross-checked between investigators to ensure a consistent and quality process.

Results

Overall results

A total of 35 articles were identified through the systematic review (Table 2), ranging in publication from 2007 to 2017 [13–47]. The most common cancer studied was breast ($n = 22$; 62.9%) [14, 15, 17, 18, 20–22, 24, 25, 28, 32, 33, 35–43, 46], followed by prostate ($n = 9$; 25.7%) [13, 22, 26, 29, 31, 34, 36, 43, 46] and gastrointestinal/colorectal ($n = 5$; 14.3%) [22, 36, 43, 44, 46] and lung ($n = 5$; 14.3%) [19, 21, 22, 30, 36]. A number of studies ($n = 9$; 25.7%) assessed multiple cancers [21–23, 27, 36, 43, 44, 46, 47]. A total of 11 studies (31.4%) focused on early-stage (0, I, or II) cancer [13–15, 18, 26, 29, 31, 34, 35, 38, 40] while only one study (2.9%) was specific to late-stage (III or IV) cancer [17]. Fifteen studies (42.9%) [16, 20, 22, 24, 25, 28, 30, 33, 37, 39, 41–43, 45, 46] assessed both early- and late-stage cancers, while in eight studies (22.9%) [19, 21, 23, 27, 32, 36, 44, 47], the stage was unclear. A total of 16 studies (45.7%) [14–16, 18, 20, 24, 26, 28, 29, 31–33, 35, 39–41] involved some form of surgical decision while eight (22.9%) [15, 16, 18, 21, 25, 27, 28, 33] involved chemotherapy and seven (20.0%) [16, 22, 26, 28, 29, 31, 33] included radiation. In five studies (14.3%) [17, 23, 27, 33, 41], physicians provided data in addition to patients. A variety of study designs were utilized, including survey questionnaires ($n = 16$; 45.7%) [16, 17, 20–22, 25, 29, 30, 32, 34, 36, 40, 41, 43, 46], qualitative analyses through focus groups/interviews ($n = 12$; 34.3%) [13, 14, 19, 28, 31, 33, 35, 38, 39, 42, 45, 47], consultations ($n = 2$; 5.7%) [23, 27], secondary analyses of other data sets ($n = 3$; 8.6%) [15, 18, 44], and prospective studies ($n = 2$; 5.7%) [26, 37].

Barriers to SDM

Three consistent themes of barriers to SDM emerged across the studies, including (1) uncertainty or lack of consensus in the treatment decision [13, 14, 31, 32, 47], (2) patient concern regarding adverse effects [13, 29, 33, 35, 37], and (3) poor physician communication [19, 23, 25, 27, 28, 30, 33, 35, 36, 38, 39, 41, 47].

In a series of individual interviews and focus groups conducted by Henrikson et al. [13], men facing treatment decisions for prostate cancer expressed struggling with the lack of a clear treatment option based on research, and felt that physicians expressed bias toward options based on their subspecialty. Xu et al. [31] found similar results in their sample of primarily African-American men, with prostate treatment decision-making largely made with a sense of fear and uncertainty, rather than full consideration of the evidence. Men expressed mixed feelings regarding the physician's presentation of treatment options: initially negative with a sense of frustration toward making a decision, but later positive and appreciative [31]. Although most women interviewed by Lally [14] found making a surgical breast cancer decision relatively straightforward, there was some concern expressed about rethinking their choice and being overwhelmed to make the "right" decision. Politi et al. [32] found that 93% of consultations for breast cancer surgery specifically discussed uncertainty, but that this ultimately led to lower decision satisfaction ($\beta = -1.77$; $p < 0.002$) from the patient perspective [32]. However, this effect was mitigated when the physician involved the patient in the decision to a greater degree [32]. Finally, Mazor et al. [47] identified that patients and family members feeling like they were not "kept in the loop" increased stress regarding their oncology care, particularly regarding patient expectations, progression of treatment, and delays in information delivery.

Adverse effects were a paramount consideration for patients and often an area of difficulty in their treatment decision. Sidana et al. [29] examined the factors dictating choice of treatment among younger men with prostate cancer and found that 98%, 84%, and 66% expressed concern about sexual, urinary, and bowel functions, respectively. Similarly, men in Henrikson et al. [13] weighed the "reversibility" of treatments and adverse effects in their decisions. In interviews with African-American women with breast cancer by Sheppard et al. [33], fear of adjuvant treatment effects such as nausea and hair loss, perception of therapies as "experimental," and worries about impacts on caregiving and activities of daily living influenced decisions. In focus groups conducted by Schubart et al. [35], fear throughout the care process was prevalent among African-American women. In a long-term focal study on tamoxifen use, Kahn et al. [37] similarly identified adverse effects (albeit, actual, as opposed to feared, effects) as a predictor of adherence. Interestingly, patients who reported being informed previously about potential adverse

Table 2 Description of studies

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
Henrikson et al. (2009) [13]	Explore whether reversibility, decision timing, and uncertainty are relevant to men deciding on treatment for localized prostate cancer	Qualitative data analysis of interviews using focused coding technique exploration	44 (*n* = 37 who had made a treatment decision and *n* = 7 who had not)	All men, mean age 68 years, 84.5% white, 70% married or partnered, 43% college graduates	Lack of consensus on recommended treatment, reversibility of damage or side effects	Desire for certainty, use of numeric or statistical probabilities for success, keeping options open, taking time to make a decision, consideration of patient decision-making preferences	8 major themes identified: reversibility, timing of decision, number of options, "getting it over with," "the way I make decisions," uncertainty among experts, desire for certainty, and probability	No quantitative examination of covariates, bias in theme definitions, unstructured interviews, constructs not in the context of other motivators of decision-making
Lally (2009) [14]	Explore the pretreatment thoughts and behaviors of women newly diagnosed with breast cancer regarding their surgical treatment decision-making experience	Qualitative data analysis of interviews using grounded theory	18	All women, age range 37–87 years, 6–21 days post diagnosis, 67% college educated, 72% married	Uncertainty in choice and recommendations made	Receiving enough information without feeling overwhelmed, physician demeanor (feeling cared for and with trust), use of family and friend's experiences	3 major themes identified: information processing, contemplating options, and interacting with others	Data originally collected with a different focus, no minority women enrolled, influence of an AOCN
Arora et al. (2009) [15]	Examine the association between receipt of helpful informational, emotional, and decision-making support from physicians and ratings of trust among women newly diagnosed with breast cancer	Secondary analysis of longitudinal survey data from an RCT (CHESS)	246	All women, mean age 44 years, 74% white, 54% with annual income > $40,000, 85% private insurance		Trust in physician	At baseline, receipt of helpful informational, emotional, and decision-making support from physicians was all significantly associated with patients' trust. By month 5, only emotional support in the 2 months prior was associated with patient trust	Older data, limited to assessing a single item from the original study, lack of validation, lack of direct connection of trust to decision-making
Shuman et al. (2017) [16]	Describe the reflections of patients treated for laryngeal cancer with regard to treatment-related decision-making	Cross-sectional survey questionnaire	57	80% men, mean age 61 years, 75% former smoker, 54% early stage, 55% treated with surgery	Worse voice-related QoL resulted in more decisional conflict and regret	First clinician seen was the most important factor in the treatment decision	The 4 most important priorities were oncologic cure (91%), maximizing survival (66%), being able to swallow (44%), and maintenance of natural voice (41%). The 4 least important priorities were having a comfortably moist	Absence of longitudinal QoL outcomes, recall bias, retrospective single-institution study, small sample size, confounder influence

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
							mouth (59%), keeping one's appearance unchanged (45%), returning to one's activities as soon as possible (45%), and keeping one's normal sense of taste and smell (33%)	
Brufsky et al. (2017) [17]	Explore the emotional needs of patients at the initial diagnosis of metastatic breast cancer and treatment change to increase awareness about gaps and facilitate communication between patients and oncologists	Cross-sectional survey questionnaire	359 (patients), 252 (oncologists)	Patients: all women, median age 53 years, 18% non-white, 77% had children, 82% had some college education, 67% HR+ cancer Oncologists: 30% women, median age 49 years, 25% in practice < 10 years, 38% affiliated with academic institution	Feelings that something could have been done to prevent disease progression	Patients wanted oncologists to show care and compassion, to discuss expectations from treatment, ways to manage symptoms and side effects, and long-term goals. Referrals to support services were important	Fewer patients reported fear of unknown (58% vs 44%) and distress over believing something could have been done to prevent disease progression (26% vs 12%), but more patients reported hope of keeping the disease stable (46% vs 59%) and confidence in treatment options (29% vs 37%) between initial diagnosis and treatment change	Patients in the study were more motivated, knowledgeable, and educated, recall bias, non-response bias
Martinez et al. (2016) [18]	Explore the association between patients' perceptions of autonomy-supportive communication by surgeons and medical oncologists and patient-appraised quality of their breast cancer surgery and chemotherapy decisions	Secondary analysis of survey data from a population-based study (iCanCare Study)	1690	All women, mean age 62 years, 55% white, 17% black, 17% Latina, 72% with some college education	N/A	Autonomy-supportive communication, solicitation of patient preferences for communication style	For surgical decisions, high-autonomy--supportive communication was associated with increased decision quality score (4.64 vs 4.34, $p < 0.001$) compared to low-autonomy--supportive communication. Similar trends were seen for chemotherapy decisions (4.67 vs 4.41, $p < 0.001$)	Dependence on self-reporting, inflation of ratings, reverse causality, use of only 2 distinct geographical areas, communication styles that may not fit into predefined categories
Lee et al. (2016) [19]	Elucidate the relationships between patient-perceived role and decision-making in lung cancer care, drawing from serial interviews on the safety-net lung cancer treatment experience with	Qualitative data analysis of interviews using iterative analysis	13 dyads	62% men, 62% age 46–60 years, 46% high school education, 46% married	Use of medical language in visits, changing groups of providers, lack of knowledge, physicians making decisions for them	Caregiver presence during visits	4 major themes in the experience of lung cancer care: challenges to effective communication, caregivers as advocate and facilitator; lack of	Small sample size, attrition

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
	African-American patient-caregiver dyads						understanding of prognosis and outcomes; clinicians make decisions	
Parker et al. (2016) [20]	Examine the psychosocial predictors and decision-making process regarding CPM among women with sporadic breast cancer	Cross-sectional survey questionnaire	117	All women, mean age 54 years, 67% Caucasian, 74% married/partnered, 50% college education or higher, 58% employed (full- or part-time)		Less knowledge and greater cancer worry	Need to provide education about CPM and address psychosocial factors that drive women's preferences for CPM	Generalizability to other racial and ethnic groups; lack of measurement of the method of diagnosis, breast density, insurance, cost, and influence of media
Colley et al. (2017) [21]	(1) Describe associations between demographics and decision-making role, (2) examine relationships between psychological characteristics (anxiety and depression) and decision-making role, and (3) identify relationships between decision-making role and psychosocial adjustment characteristics, such as coping style, personality, and mental adjustment to cancer	Cross-sectional survey questionnaire using data from a larger longitudinal study on symptom experience	765	71–81% women, median age 53–59 years, 66–74% white, 64–68% married or partnered, 28–40% currently employed	Passive decision-making style	Active or collaborative decision-making style	56.3% of patients reported preferring and acting in a collaborative role; those preferring the passive role were older and less educated, had lower income, and were less resilient. Passive coping styles were less likely to want to contribute or control the decision-making process and were more fatalistic, less likely to use humor, and less adaptive coping strategies	Single-time point study, only relating to general treatment, selection bias potential due to 40% refusal rate, overrepresentation of white and highly educated/highly earning individuals
Shabason et al. (2014) [22]	(1) Determine the association between SDM and patient satisfaction during RT and (2) explore patient desire for and perception of control during RT, and how these factors relate to patient satisfaction, anxiety, depression, and fatigue	Cross-sectional survey questionnaire	305	53% men, largest age group 55–65 years (38.7%), 75.7% white, 22% completed college, 51.5% not employed, 65.3% married/partnered, 31.8% report having SDM	Desire but no perception of control of treatment decisions	SDM, perceived control of treatment decisions	32.3% report having control of treatment, 72.6% report satisfaction with treatment Increase in the perception of control and SDM correlated with an increase in patient satisfaction (84.4% vs 71.4% satisfaction with and without SDM, respectively; $p < 0.02$) Higher satisfaction seen in patients reporting more perceived control over treatments vs those reporting no control regardless if the patient	Time point study, correlations vs causation; controls for emotional responses may have subject bias, and the study was done during the last week of RT with most side effects, which may skew answers

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
							preferred control or not, satisfaction percentages, respectively (89.7% vs 69.2%, $p < 0.001$) In patients desiring control but who did not receive it, more adverse emotional responses, such as anxiety and depression, were experienced	
Chhabra et al. (2013) [23]	Characterize practices in subspecialist physicians' communication styles, and their potential effects on shared decision-making, in second-opinion consultations	Qualitative analysis of recorded consultations using theme-oriented discourse analysis	20 visits (between 20 patients and 15 physicians)	Patients: 60% women, largest age groups 30–39 years and 50–59 years (30% each), 60% white, 90% with college education Physicians: 85% men, largest age group 50–59 years (40%)	Long narratives with no time for processing/questions, physician control of topics, directive/deferential speech	Inviting speech: open-ended questions, affirmations, periodic pauses	Major finding was broadcasting, pattern of lengthy physician monologs on disease mechanisms and history, treatment options, or prognostic information Other techniques included deferential (physician minimizing their role), directive (physician implying their decision is right), or inviting speech (encouragement of patient input)	Small sample size, 2 sites, no validation of judging patient's reactions, and treatment options may have dictated physician's approach regardless of general demeanor
King et al. (2013) [24]	Examine variables associated with decisional conflict related to surgical treatment for unilateral breast cancer and preferences for BM in younger women with a new diagnosis of breast cancer	Cross-sectional survey questionnaire using data from a larger RCT evaluating a rapid genetic counseling and testing intervention	284	All women, mean age 43 years, white (65%), college educated (79%), married (63%), employed full-time (72%) Average = 0.87 (SD = 1.13), first- or second-degree relatives with breast or ovarian cancer Average estimated risk of having a BRCA 1/2 mutation = 13.06% (SD = 22.88%)	Higher conflict if less educated, unmarried, not a candidate for lumpectomy, not received a surgical recommendation, more neurotic, more generally distressed, or more afraid of radiation	Lower conflict if stronger guidance from physician	Higher decisional conflict regarding the surgical decision was associated with having less than a college education ($p = 0.002$), being unmarried ($p = 0.02$), not being a candidate for lumpectomy ($p = 0.04$), not having received a specific surgical recommendation ($p \leq 0.001$), higher neuroticism ($p \leq 0.01$), higher cancer specific ($p = 0.002$) and general distress ($p \leq 0.001$), and more concerns about the impact of radiation ($p = 0.03$)	Self-reported results from only patient perspective, no other prognostic information, small sample size, generalizability

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
Shelton et al. (2013) [25]	Examine psychosocial factors (e.g., attitudes, social support), provider-related factors (e.g., communication, trust), and treatment considerations in a prospective study of a sample of early-stage breast cancer patients eligible for chemotherapy and/or hormonal therapy (BQUAL cohort)	Cross-sectional survey questionnaire and medical record review using data from a larger cohort study evaluating influences on treatment non-adherence	1145	All women, 47% aged 50–64 years, 69% Caucasian, 30% with household income over $90,000, 49% with at least some college education, 53% married, 32% retired, 31% full-time employment, 70% employer-sponsored insurance	Older patient age reduced communication quality and family support, and higher fatalism, communication quality, and provider involvement were reduced in black patients while mistrust was higher	Secondary person to help make decision/be present during consultation, shared or patient-centered decision--making, positive beliefs about treatment (e.g., belief in reducing risk of recurrence)	Majority of participants (76%) reported that someone was with them when the doctor talked to them about choosing their treatment. 38% of women wanted equal decision-making power with a doctor while 33% wanted to make decisions on their own but consider the doctor opinion. Provider communication was lower among black patients compared to whites ($p < 0.0001$). Provider communication was also lower among patients 65 and older, particularly communication related to chemotherapy treatment	Small sample size, limited inclusion of racial and ethnic minorities, generalizability
Song et al. (2013) [26]	Examine how patients' sociodemographic, cancer-related, and subjective affective factors impacted their role in treatment decision-making	Prospective follow-up from a larger cohort study (HCaP-NC) exploring racial differences in prostate cancer aggressiveness	788	All men, 63% < 65 years, 79% married, 43% white, 57% at least some college education, 63% stage I, 54% low disease aggressiveness	Not having enough time for decision-making, higher cancer aggressiveness	Receiving advice from others, concerns about physical impact of treatment	Approximately 41% of patients reported patient-only decision-making, 45% reported shared decision-making, and 13% reported physician-only decision-making. Age, cancer aggressiveness, concerns about the physical impact of treatment, having enough time for decision-making, and receiving advice from others were found to be significantly associated with treatment decision-making	Data obtained 3 years after patients completed treatment (subject to recall bias)
Alexander et al. (2012)	Describe and quantify the content of the subspecialty consultation in regard to	Qualitative data analysis of recorded consultations using content analysis	236 (patients) and 40 (hematologists)	Patients: 53% men, median age 55 years, 89% white, 78%	Hedging, ambiguous prognostic conversations	Unmarried or lower education patients, longer	Discussions about the purpose of the visit and patient's knowledge	Generalizability; non-verbal behaviors that might influence the

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
[27]	exchanging information and identify patient and provider characteristics associated with discussion elements			married/living with a partner Physicians: 85% men, median age 47 years, median 8 new patients consultations/month		consultation time, more questions from patient/support person	about their disease were common. Other elements such as patient's preference for his/her role in decision-making, preferences for information, or understanding of presented information were less common. Treatment recommendations were provided in 97% of the consultations and unambiguous presentations of prognosis occurred in 81% of the consultations. The median duration of consultations was 80 min	interaction were not captured; physician awareness of audio recording
Pieters et al. (2012) [28]	Understand how women aged 70 years and older who had recently undergone treatment for early-stage breast cancer experienced treatment decision-making	Qualitative data analysis of interviews using grounded theory	18	All women, 34% married, 50% high school graduate, range 3–30 months since diagnosis	Not knowing what to ask, negative clinician dispositions, ageism, power balance	Mutuality of caring, social support, asking questions, plurality of information, receiving satisfactory answers, making own decisions	A major finding was that the power of relating spontaneously was used as a vehicle to connect with others. Instrumental relating (mutual caring) depicted that the women participated in 3 ways of relating to share in treatment decision-making: obtaining information, interpreting healthcare providers, and determining the trustworthiness of their providers	Sampling technique and active engagement may have influenced women's perception of clinical decision-making, results based on self-reported measures which may not correlate with actual behavior
Sidana et al. (2012) [29]	Provide an insight into information sources consulted and factors dictating treatment decision-making in young prostate cancer patients	Cross-sectional survey questionnaire	488	All men, mean age 45.7 years, 88% white, 85% married, 95% employed	Concern for side effects, unmarried patients, choice of radiation	Doctor's recommendation (most influential factor), shared/patient--centered decision--making, social	Most common therapy was surgery (81.4%). Participants with at least some college education or annual income > $100,000 were more likely to consult 3 or more	Lack of detailed information on the non-responders, recall bias

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
						support, high education/-income	doctors. Doctor's recommendation was the most influential information source followed by the Internet. Informed decision-making was chosen by patients preferring radiation and active surveillance, whereas shared decision-making was preferred by surgery cohort. 89% did not regret their treatment decision	
Nelson et al. (2011) [30]	Evaluate the extent of communication of patients who had been diagnosed within the previous year with all stages of lung cancer they had with their physicians on topics related to goals and preferences for treatment and to patients' physical, emotional, practical, and spiritual needs	Cross-sectional survey questionnaire	76	44% men, mean age 65.3 years, 55% white, 21% African-American, 19% Hispanic, 47% stage 1, 8% stage 2, 22% stage 3, 22% stage 4, median time from diagnosis 3.3 months	Inadequate physician communication (> 30%) on spiritual concerns, practical needs, life support preferences, living will, healthcare proxy and hospice	Adequate physician communication on physical symptoms, emotional symptoms, changes of cure, treatment complications, treatment goals	20% of respondents reported that their physicians communicated "not at all" or "a little bit" on all 11 topics. Rates of inadequate communication were equally high for patients with late-stage disease and early-stage disease. Multiple logistic regression analysis indicated that these rates were also similar among patients of different ages, sex, income, and pathologic stage. Compared with whites, blacks reported similarly high rates (OR = 0.66; 95% CI = 0.32–1.4); however, Hispanics were less likely (OR = 0.31; 95% CI = 0.15–0.65) to report inadequate communication with their healthcare providers	Non-response bias, focused on communication with lung cancer physicians and did not ask patients whether they had discussed these topics with a palliative care clinician or with another professional caregiver, such as a nurse or a chaplain
Xu et al. (2011) [31]	Gain perspective on men's thoughts and perceptions		21	All men, age range 48–70 years, 38%	Emotional context of fear/uncertainty,	Valuing quality of life and cure,	Men with localized prostate cancer	Exploratory, small sample size, lack of watchful

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
	regarding choosing their prostate cancer treatment	Qualitative data analysis of interviews using conceptual model		married, 38% college graduates, 81% private insurance	frustration with lack of single recommendation over other options, conflicting recommendations, physician distrust	self-reliance, higher educational level, professionalism of physician, agreement among physicians, social support	reported making “the best choice for me” by considering medical information gained from all sources and personal factors while personally framing the meaning of the diagnosis and treatment. Cancer eradication was nearly every patient’s initial goal, and for many men, it remained the primary factor in their decision, but for some, quality-of-life issues were almost equally important. A direct recommendation from a physician influenced men’s decisions. However, when physicians did not directly recommend a treatment, their description of efficacy and side effects of the different options was influential. Anecdotal experiences of family and friends were also important, especially in deciding “what not to do”	waiting participants, generalizability
Politi et al. (2011) [32]	Examine physicians’ communication of uncertainty and its impact on patients’ decisions and decision satisfaction	Longitudinal survey questionnaire and medical record review and appointment observation	75 (all), 46 (with cancer)	Overall: all women, mean age 51 years, 76% white, 56% without college degree, 55% satisfied with decision, 15% choice not in line with physician recommendation	More education with greater physician communication of uncertainty	Greater involvement in decisions	The mean translated score of the OPTION scale was 68.0 (SD = 18.3), but only 33.2 (SD = 19.1) for the uncertainty items. Among cancer patients, communicating uncertainty was negatively related to decision satisfaction ($p < 0.002$), and there was an interaction between patient involvement in	No audio of conversations, extra person in the room may have added bias, only one item in survey about satisfaction, subjective scale of numeracy, mixed results of cancer and cancer prevention

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
							decisions and communicating uncertainty in relation to patients' decision satisfaction ($p < 0.03$)	
Sheppard et al. (2010) [33]	(1) Use qualitative methods to describe factors that influence black women's adjuvant therapy decisions, (2) use these formative data to develop messages for a treatment decision-support intervention, and (3) pilot test the acceptability and utility of the intervention with community members and newly diagnosed women	Qualitative data analysis of interviews using cultural framework	14 (patients), 10 (survivors), 10 (providers)	Overall: all women, 81% with at least high school education, 50% unmarried/unpartnered, 3% stage 0, 25% stage 1, 34% stage 2, 9% stage 3, 3% stage 4	Communication with provider, fear of side effects, beliefs that therapies were experimental, concerns about being unable to care for family members, feelings of mistreatment by medical community, fatalism	Information provision, patient empowerment, hope, determination, faith in God and acceptance of diagnosis, adherence, nurse involvement, addressing the emotional aspects, social support	Most women relied on their providers for treatment recommendations. Several women reported problems communicating with providers and felt unprepared to ask questions and discuss adjuvant treatment options. Using qualitative data, an intervention and guidebook to interact with patients was developed and assessed by patients, survivors, and physicians, to be tested in RCT	Small convenience sample, self-reports of communication efficacy
Orom et al. (2016) [34]	Determine if active patient participation in treatment decision-making and patient knowledge had an effect on treatment decision-making success and quality of life	Cross-sectional survey questionnaire using data from a multi-site longitudinal observational study	1529 (with decision experience data), 1342 (with 6-month follow-up data)	All men, mean age at diagnosis 63.1 years, 82% non-Hispanic white, 30.7% with graduate degree, 84% married/cohabitating, 53% > $100,000 annual income, 51% full-time employed		Less decisional conflict, more active role in decision--making, higher baseline knowledge	Among those with 6-month follow-up data and confirmed treatment-type data, 22.3% ($n = 294$) received active surveillance, 26.8% ($n = 353$) received radiation, and 51.0% ($n = 672$) received surgery. For men deciding how to treat their prostate cancer, the more decisional control they had, the less decisional conflict they experienced, and the more satisfied they were with the decision-making process	Cannot infer causality, difference between actual and self-reported knowledge, difference between difficulty in making decisions and self-report
Schubart et al. (2015) [35]	Identify key issues faced by African-American women		14	All women, median age 61.5 years, 57% high	Fear with diagnosis/treatment,	Strong informal support,	3 major themes identified: fear across the breast	Sample size, generalizability, recall

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
	diagnosed with breast cancer regarding treatment decisions	Qualitative data analysis of focus groups using thematic analysis		school education or less, 100% insured	unsure how to tell loved ones, limited recall of information due to shock of diagnosis, usefulness of information provided, unanswered concerns with aging	spirituality/-prayer, family/friends to provide information	cancer disease trajectory, preference for visual information for understanding diagnosis and surgical treatment, and reliance on family and friends for support	bias, limited demographic information
Walsh et al. (2010) [36]	(1) Determine the total number of information sources obtained and used to influence treatment decisions, and (2) determine the clinical and demographic factors associated with the use of specific sources of information in cancer patients	Cross-sectional survey questionnaire using data from a larger study on cancer patient satisfaction (ACCESS study)	1784 ($n = 592$ breast, $n = 503$ colorectal, $n = 149$ lung, $n = 539$ prostate)	45.7% (colorectal) and 52.3% (lung) women, most common age < 55 years (breast, 39.8%), 65–75 years (colorectal, 37.4%; lung, 41.6%; prostate, 44.5%), 34.1–45.1% with high school education	Colorectal and lung cancer patients utilized less sources of information, lack of staff discussion about other treatments like alternative medicine	Breast and prostate cancer patients, younger age, higher income/-education, those who used CAM, those with very good or excellent self-reported health status, and those reporting SDM utilized more sources of information	Over 69% of study participants reported obtaining information from a source other than the treatment staff. Participants with a college degree were more likely to use the Internet (OR = 3.7; 95% CI = 1.5–9.0) and scientific research reports (OR = 3.3; 95% CI = 1.6–6.9) to influence treatment decisions	Focused only on sources of information, recall bias, influence of death, sample lacking diversity
Kahn et al. (2007) [37]	Examine the influence of patient-centered care activities on ongoing tamoxifen use 4 years after initiation	Prospective cohort study and observational data from the NCCQ	881	All women, ~33%, 65+ years old, ~25% lymph node involvement at diagnosis, 54% stage 1, 40% stage 2, 92% ER/PR positive	Experience of side effects not told about in advance led to less continuation of tamoxifen	Receiving what was considered “the right amount of support” from healthcare professionals and “about right” role in decision-making during initial treatment led to more continuation of tamoxifen	Patients reporting less support than they needed while being treated for cancer were significantly less likely to continue tamoxifen use, even after adjusting for symptom intensity ($p = 0.0051$). Significant predictors of receipt of all 4 patient-centered processes (support, decision-making role, provider input, side effects) include age greater than 65 years (OR = 1.71; 95% CI = 1.15–2.55), moderate or severe side effects (OR = 2.58; 95% CI = 1.82–3.65), and stage 2 or 3 cancer compared with stage 1	Observational data, confounding, generalizability, non-response bias, recall bias

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
							(OR for stage 2 = 0.54; 95% CI = 0.34–0.84; and OR for stage 3 = 0.20; 95% CI = 0.08–0.51)	
Livaudais et al. (2012) [38]	Explore a variety of factors associated with discussion, use, and discontinuation of HT for DCIS, including patient, tumor, and treatment-related characteristics and physician-patient communication factors	Quantitative analysis of telephone interviews	744	All women, mean age 56.5 years, 53% non-Latina white, 21% Latina English speakers, 26% Latina Spanish speakers, 30.6% single, 50% private insurance	Spanish speakers, with ER/PR-negative tumor status, were less likely to have discussed adjuvant HT	Patients receiving breast--conserving surgery or radiation, who saw an oncologist for follow-up care and whose physician emphasized the necessity of treatment, were more likely to have discussed adjuvant HT	Although 83% of women discussed adjuvant HT with a physician, 47% used adjuvant HT, and 23% of users reported discontinuation by a median of 11 months. Physician recommendation is an important factor associated with use and discontinuation of adjuvant HT for DCIS	ER/PR status of participants, self-report of HT, time diagnosis bias
Yanez et al. (2012) [39]	Propose a model to elucidate pathways though which acculturation (indicated by language use) and reports of communication effectiveness specific to medical decision-making contribute to decisional outcomes (i.e., congruency between preferred and actual involvement in decision-making, treatment satisfaction) and quality of life among Latinas and non-Latina white women with breast cancer	Quantitative analysis of telephone interviews	494 ($n = 326$ Latina, $n = 168$ white)	All women, mean age 50–53 years, 80% Latinas born in Mexico or South/Central America, 53–56% lumpectomy, educational and income balances between groups	Latinas reported worse communication, poorer breast cancer emotional health, but higher treatment satisfaction	Greater use of English was associated with greater patient-reported physician adequacy in the decision process and greater patient self-efficacy in communication	Among Latinas, 63% reported congruency in decision-making, whereas 76% of non-Latina whites reported congruency. Language use, congruency in decision-making, and patient-reported physician adequacy in the decision process explained 16.0% of the variance in treatment satisfaction. Patient-reported physician adequacy in the decision process explained 28.0% of the variance in patient-reported quality of physician communication	Self-report, recall bias, response bias, language as proxy for acculturation, single-item measure of treatment satisfaction, imbalance in cultural origins
Hawley et al. (2009) [40]	(1) Evaluate the association between patient involvement in decision-making and the	Cross-sectional survey questionnaire	1651	All women, mean age at diagnosis 55–59 years, 23.9% Latina (12.0% low acculturated,	Low-acculturated Latina patients reported a surgeon-based treatment decision	More patient involvement in decision--making,	38.1% of women reported a shared surgical treatment decision, 34.4% reported a	Self-report, cross-sectional nature, generalizability, no control for site effects, lack of

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
	receipt of mastectomy among racially and ethnically diverse patients with early-stage breast cancer, and (2) assess factors associated with choice of mastectomy as the initial treatment for breast cancer, including patient attitudes regarding surgery and the involvement of others in the decision-making process			11.9% high acculturated), 27.1% African-American, 48.9% white, 38–58% not married/partners, 17.2% mastectomy	more often. Body image concerns and spouse input resulted in less mastectomy	concerns about recurrence and radiation, and accompanying of support to surgery consultation resulted in more mastectomy, regardless of race/ethnicity	patient-based decision, and 27.5% reported a surgeon-based decision. For each racial or ethnic group, the proportion of women who received mastectomy initially was substantially greater among women who reported a patient-based decision compared with those who reported a shared or surgeon-based decision	validation of some measures
Hawley et al. (2007) [41]	Evaluate factors associated with women's reported level of involvement in breast cancer surgical treatment decision-making, and the factors associated with the match between actual and preferred involvement in this decision	Cross-sectional survey questionnaire	1038 (patients) and 270 (surgeons)	Patients: all women, mean age 59 years, 68% white, 64% some college education or more, 25% mastectomy, 44% ductal carcinoma in situ Surgeons: 15% women, mean years of experience 17, 51% perform ≥ 50 procedures/year	Discussion of only 1 of the surgery types, younger age, lower education, high-volume surgeons were associated with too little patient involvement in decision		38% of women reported a shared surgical treatment decision, 39% reported a patient-based decision, and 22% reported a surgeon-based decision. There was a substantial variation in the 4 categories of the patient request/surgeon recommend variable: (1) women who asked for and received a treatment recommendation (48%), (2) women who asked for but did not receive a treatment recommendation (20%), (3) women who did not ask for but did receive a treatment recommendation (16%), and (4) women who did not ask for and did not receive a treatment recommendation (16%)	Self-report, recall bias, generalizability, missing data, limitations of measures used
Andersen et al. (2009) [42]	Examine the long-term effects on women's HRQoL of involvement in	Quantitative analysis of telephone interviews	250 (2 years), 212 (5 years), and 174 (10 years)	100% women, 83% white, mean age 55 years, 73% some college		Increased age, income, and education	After controlling for demographic and disease variables,	Bias of treatment outcome, self-report, time limits on decision-making

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
	decision-making about their treatment for breast cancer and about follow-up care after treatment			education, 51% annual income ≥ $40,000, 39.5% 2 years post diagnosis, 31.5% 5 years post diagnosis, 29% 10 years post diagnosis		predicted involvement in decision-making	involvement in decision-making overall significantly predicted survivor quality of life related to the general health and vitality subscales ($p < 0.01$ and $p < 0.05$, respectively). All other types (surgery, radiation/-chemotherapy, and follow-up) of involvement in decision-making also significantly predicted the general health and vitality subscales. Congruence of involvement in decision-making with a patient's preferred level of involvement was also associated with improved survivor HRQoL on several subscales	
Martinez et al. (2009) [43]	Examine how PCIE may operate through feeling informed to influence patients' TDS	Longitudinal survey questionnaire	2013 (baseline) and 1214 (follow-up)	Baseline: 49% men, 86% white, 44% some college education, 69% married, 34% breast, 32% prostate, 34% colorectal, 15% metastatic Follow-up: 48% men, 89% white, 48% some college education, 72% married, 35% breast, 33% prostate, 33% colorectal, 13% metastatic	Breast cancer (compared to other types) and higher stage decrease TDS	PCIE, married status, increased health status, and feeling informed increase TDS. Feeling informed and satisfied at baseline predicted satisfaction at follow-up	PCIE was related to concurrent TDS ($\beta = 0.06$) and feeling informed ($\beta = 0.15$), after confounder adjustments. A mediation analysis was consistent with PCIE affecting TDS through feeling informed. Baseline PCIE predicted feeling informed ($\beta = 0.04$) measured 1 year later, after adjustments for baseline feeling informed and other confounders. Feeling informed was related to concurrent TDS ($\beta = 0.35$) after confounder adjustment and follow-up TDS	Small effect sizes, self-report, limited cancer types; PCIE is a measure of breadth and not of depth

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
							($\beta = 0.13$) after baseline TDS and confounder adjustment	
Arora et al. (2009) [44]	Evaluate pathways linking physicians' decision-making style with cancer survivors' HRQoL	Secondary analysis of survey data from a population-based study (APECC)	395	43.3% women, mean age 62.6 years, 73.8% non-Hispanic white, 51% with at least some college education, 27% annual income > $100,000, 39.5% working, 71.5% married/partnered, 26.2% bladder, 59.6% colorectal, 14.3% leukemia	Employed patients reported suboptimal physician decision-making style	Resident of medically underserved area, treatment in the last 12 months, reported more optimal physician decision-making styles. Optimal style increases patient self-efficacy and trust (proximal), and personal control and less uncertainty (intermediate) which affect HRQoL (distal outcome)	The percentage of cancer survivors reporting suboptimal communication on each of the 5 PDEMS items (discussing in a way patient understood, encouraged questions on options, encouraged questions on recommendations, encouraged patient opinion, involved patient as much as they wanted) ranged from 21 to 49%. Except for physical health, physician style was associated with all proximal, intermediate, and distal outcomes ($p \leq 0.01$). 2 significant pathways by which a participatory physician style may be associated with survivors' mental health: (1) by increasing survivors' participation self-efficacy and thereby enhancing their perceptions of personal control ($p < 0.01$) and (2) by enhancing survivors' level of trust and thereby reducing their perceptions of uncertainty ($p < 0.05$)	Cross-sectional data, self-report, PDEMS assessment over a 1-year time frame, patient definition of decision-making
Davies et al. (2010) [45]	Describe patterns of patient involvement in head and neck cancer decision-making	Qualitative analysis of audio recordings, audio diaries, and interviews using grounded theory	39 (all) and 22 (interviewed)	All: 56% men, 49% known cancer, 15% stage 1, 3% stage 2, 13% stage 3, 13% stage 4 Interviewed: 64% men, 50% known cancer, 2%	Serious illness and experiencing considerable pain, discomfort, alteration in the ability to perform activities of daily living, fear for their life	Trust and confidence in physician	Among the 44 visits, the overall length was a median of 25 min (mean, 27 min; range, 9–65 min). Conventional decision-making was	Non-exhaustive, geography, sample size

Table 2 (continued)

Author (year)	Study aim	Study design	Sample size	Sample description	Barriers	Facilitators	Key findings	Limitations
				stage 1, 0% stage 2, 18% stage 3, 23% stage 4			formulated into a 3-step model: (1) exchanging information, (2) discussing options, and (3) making a decision	
Lee et al. (2010) [46]	Examine whether cancer patients' Internet use leads them to prefer a more active role in medical decision-making and whether the effects of Internet use on active participation preferences vary according to patients' education levels	Longitudinal survey questionnaire	2013 (baseline) and 1214 (follow-up)	Baseline: 50.9% women, mean age 66.2 years, 85.6% white, 67.1% married, 15.5% metastatic, 34% colorectal, 33.7% breast, 32.3% prostate Follow-up: 51.4% women, mean age 65.5 years, 88.2% white, 70% married, 12.9% metastatic, 31.9% colorectal, 34.8% breast, 33.3% prostate		Internet use for health information led to more active decision-making	In 2007, 37.1% of the respondents reported that they acquired health information on the Internet. There was no interactive effect of Internet use and education on active participation preference	Small effect sizes, self-report, limited cancer types
Mazor et al. (2013) [47]	Explore patients' and family members' views on communication during cancer care, and to identify those aspects of clinician-patient communication which were most important to patients and family members	Qualitative analysis of patients/family members using grounded theory, secondary analysis in the context of the HMORN Cancer Research Network and the CNR Cancer Communication Research Center	120 (patients) and 17 (family members)	88% female, age range 37–81 years, 21 different types of cancer (breast/colorectal most common)	Jargon, uncertainty, inaccurate information	Information exchange, hope/optimism, positive attitudes, fostering relationships, interpersonal manner, enabling patient self-management	Patients want sensitive, caring clinicians who provide information that they need, when they need it, in a way that they can understand; who listen and respond to questions and concerns; and who attempt to understand the patient's experience	Diversity among original studies, use of themes vs experience, interviews at different stages

ACCESS Assessment of Cancer Care and Satisfaction; *AOCN* advanced oncology certified nurse; *APECC* Assessment of Patients' Experience of Cancer Care; *BM* bilateral mastectomy; *BQUAL* Breast Cancer Quality of Care; *CAM* complementary and alternative medicine; *CHESS* Comprehensive Health Enhancement Support System; *CI* confidence interval; *CPM* contralateral prophylactic mastectomy; *DCIS* ductal carcinoma in situ; *ER* estrogen receptor; *HCaP-NC* Health Care Access and Prostate Cancer Treatment in North Carolina; *HT* hormonal therapy; *HRQoL* health-related quality of life; *NCCQ* National Initiative for Cancer Care Quality; *OPTION* observing patient involvement in decision-making; *OR* odds ratio; *PCIE* patient-clinician information engagement; *PDEMS* physicians' decision-making style scale; *PR* progesterone receptor; *QoL* quality of life; *RCT* randomized controlled trial; *RT* radiotherapy; *SD* standard deviation; *SDM* shared decision-making; *TDS* treatment decision satisfaction effects had better long-term adherence compared to those who reported not being informed (82% vs 72%, $p = 0.0016$), regardless of actual occurrence [37].

Physician communication appeared to be the largest barrier to SDM across studies. Women in Schubart et al. [35] found physician communication to vary in utility, with recall obscured by the emotional response they felt after delivery of the diagnosis. Livaudais et al. [38] identified that physician communication regarding the use of hormonal therapy for ductal carcinoma in situ varied, and that the strength of language for the recommendation was strongly associated with long-term patient use (OR = 11.2; 95% CI = 6.50–19.4) and discontinuation (OR = 0.38; 95% CI = 0.19–0.73). Breast cancer patients facing surgical treatment in Hawley et al. [41] were more likely to report too little involvement in the decision-making process when physicians failed to fully discuss both mastectomy and breast-conserving surgery options. Other concerns identified in studies ranged from use of technical medical language among African-American patient-caregiver dyads with lung cancer in Lee et al. [19] to patterns of "broadcasting," or lengthy monologs by the physician, in consultations for hematological cancer in Chhabra et al. [23]. Physicians in Alexander et al. [27] were found to have generally underutilized communication behaviors such as determining patient preference and verifying patient understanding, while patients with advanced lung cancer in Nelson et al. [30] noted a number of topics where communication was lacking, such as hospice, living wills, spiritual concerns, and life support preferences.

Facilitators of SDM

Three consistent themes of facilitators for SDM were also identified, including (1) physician consideration of patient preferences [13, 18, 21, 25, 27–29, 32–34, 37, 40, 47], (2) positive physician actions/behaviors (caring, trusting, relationship building, strong communication) from patient perspective [14, 15, 17, 18, 21–24, 28–30, 45, 47], and (3) use or encouragement of support systems [14, 17, 19, 25–29, 31, 33, 35].

Physician understanding of patient needs makes treatment decisions more likely to be discussed between the parties as partners, often increasing patient satisfaction. This was demonstrated in the secondary analysis of the iCanCare study where Martinez et al. [18] discovered that women who received high-autonomy-supportive conversation reported significantly higher decision quality scores than those who received low-autonomy-supportive conversations, regarding both chemotherapy and surgery ($p < 0.001$). Women in Shelton et al. [25] expressed desire for connection and communication with their doctor, with 38% wanting equal power with their doctor regarding their treatment and 33% desiring full control of their treatment with advice from the physician. Room for improvement on the part of providers was noted, with black women receiving less communication than white women ($p < 0.0001$) and women over 65 years who were also less informed [25]. In a qualitative study of older women, Pieters et al. [28] discovered that while support from physicians was crucial for patients, many felt that they had control over their treatment from the options presented to them. This type of shared experience allowed for an empowered feeling that the women found to be a positive experience [28]. Mazor et al. [47] determined that patients who were included in information sharing and decision-making were more satisfied with treatment, and those who experienced a physician deciding everything for them often felt confused and dissatisfied. Finally, there was a growing trend in assessing patients' preferences for SDM, as seen in the work by Alexander et al. [27], where 37% of patients were asked during consultation with their physician about their role preference. The study concluded that despite this work toward SDM, gaps exist as only 5% of conversations included an inquiry into the patient's preferences for information [27].

Positive patient-physician interactions account for increased trust among patients in their physicians. Arora and Gustafson [15] examined randomized data on helpful informational, emotional, and decision-making support given by physicians to their patients. Initially, each type of support significantly increased patient's trust in their physicians, ($p < 0.05$, $p < 0.001$, and $p < 0.01$, respectively), but at 5 months, only emotional support was associated with increased trust ($p < 0.01$), although trust was still high regardless [15]. Alongside trust, patient confidence in the physician was a notable facilitator in several studies, as demonstrated by Davies et al. [45]. According to Brufsky et al. [17], patients expected a level of concern and empathy from their physicians regarding treatment, side effects, and goals. Not only was compassion expected from physicians, but patients also desired strong guidance and advice in their treatment regimens. King et al. [24] determined that there was less conflict in surgical decision-making on the part of the patients when a physician provided a strong endorsement of a particular treatment regimen. This trend was reversed however, when the physician provided no guidance regarding treatment; significantly higher instances of surgical decision conflict were reported in those cases ($p < 0.001$) [24]. This finding was further corroborated by a cross-sectional study by Sidana et al. [29], in which the authors determined that the most significant factor in patient decision-making was the recommendation of a physician. Finally, secondary analysis of data by Mazor et al. [47] collected from several cancer research centers summarizes this sentiment by asserting patients' desire for a physician who cares for them, supports them with easily understandable information, is able to listen actively and honestly, and can empathize with the patient journey.

The final major facilitator was patients seeking out support from sources other than their physicians, such as family members, friends, support groups, and religion. Brufsky et al. [17] recognized this as 70% of women at initial diagnosis and 66% of women later in breast cancer disease progression desired referral to support services. Unfortunately, a gap existed despite this element being seen as important, as only 36% of patients reported receiving that referral at their initial diagnosis [17]. Shelton et al. [25] found that 76% of women in a cross-sectional survey cohort had the physical support of a close confidant at their treatment-choosing appointments with physicians. These support figures helped, in many cases, the women decide upon a treatment path [25]. Lee et al. [19] reported similar findings. Further, several studies report stories and anecdotes of friends/family who had gone through similar disease processes, playing a role in helping a patient make decisions [14, 26, 31]. Of the men surveyed in Xu et al. [31], 90.5% reported that discussions with acquaintances who had also been treated for prostate cancer helped to inform their decisions, particularly what treatment pathways they would not choose. Similarly, Song et al. [26] reported that having time to speak with and understanding their diagnosis with support systems are among the most important factors in a patient's decision. Finally, Sheppard et al. [33] reported that for many patients, it was reported that having faith in a higher power allowed them to cope with their diagnosis and treatment and believe that they would be able to persist through cancer-related treatments.

Discussion

A wide array of research assessing contributors to SDM in the field of oncology was discovered through this systematic literature review, allowing for identification of themes under barriers and facilitators to SDM. Major barriers from the patient perspective included uncertainty or lack of consensus in the treatment decision, concern regarding adverse effects, and poor physician communication. Major facilitators to SDM included physician consideration of patient preferences, positive physician actions/behaviors, and use or encouragement of support systems. With this synthesis of the literature, there is potential to improve the design and implementation of SDM into oncology care.

Joseph-Williams et al. [48] conducted a systematic review regarding patient-reported barriers and facilitators to SDM across broad (non-cancer), specific care, including areas such as hemodialysis, heart failure, primary care, and end of life. The analysis grouped barriers/facilitators under two broad analytical themes, including organization of the healthcare system (factors largely not within control of physicians and patients) and attributes of the encounter itself (factors driven by the SDM participants themselves) [48]. For the former, time, continuity of care, workflow, and environmental considerations were discussed as key contributors [48]; these were largely not noted in our present study regarding cancer-specific SDM. For the latter theme, contributors such as power imbalances between physician and patient, physician presumptions about patient role, trust, and positive interpersonal physician characteristics overlapped with the results of the present study [48]. Though the results of this previous review were greatly informative to the present analysis, an evaluation of facilitators and barriers specific to oncology care was still deemed necessary for several reasons. First, decisions regarding cancer treatment are weighted heavily in significance by patients and, in many cases, are irreversible. Second, treatment regimens are often complex and unfamiliar, rendering a larger knowledge deficit between physicians and patients compared to therapies for more well-known chronic disease. Finally, in many cases, multiple treatment options are recommended and driven broadly by patient preferences regarding efficacy and adverse effects; this inherently renders a more difficult decision for patients.

Patient approval regarding their physician's communication and behavioral style during consultations appears to be the most important consideration, rendering a large barrier to SDM when communication is poor, and a significant facilitator to SDM when a relationship is appropriately established. Trust in the physician or health system has been identified as a key factor not just in patient satisfaction with their care but also in their decision to accept or adhere to cancer treatment at all [49, 50]. Establishing trust starts as early as disclosure of the diagnosis [51], by the provision of patient-centered care through methods such as maintaining eye contact, expressing emotional support, and providing information at an appropriate pace. The development of optimal consultation skills does not appear to be related to the degree of physician experience or attributes, but communication and empathy can be improved through focused training efforts [52, 53].

DAs, or patient-oriented informational tools designed to help patients prepare for medical decisions by weighing benefits and risks, are commonly employed as a major component of SDM [54]. Across treatment or screening decisions, a recent review by Cochrane showed DAs to improve patient knowledge and help patients identify their priorities and feel more informed [4]. Although DAs are a useful component of the process, it is important to recognize that SDM should consider far wider implications beyond short-term cognitive and affective outcomes [55]. As demonstrated in this review, patients value and desire consideration of aspects of their treatment beyond the simple balance of efficacy and adverse effects, such as the presence of support systems throughout their care. Although value frameworks from groups like ASCO have expanded to include patient considerations such as cost or quality of life, it is prudent that SDM considers the humanistic aspects of cancer treatment as well. Many of these items may not be able to be addressed using a DA and require an engaged physician and a thorough consultation to tackle.

Emerging evidence suggests that the value that SDM provides extends beyond patients to benefit the healthcare system as a whole. Physicians express broad support for the use of SDM as a mechanism to help contain costs [56], and a large-scale analysis by the Lewin Group estimated that the use of

SDM across 11 procedures among the Medicare population could result in savings of over $9 billion in the national health expenditure over a 10-year time frame [57]. Understanding the optimal approaches to implementing SDM has the potential to help deliver significant impact through cost savings, particularly for cancer care where costs of care impact decision-making [58]. In addition to reducing unnecessary costs, these patient-centered approaches also provide opportunities to improve the quality of care and optimize healthcare utilization [59, 60], which can play a critical role in supporting the progression toward a value-based healthcare system.

Limitations

The heterogeneity of the literature identified in this review made individualized assessments of study quality difficult, particularly using a method that could be compared across studies with different designs. Accordingly, in our summary of evidence, we provided an assessment of study limitations as transparent as possible. Second, the mixture of qualitative and quantitative data made the comparisons across studies difficult; however, this provides a rich view of the field using different methodologies that each has inherent strengths and limitations. Third, the study focused specifically on barriers/facilitators among studies conducted in the USA, and therefore, additional considerations identified in the international literature may have been omitted in this analysis. However, the authors specifically chose to focus on US-based studies due to the uniqueness of the US healthcare system, compared to socialized or single-payer systems that are prevalent internationally. Finally, although cancer is an overarching theme, it is recognized that different tumor types and treatment modalities may have individualized considerations not captured in detail by this analysis. Despite this, the goal of the study was to render broad outcomes with maximum generalizability across patients with cancer, which was accomplished.

Conclusion

Overall, this study provided indication of clear themes regarding barriers and facilitators to SDM in oncology care. These attributes could be useful in the development of a clear SDM strategy, including interventions and decision aids, for oncology care through understanding patients' values when making treatment decisions and for optimizing training opportunities for medical personnel involved in oncology care delivery.

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Compliance with ethical standards

Conflict of interest Covvey and Kamal have received research funding from Novartis Pharmaceuticals Corporation and the College of Psychiatric and Neurologic Pharmacists. Rao has received funding from the College of Psychiatric and Neurologic Pharmacists for an unrelated project. Zacker is employed by Novartis Pharmaceuticals Corporation. Gorse was employed by AbbVie through an internship at the time of writing.

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