



Use of Decision Aids with Minority Patients: a Systematic Review

Aviva G. Nathan, MPH, Imani M. Marshall, Jennifer M. Cooper, MPH, and Elbert S. Huang, MD, MPH, FACP

Section of General Internal Medicine, University of Chicago, Chicago, IL, USA.

BACKGROUND: One potential approach to reducing health disparities among minorities is through the promotion of shared decision making (SDM). The most commonly studied SDM intervention is the decision aid (DA). While DAs have been extensively studied, we know relatively little about their use in minority populations. We conducted a systematic review to characterize the application and effectiveness of DAs in racial, ethnic, sexual, and gender minorities.

METHODS: We searched PubMed for randomized controlled trials (RCTs) evaluating DAs between 2004 and 2013. We included trials that enrolled adults (> 18 years of age) with > 50 % representation by minority patients. Four reviewers independently assessed 597 initially identified articles, and those with inconclusive results were discussed to consensus. We abstracted decision quality, patient-doctor communication, and clinical treatment decision outcomes. Results were considered significantly modified by the DA if the study reported $p < 0.05$.

RESULTS: We reviewed 18 RCTs of DA interventions in minority populations. The majority of interventions (78 %) addressed cancer screening. The most common mode of delivery for the DAs was personal counseling (46 %), followed by multi-media (29 %), and print materials (25 %). Most of the trials studied racial (78 %) or ethnic (17 %) minorities with only one trial focused on sexual minorities and none on gender minorities. Ten studies tailored their interventions for their minority populations. Comparing intervention vs. control, decision quality outcomes improved in six out of eight studies and patient-doctor communication improved in six out of seven studies. Of the 15 studies that reported on clinical decisions, eight demonstrated significant changes in decisions with DAs.

DISCUSSION: DAs have been effective in improving patient-doctor communication and decision quality outcomes in minority populations and could help address health disparities. However, the existing literature is almost non-existent for sexual and gender minorities and has not included the full breadth of clinical decisions that affect minority populations.

KEY WORDS: shared decision making; disparities; race and ethnicity; minority health; systematic reviews; medical decision making.

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INTRODUCTION

Health disparities negatively impact the lives of many minorities, but especially racial, ethnic, sexual and gender minorities. Racial and ethnic minorities have higher rates of chronic diseases, such as cancer, cardiovascular disease and diabetes. Moreover, when they develop these conditions, they suffer higher mortality rates than their white counterparts.¹ Similarly, sexual and gender minorities suffer from higher rates of physical and mental illness than majority populations. Lesbian, gay, bisexual, and transgender individuals have higher rates of mood anxiety disorders and suicidal ideation than majority populations.² Racial, ethnic, sexual, and gender minorities' health care has been hindered by the failure to include these patients in clinical research that has left health care providers with a modest evidence base and an absence of implementation strategies.

Shared decision making (SDM) is one important potential conceptual approach to alleviating health disparities. SDM is the practice of facilitating patient-physician discussions to determine health care plans. One of the most widely disseminated conceptual models of SDM is grounded in three pillars: 1) information-sharing, 2) deliberation and/or physician recommendation and 3) decision making.^{3,4} SDM has the potential to increase patient satisfaction, align the selection of treatments with patients' preferences, increase adherence to therapies, and improve clinical outcomes.^{5–8}

While SDM has great promise, patients of minority backgrounds experience SDM less often than non-minority populations.^{9–11} Minority populations may also have alternative conceptions and definitions of SDM that raise questions about the effectiveness of this model of care. For example, Peek et al. explored SDM among African American patients and discovered that information sharing preferences differed significantly from the traditional SDM model among these patients.¹² In addition to differences in preferences for information sharing, some minority populations may have higher rates of

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Table 1. Search Terms—MeSH and Keywords

Population	MeSH	Keywords
Minority	"Minority Groups"	"Minority Groups" OR "Minority Group" OR Minority OR Minorities
Shared Decision Making	Decision Making OR Decision Theory OR Decision Support Techniques OR Health Knowledge, Attitudes, Practice, Attitude of Health Personnel OR Professional Patient Relations OR Physician Patient Relations OR Consumer Participation	"shared decision making" OR "patient perception" OR "patient participation" OR "health communication" OR "healthcare decisions" OR "health care decisions" OR "patient-centered communication" OR "participatory decision making" OR "patient-provider communication" OR "provider-patient communication" OR "patient-provider communications" OR "provider-patient communications" OR "provider-patient relationships" OR "patient-provider relationships" OR "provider-patient relationship" OR "patient-provider relationship" OR "provider-patient relations" OR "patient-provider relations" OR "patient-provider relation" OR "patient-physician communication" OR "physician-patient communication" OR "patient-physician communications" OR "physician-patient communications" OR "physician-patient relationships" OR "patient-physician relationships" OR "physician-patient relationship" OR "patient-physician relationship" OR "physician-patient relations" OR "patient-physician relations" OR "physician-patient relation" OR "patient-physician relation" OR "patient-clinician communication" OR "clinician-patient communication" OR "patient-clinician communications" OR "clinician-patient relationships" OR "patient-clinician relationships" OR "clinician-patient relationship" OR "patient-clinician relationship" OR "patient-doctor communication" OR "doctor-patient communication" OR "patient-doctor communications" OR "doctor-patient communications" OR "doctor-patient relationships" OR "patient-doctor relationships" OR "doctor-patient relationship" OR "patient-doctor relationship" OR "doctor-patient relations" OR "patient-doctor relations" OR "doctor-patient relation" OR "patient-doctor relation" OR "decisional conflict" OR "decisional conflicts" OR "patient engagement" OR "patient partnership" OR "patient empowerment" OR "shared role" OR "shared roles" OR "agenda-setting" OR "goal-setting" OR "information-sharing" OR "information-seeking" OR "initiate discussions" OR "initiating discussion" OR "initiating discussions" OR "treatment decisions" OR "treatment decision" OR "treatment preferences" OR "decision aid" OR "decision aids" OR "decision support tool" OR "decision support tools" OR "decision support"
African American	African American OR African Continental Ancestry Group	"African Americans" OR black OR blacks OR "African American"
Latino Americans	Hispanic Americans OR Mexican Americans	"Hispanic American" OR "Hispanic Americans" OR "Spanish Americans" OR "Spanish American" OR Puerto Ricans OR Puerto Rican OR Latinas OR Latina OR Latinos OR Latino OR "Cuban Americans" OR Cuban OR "Cuban American" OR Hispanics OR Hispanic OR "Mexican American" OR "Mexican Americans" OR Chicanos OR Chicano OR Chicana OR Chicanas
Asian Americans	Asian Americans OR Asian Continental Ancestry Group	Burmese OR Burmese OR Cambodians OR Cambodian OR Vietnamese OR Vietnamese OR Japanese OR Koreans OR "Race, Asiatic" OR "Races, Asiatic" OR Thai OR Asians OR Asian OR Chinese OR "Asian American" OR "Japanese American" OR "Korean Americans" OR "Korean American" OR "Chinese Americans" OR "Americans, Chinese" OR "Chinese American"
LGBT (including MSM, WSW, FTM, MTF)	Homosexuality OR Bisexuality OR Transgendered Persons OR Transsexualism OR Homosexuality, Female OR Homosexuality, Male	homosexual OR homosexuals OR homosexuality OR bisexual OR bisexuals OR bisexuality OR queer OR gay OR transgender OR transgenderism OR transsexual OR transsexuals OR transsexuality OR transsexualism OR "transgendered persons" OR "trans persons" OR "trans people" OR "same sex" OR same-sex OR "transitioned people" OR "transitioned persons" OR lesbian OR lesbians OR lesbianism OR women who have sex with women OR wsw OR men who have sex with men OR msm OR ftm OR "female to male" OR "trans male" OR "trans men" OR transman OR transmen OR mtf OR "male to female" OR "trans women" OR transwoman OR transwomen

Abbreviations: MSM = men who have sex with men; WSW = women who have sex with women; FTM = female to male; MTF = male to female

low literacy that may require significant modification of material designed to engage patients.^{7,13}

The most commonly studied intervention to facilitate SDM in clinical practice is the decision aid (DA). DAs are educational tools designed to encourage patients to participate in medical decisions by displaying the benefits and harms of treatment options and by eliciting patient preferences, particularly for decisions with scientific uncertainty.¹⁴ Over the past several decades, the field has matured significantly. There are now over 115 DAs described in the literature and established best practices for evaluating DAs.¹⁴

Despite the extensive DA literature, we know little about how frequently minority populations experience DAs or how much they have been tailored to their populations' specific needs (e.g., low literacy). We reviewed existing randomized controlled trials (RCTs) that examine DAs with underrepresented minority populations. By conducting this review, we hoped to identify the gaps in knowledge and research opportunities about the best practices for DAs within minority patient populations. The following systematic review aimed to answer: 1) what types of DA interventions are being tested within minority populations, 2) what conditions do these tested interventions address, and 3) what DA interventions have changed decision quality, patient–doctor communication, and clinical decision outcomes within minority populations?

METHODS

We conducted our systematic review by: 1) defining our key research questions, 2) identifying search terms and literature search, 3) reviewing abstracts and screening for inclusion/exclusion criteria, 4) abstracting data, and 5) analyzing data. This systematic review adhered closely to the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA).¹⁵

Data Search

Our primary research question was: what types of DA interventions have been tested in minority populations; specifically, racial, ethnic, sexual and gender minority individuals in the past decade? We also sought to discover what conditions these interventions addressed and in which minority populations these interventions were tested. We additionally explored whether DAs were being tailored for minority populations.

We searched PubMed from 1 January 2004 to 31 December 2013 for RCTs of DAs conducted in minority populations. Search terms were developed and tested with assistance from librarians to ensure a comprehensive and inclusive search. We used pre-specified and tested Medical Subject Headings (MeSH) terms and keywords to identify RCTs evaluating DAs and SDM tools (e.g., Decision Making, Decision Theory) within racial, ethnic, sexual, and

gender minority populations (e.g., "Minority Groups", Homosexuality, Transgendered Persons) (Table 1).

Inclusion and Exclusion Criteria

Our search included English RCTs that evaluated DAs within minority populations. Based on established models of SDM and DAs,¹⁴ we included studies with an intervention that included 1) information sharing or education and 2) risks and benefits of treatment options, to enable SDM. Studies in which < 50 % of the participants identified as part of a racial (African American, Asian American), ethnic (Hispanic/Latino), sexual (LGB) or gender (Transgender) minority were excluded.^{12,16} Studies with individuals younger than 18 years old were excluded.

Study Selection and Data Extraction

Four raters independently reviewed a randomly selected, 10 % sample of articles from our search and identified articles for inclusion. The inter-rater reliability of the raters was 0.83. The remaining articles were divided among the raters and assessed for eligibility. Articles with inconclusive results were discussed to consensus among the raters. Finally, we performed a hand-search of the 2014 Cochrane Collaboration review and found six DA interventions that met our criteria.¹⁴ We found that only one article was not previously discovered in our search of PubMed.

Outcomes of Interest

We focused our review on three sets of outcomes that are relevant to SDM. We first reviewed studies with results on **decision quality outcomes**. This outcome category included decisional conflict, satisfaction with decisions, and worry or anxiety regarding a decision. Second, we examined the impact of DAs on **patient–doctor communication**. Communication is one pillar of SDM, and includes the patient stating their intent or if they actually reported having a discussion with their provider about their treatment decision. We also included quality of communication in this outcome. Our third outcome was **clinical treatment decisions**, and included all outcomes relating to the treatment decision under investigation. This outcome category included the willingness to undergo treatment, readiness for treatment, intent to complete treatment and completion of treatment.

When assessing outcomes, we classified interventions as effective if decision quality outcomes improved (e.g., less decisional conflict, less worry), if communication outcomes improved (e.g., more communication, greater quality of communication), and if treatment decisions were moved by the intervention. We required statistical significance at $p < 0.05$ to be considered a positive result. For all three outcomes, we examined whether culturally tailored interventions were more effective compared to interventions that were not culturally tailored.

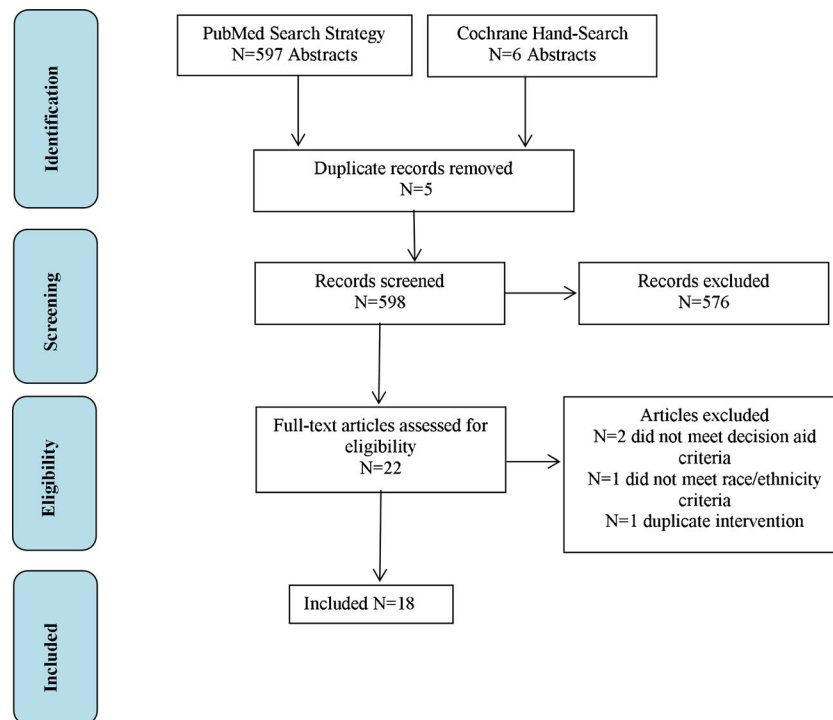


Figure 1. Flow diagram of study selection process for systematic review.

Data Synthesis and Analysis

The included articles were divided among the reviewers, and data were abstracted from full text articles using an adapted abstraction form from Zaza and colleagues.¹⁷ For included studies, we abstracted data on population characteristics, intervention characteristics, intervention outcomes, tailoring of interventions, and feasibility considerations. After data were abstracted, two reviewers checked the content for consistency. In addition, the research team scored each included study for quality by using a tool based on the Downs and Black (1998) guidelines (28 point scale: 0 worst, 28 best). One article was removed from inclusion for failure to meet the minority inclusion requirement, and two articles were removed for failure to qualify as a DA. Data were synthesized and analyzed by using tables and primary research questions to compare the included studies. The details of the data abstraction forms were entered into tables and the main findings were contrasted and tabulated.

RESULTS

Our search identified 597 abstracts for screening and review. After abstract, title and full text review, we included 22 articles for data abstraction and analysis. During data abstraction, we discovered three articles could not be included due to exclusion criteria. This resulted in inclusion of 19 articles for data analysis (Fig. 1), (Online Appendix). The majority of publications were excluded for failure to meet multiple inclusion criteria. The most common reason for excluding a study was

that the intervention was not a DA. Five articles were excluded because their study populations did not meet the > 50 % minority criteria. This review represents data on the reports of RCTs that used decision support tools in minority populations (Table 2).^{18–36} Two of the articles described different outcomes from one RCT.^{31,32} Thus, we considered these two papers one intervention, resulting in a total of 18 interventions with data. The results describe select studies from our review that highlight the types of health conditions, populations studied, DA type and delivery mode, and cultural tailoring used.

Decision Aid Type and Delivery

Many of the trials attempted to test their SDM intervention through multiple modalities (Table 3). Eight studies utilized more than one method to deliver their intervention (e.g., print and phone counseling), and the remaining ten studies used one method each. Counseling or interviewing was the most common mode of delivery for DAs ($n=13$); however, several types of counseling were utilized: one-on-one counseling or interviewing ($n=6$), group counseling ($n=4$), and telephone ($n=3$). The second most common form of DA was multimedia delivery. These varied from DVDs, computer kiosks with touch screens, and desktop computers with interactive displays. This type of DA was most often self-guided ($n=7$); however, one study did use an assisted multi-media DA.

One example of an intervention that used multiple DA delivery modalities was the study by Glanz et al. (quality score 19). The authors used counseling, print materials, and phone calls to deliver decision support.²³ Counseling sessions were led by a nurse or health educator, and were tailored to the

Table 2. RCTs of Decision Aids in Minority Populations

Authors	Study Aims	Population	Health Condition	Cultural Tailoring	Decision Quality Outcomes	Communication Outcomes	Clinical Decision Outcomes	Other Key Outcomes	Quality Score (out of 28)
Bowen, D., 2006 ¹⁸	Test the effects of breast cancer risk counseling on sexual minority women (SMW)	150 (69 Intervention, 81 Control), Women 18–74 years, self-identified as lesbian or bisexual	Breast cancer	Counseling sessions run by SWM counselors and content of sessions designed to address concerns of SMW population	At 24 months, perceived risk (0–100), (control 33 vs. intervention 17) and cancer worry (4–16 scale, control 6.2 vs. intervention 5.2) decreased while mental health (0–100), (control 74.8 vs. intervention 80.3) increased. $p < 0.01^*$ for all three outcomes	N/A	Rates of breast self-examination – increased by 17 % to 52 %, ($p < 0.01^*$) and mammogram – increased from 12 % to 87 %, ($p < 0.05^*$) for participants that received the intervention		17
Chan, E., 2011 ¹⁹	Promote informed decision making (IDM) about prostate cancer screening	321 (161 intervention, 160 control) Hispanic/Latino male, 40+ years	Prostate cancer	Interviews and focus groups held to explore needs and communication preferences to promote IDM. Sixteen Hispanic/Latino men participated in mapping activities	N/A	N/A	No effect of the intervention on desire to be screened 95 % CI: control M = 4.0, 4.7. intervention M = 3.9, 8.7 ($p = 0.001^*$)	Knowledge (12-item) scores increased pre/post: control M = 4.0, 4.7. intervention M = 3.9, 8.7 ($p = 0.001^*$)	19
Christy, S., 2013 ²⁰	Compare the effects of interventions on patient-provider discussions about colorectal cancer (CRC) screening	693 (319 Intervention, 340 Control) African American, male and female, 51–80 years	CRC	N/A	N/A	Intervention group more likely to engage in CRC screening discussion with provider (63 % vs. 49 %, OR = 1.81, ($p = < 0.001^*$))	N/A	Intervention group more likely to engage in CRC screening discussion with provider (63 % vs. 49 %, OR = 1.81, ($p = < 0.001^*$))	20
Ellison, G., 2008 ²¹	Determine if web-based DA increases knowledge of prostate cancer screening	87 (46 Intervention, 41 Control) African American, male, 40–65 years	Prostate cancer	DAs were designed specifically for African American men	N/A	N/A	N/A	Knowledge Intervention had higher average scores vs. usual care. M = 7.67, standard error (SE) = 0.25 vs. M = 6.78, SE = 0.23; ($p < 0.01^*$)	19

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Table 2.. (continued)

Authors	Study Aims	Population	Health Condition	Cultural Tailoring	Decision Quality Outcomes	Communication Outcomes	Clinical Decision Outcomes	Other Key Outcomes	Quality Score (out of 28)
Geller, K., ²² 2011	Encourage increased physical activity	21 (12 Intervention, 9 Control) Hawaiian (multiethnic), male and female, mean age 72.2	Healthy Lifestyle	N/A	N/A	N/A	Both groups improved moderate physical activity minutes, fruit and vegetable participants had a greater mean increase (15.19 more minutes). The physical activity program participants had a greater increase in their daily fruit and vegetable intake (1.01 more servings). No <i>p</i> values reported		13
Glanz, K., ²³ 2007	Increase CRC screening	108 (54 Intervention, 54 Control) Male and female siblings, living in Hawaii age \geq 40 years	CRC	Intervention material was culturally sensitive in the context of multi-ethnic Hawaiian	N/A	N/A	Adherence to CRC screening Intervention group: 29 % (baseline), 49 % (4 months) ($p=0.05^*$), 53 % (12 months) Control group: 31 % (baseline), 38 % (4 months), 44 % (12 months)		19
Holt, C., ²⁴ 2009	Increase knowledge of prostate cancer and screening. Increase self-efficacy for screening/ decision making. Ascertain perception of barriers to screening.	49 (31 Spiritual group, 18 Non-spiritual group), African American, male, age \geq 45 years	Prostate cancer	One study arm was spiritually tailored to include religious themes or scripture	N/A	N/A	At baseline, 26.5 % reported a decision had already been made, and increased to 36.7 % after the session ($p = 0.07$)	Knowledge of prostate cancer and risk factors increased for both in pre/post-test change (M = 1.82* non-spiritual group, M = 2.15* spiritual group). Knowledge of screening controversy increased for spiritual group (M = 0.76* vs. M = 0.36)	17

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Table 2. (continued)

Authors	Study Aims	Population	Health Condition	Cultural Tailoring	Decision Quality Outcomes	Communication Outcomes	Clinical Decision Outcomes	Other Key Outcomes	Quality Score (out of 28)
<i>Ibrahim, S., 2013</i> ²⁵	Examine efficacy of patient-centered educational intervention on patient willingness and likelihood of receiving referral to orthopedics	639 (162 DA, 158 Motivational Interview (MI), 158 DA + MI, 161 Control) African American male and female, > 55	Osteoarthritis	No	N/A	All interventions groups were more likely to be referred (18 % versus 13 %, $p = 0.12$)	Across all study arms, patient willingness increased from baseline to 1 month (chi-square = 21.39, $p < 0.0001$ *)	One-month follow-up: AC (Control): no increase, DA: 9.5 % to 23 % answered 3/4 questions correctly ($p < 0.05$ *). MI: 8 % to 15 % had 3/4 correct answers ($p = 0.09$). DA + MI: 9.5 % to 23 % answered 3/4 questions correctly ($p < 0.05$ *)	24
<i>Jibaja-Weiss, M., 2011</i> ³⁶	Evaluate an entertainment-based patient DA for early stage breast cancer surgery in low health literacy patients	76 (40 Intervention, 36 control), Diverse racial and ethnic women with early stage breast cancer, mean age 51	Breast cancer	Intervention developed for multi-ethnic women with minimal computer experience and low health literacy. Based on education entertainment theory	Intervention and control groups had decreased decisional conflict ($p = 0.001$ *). Intervention patients reported being more informed about surgical options and risks vs. control patients ($p = 0.007$ *) prior to surgery and being clearer about their personal values (trend at $p = 0.053$)	N/A	Intervention arm less likely than control to indicate preference for breast-conserving surgery (40.5 % vs. 50.0 %), and more likely than control to indicate a preference for modified radical mastectomy (59.5 % vs. 39.5 %, $p = 0.018$ *). No intervention patients were unsure about their surgical preference, 0.5 % of controls were unsure	No difference between intervention and control groups prior to decision. Intervention patients showed improvement in knowledge (pre-surgery) vs. no change for control ($p < 0.001$ *). At 1-year, control patients' knowledge had increased nearly to the level of the intervention patients	18
<i>Lam, W., 2013</i> ²⁶	Determine if a DA can help decision on breast cancer surgery and immediate breast reconstruction	276 (138 Intervention, 138 Control) Cantonese and Mandarin-speaking Chinese, female	Breast cancer	Traditional Chinese language used in materials, DA booklet based on prior findings on breast cancer treatment decision making among Chinese women	Decreased depression scores for intervention arm 10 months post-surgery ($p = 0.001$ *). Post-surgical anxiety scores at 1, 4, and 10 months did not differ between groups	N/A	Choice of surgery did not differ between arms		24

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Table 2.. (continued)

Authors	Study Aims	Population	Health Condition	Cultural Tailoring	Decision Quality Outcomes	Communication Outcomes	Clinical Decision Outcomes	Other Key Outcomes	Quality Score (out of 28)
Lepore, S., 2012 ²⁷	To provide information and exercises to help men make an informed decision about prostate cancer screening consistent with their values	490 (Intervention 244, Control 246) men of African origin, age 45–70 years	Prostate cancer	N/A	The intervention group reported a lower lever of DC than the control group, ($p < 0.05^*$)	8.3 % of controls vs. 15.8 % of intervention stated they had a visit to discuss prostate cancer with their doctor ($p < 0.001^*$)	Congruence between intention to test and verified PSA test similar for both arms at 1 year (intervention 55.3 % vs. control 58.1 %) and 2 year follow-up (intervention 59.0 % vs. control 59.3 %)	Knowledge increased more for pre to post-test (M = 51.7, SE = 0.012) to (M = 61.6, SE = 0.009) vs. control (M = 49.6, SE = 0.012) to (M = 54.7, SE = 0.009) ($p < 0.001^*$) Increased knowledge of anatomy and key terms (e.g., polyp), primary screening options (FOBT, flexible sigmoidoscopy, colonoscopy), and risk information ($p < 0.001^*$ for all)	17
Makoul, G., 2009 ²⁸	To test the extent to which the intervention affects knowledge and willingness to considered CRC screening for Hispanic/ Latino patients	270 (136 Positive appeal DA, 134 Negative appeal DA) Latino, 50–80 years	CRC	Intervention content was based on interviews with Latino patients, material was available in Spanish and English and the use of promotores also part of tailoring	N/A	90 % reported intent to discuss with provider—no p values reported.	Willingness to undergo tests significantly increased for all three types of screening (24 % increase for fecal occult blood test, 24 % increase for flexible sigmoidoscopy, 19.6 % increase in colonoscopy, $p < 0.001^*$ for all)		14
Miller, D., 2011 ²⁹	Determine if web-based multimedia CRC screening patient DA could increase CRC screening	264 (N=132 Intervention, N=132 Control), Racially diverse, male and female, 50–74 years	CRC	N/A	N/A	N/A	Intervention arm increased readiness for screening vs. control ($p < 0.001^*$). Non-significant difference for intervention vs. control for completing a screening test within 24 weeks ($p = 0.12$). Intervention group (84 %) reported a test preference than the control group (55 %) post intervention ($p < 0.001^*$)		23

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Table 2. (continued)

Authors	Study Aims	Population	Health Condition	Cultural Tailoring	Decision Quality Outcomes	Communication Outcomes	Clinical Decision Outcomes	Other Key Outcomes	Quality Score (out of 28)
Myers, R., 2005 ³⁰	To test the effect of decision education, and IDM method on prostate cancer screening	242 (N=121 Enhanced intervention, N=121 Standard intervention), African-American men, 40–69 years	Prostate cancer	N/A	No reported follow-up from baseline	N/A	Screening use among the enhanced group was twice as high as among the standard intervention group although non-sign ($p = 0.081$)		16
Schroy, P., 2011 & 2012 ^{31,32}	Assess the effectiveness of a novel DA on SDM in the primary care setting and on CRC screening uptake	666 [212 DA alone, 223 DA + Personalized Risk Assessment (YDR), 231 Control], Racially diverse, male and female, age 50–75 years	CRC	DA modules performed by racial and ethnic minority actors	Satisfaction with decision-making scores higher for two intervention arms vs. control ($p < 0.0001^*$). Both DA + YDR and DA alone interventions had similar scores [50.5 (6.2) and 50.7(6.2), respectively]	At 12 months DA alone (80.7 %) was more likely than the DA + YDR (73.6 %) and the control arm (71.4 %) to order a test ($p < 0.05^*$)	Intention scores were higher for DA + YDR [4.3 (1.0)] and DA alone [4.4(1.0)] compared to the control arm [3.9(1.4), ($p < 0.001^*$]. At 12 months, DA alone (80.7 %) was more likely than the DA + YDR (73.6 %) and the control arm (71.4 %) to order a test ($p < 0.05^*$)		20, 23
Song, M., 2009 ³³	Enhance communication and cognitive and emotional preparation regarding end-of-life care (in the context of End Stage Renal Disease (ESRD) between patients and their surrogates	58 Patient + Surrogate Dyads (29 Intervention, 29 Control) African American, receiving dialysis for at least 3 months prior to enrollment with surrogate, over 18 years	ESRD	N/A	Decisional conflict did not differ significantly over time or between groups (reduction in DCS for intervention 0.13 vs. control 0.9).	Quality of communication scores at t2 higher for intervention (11.18 vs 8.83 in control ($p = 0.03^*$). At t3, 7.52 in control versus 11.3 in intervention ($p < 0.01^*$). Intervention reported better quality of interaction during intervention at t2, 5.56 in intervention vs. 7.29 control ($p = < 0.01^*$). At t3, 5.68 in intervention vs. 7.29 in control	Surrogate decision making confidence and both patients and surrogates psychosocial-spiritual well-being improved but no difference between the two (from t1-t3, the average patient well-being score was: 1.59 intervention and 1.76 control. For surrogates, it was 1.54 intervention and 1.81 for controls. scale from 0 = not confident at all to 4 = very confident		17

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Table 2. (continued)

Authors	Study Aims	Population	Health Condition	Cultural Tailoring	Decision Quality Outcomes	Communication Outcomes	Clinical Decision Outcomes	Other Key Outcomes	Quality Score (out of 28)
Song, M, 2010 ^{3,4}	Help patients and surrogates understand course of patient's illness, clarify treatment values, and use Patient-Centered Advanced Care Planning	17 Patient+Surrogate Dyads, (10 Intervention, 7 Control), male and female African American, over 18 years	Chronic Kidney Disease	N/A	Decisional conflict two groups were not statistically significant. No changes in psycho-spiritual well-being of patient and surrogate in either group	Perceived quality of communication about end of life care was higher in the intervention than control (10.10 in intervention versus 8.14 in control group $p < 0.05^*$)	N/A		15
Taylor, K., 2006 ⁵	Determine the effect of the interventions on knowledge, decisional conflict, satisfaction with screening decision and self-reported screening	238 (95 Video DA, 98 Print, 92 Waitlist) African American, male, 40-70 years, Members of Prince Hall Masons	Prostate cancer	Conducted focus groups to determine educational needs of AA men of 40-70 years	Relative to the control arm, the print and video arm resulted in significantly reduced DC ($p < 0.01^*$). No significant difference for satisfaction with decision between arms at 1 month follow-up. Satisfaction with the screening decision was not related to intervention arm (OR, 0.64; 95% CI, 0.28-1.4)	N/A	Increase in screening uptake for prostate-specific antigen and digital rectal exam screening from baseline to 1-year follow-up (combined, 38.5% received both tests within past year at baseline compared with 62.2% at the 1-year assessment [$p = 0.001^*$])	Knowledge improved from baseline to 1-month assessment within both print ($p < 0.0001^*$) and video ($p < 0.0001^*$) arms. Relative to wait list arm, knowledge was higher in print ($p < 0.0001^*$) and video arms ($p < 0.0001^*$)	19

M, mean; AC, attention control

Table 3 Decision Aid Modality

Authors	Group Counseling	Individual Counseling	Self-Guided Multi-Media	Assisted Multi-Media	Print	Phone	Total
Bowen, D., 2006 ¹⁸	•						1
Chan, E., 2011 ¹⁹	•						1
Christy, S., 2013 ²⁰			•				1
Ellison, G., 2008 ²¹			•				1
Geller, K., 2011 ²²	•						1
Glanz, K., 2007 ²³		•			•	•	3
Holt, C., 2009 ²⁴	•				•		2
Ibrahim, S., 2013 ²⁵		•	•				2
Jibaja-Weiss, M., 2011 ²⁶			•		•		2
Lam, W., 2013 ²⁶		•			•		2
Lepore, S., 2012 ²⁷					•	•	2
Makoul, G., 2009 ²⁸				•			1
Miller, D., 2011 ²⁹			•				1
Myers, R., 2005 ³⁰		•			•	•	3
Schroy, P., 2011 ³¹			•				1
Song, M., 2009 ³³		•					1
Song, M., 2010 ³⁴		•					1
Taylor, K., 2006 ³⁵			•		•		2
Total	4	6	7	1	7	3	28

diverse and multiethnic population of Hawaii. The study aimed to increase colorectal screening among children and siblings of CRC patients. Using an attention control design, the study found that adherence to screening guidelines among intervention subjects compared to controls was statistically significant ($p=0.03$) when measured at the 4-month follow-up. The intervention group showed a 13 percent increase in adherence at 4 months, which was reduced to 11 percent at 12-month follow-up ($p=0.09$).

Health Conditions

Of the 18 studies included in this review, the majority ($n=14$) focused on cancer prevention through screening or other means. The type of cancer evaluated among these 14 studies was limited to prostate, colorectal (CRC), and breast cancer. The remaining four trials evaluated DAs in three unique health conditions: kidney disease (end-stage renal disease and chronic kidney disease)^{33,34}, osteoarthritis²⁵, and healthy lifestyle change.²²

The most commonly studied medical condition in our review was prostate cancer. Prostate cancer screening is an area surrounded by clinical uncertainty and is sensitive to patient preferences. In one of the six prostate cancer studies we reviewed, Lepore and colleagues tested a DA in African American men aged 45–70 (quality score 17). We highlight this study because it reported the largest number of SDM outcomes among the prostate cancer DAs. The purpose of this intervention was to provide information and exercises to enable men to make an informed decision about prostate cancer screening that would be consistent with their values.²⁷ The DA consisted of a printed pamphlet with pros and cons of prostate specific antigen (PSA) testing, and was followed by a phone call or in person counseling session. The study used an attention control design where control subjects received phone calls about fruits and

vegetables. The education portion of the counseling sessions was tailored based on the patient's knowledge. When compared to the control arm, the intervention arm showed increased uptake in PSA testing, and 8.3 % of controls versus 15.8 % of intervention stated they had a visit to discuss prostate cancer with their provider ($p<0.001$). The intervention group reported lower decisional conflict than the control group ($p<0.014$). Both 81 % of control and intervention patients said they planned on a prostate test at the post-test (not significant).

Population Characteristics

Seventeen studies focused on racial or ethnic minorities. Eight of the interventions studied African Americans, two studied Hispanic or Latino populations, one studied a predominately Asian population, and the remaining six studies consisted of diverse minority populations (three majority African American, two majority Asian, and one majority Hispanic). Of the 18 studies we reviewed, one studied a DA in a sexual minority population.

In the only study focused on sexual minorities, Bowen and colleagues tested the effects of breast cancer risk counseling on sexual minority women (SMW) (quality score 17).¹⁸ One hundred and fifty self-identified bisexual and lesbian women participated in the study. The study utilized four group counseling sessions of five to eight women with a trained SMW health counselor to cover risk assessment, education, breast cancer screening, stress management, and social support. Three options for breast cancer screening were covered: mammography, clinical breast exam, and breast self-exam. The study used a delayed intervention control group to study the effects of the program. This program had a positive effect; perceived risk (0–100 scale, control=33, intervention=17), cancer worry (4–16 scale, control=6.2, intervention=5.2) and mental health scores (0–100 scale, control=74.8,

intervention = 80.3) improved over 24 months for both groups, but the improvement was greater for the intervention group ($p < 0.01$). Rates of breast self-examination, increasing by 17 % to 52 % ($p < 0.01$), and mammogram, increasing from 12 % to 87 % ($p < 0.05$), increased for participants that received the intervention, while it remained stagnant for the control group.

Tailoring of Intervention for Population of Interest

The extent of cultural tailoring varied across interventions. We found that ten of the studies used some form of tailoring to customize their interventions for their racial, ethnic, or sexual minority populations. The remaining eight studies did not report an attempt to culturally tailor their interventions. However, three of the non-culturally tailored studies did tailor their intervention for other characteristics of their population, such as low or mixed-literacy.

An excellent example of cultural tailoring was found in the study by Makoul et al. Investigators customized their intervention after extensive interviews with Latino patients (quality score 14).²⁸ The final intervention was an interactive multi-media format that was accompanied by *promotores* (lay Hispanic/Latino community health workers) who helped participants use the DA.³⁷ The DA included education about CRC, screening options and risks for CRC, and explored how communication with the provider could aid in SDM. The results of the study were positive; they indicated both an increase to 90 % in patients' intent to discuss CRC screening with their providers (no p value reported) and an increased willingness to consider all three screening options—24 % increase for fecal occult blood test, 24 % increase for flexible sigmoidoscopy, 19.6 % increase in colonoscopy ($p < 0.001$).

Outcomes

The majority of studies showed improvement in the intervention vs. control arm in their reported outcomes (Table 2). Out of the seven studies that tested and reported on communication, six of them showed statistically significant improvement. There were eight studies that tested and reported on decision quality outcomes (e.g., decisional conflict), and six of those studies showed improvement in the quality of the decisions of their subjects. The most frequently reported outcome was on clinical decisions, with 15 studies reporting results. Eight of these studies showed significant changes in clinical decision behavior (e.g., screening test uptake).

To compare interventions that did and did not culturally tailor, we focused on the clinical decision outcome, which was the most frequently reported ($n = 15$). Six out of nine culturally tailored interventions reported significant changes in clinical decisions, while only two out of six non-tailored interventions reported significant changes.

DISCUSSION

In health policy circles, SDM has been promoted as a means of improving quality of care and was included as a provision within the Affordable Care Act to support the development and use of DAs.³⁸ In light of new policies, it is more important than ever to understand the evidence regarding the effectiveness of interventions designed to encourage SDM. Encouraging SDM is a primary component of DAs, which do have a robust evidence base that developed over the past several decades. One concern regarding DAs is that their impact on minority populations and health disparities has received almost no attention. In this systematic review, we conducted one of the first focused efforts to characterize the DA literature in minority populations. We found a small body of evidence (18 studies) illustrating the effectiveness of DAs in minority populations. Considering the broader DA literature, this suggests that only 14 % of DA trials (18/129) have had significant minority representation.¹⁴

Despite the small size of the existing evidence, we did find that the pattern of effectiveness of DAs in racial, ethnic, and sexual minority populations mirrors findings from the prior literature regarding DAs. In the studies included in this review, DAs consistently produced improved decision quality for patients and improved patient–doctor communication. A narrow majority of DAs moved treatment decisions. The confirmation that DAs can be effective tools within minority populations is an important finding that may have broader, positive implications for the alleviation of health disparities within racial, ethnic, sex and gender-based minorities.² In a sensitivity analysis, we also found that interventions that were culturally tailored appeared to have a larger impact on clinical decisions than those that did not tailor. This finding should be viewed cautiously, given the small sample of studies available.

While the overall findings are positive, the minority DA literature is extremely limited in terms of the range of study populations that have been evaluated. The populations that have been studied are primarily ethnic/racial minorities, with only one study focused on sexual minority (self-identified lesbian and bisexual) women and none in gender minorities. No studies focused on populations that are both racial and sexual minorities. Peek et al. conducted a systematic review of SDM at the intersection between African Americans and LGBT patients and found only three publications, so it is not surprising that this intersectionality does not exist in the DA literature.³⁹

Another important limitation of the literature is that the range of clinical topics in these interventions does not reflect the wide range of medical needs of minority populations. The vast majority of interventions we found focused on cancer screening. Historically, DAs have been limited to the study of single event decisions and have not focused on highly prevalent chronic conditions that require recurrent medical decisions.⁴⁰ DAs could be expanded into a diverse range of clinical topics that are relevant in the lives of minority patients.

For example, among sexual minorities and gender minorities there are a number of clinical topics that have a cloud of uncertainty and would benefit from an SDM approach. Pre-exposure prophylaxis (PrEP) is a new treatment that has great potential to lower the risk of HIV, but may have the burden of pill taking and unanticipated long-term side effects. The decision to use PrEP would benefit from understanding the preferences of individual patients. Another important area that may fit this paradigm are decisions to undergo gender-affirming surgeries or hormone therapies. Decisions regarding the medical and surgical options for gender transition should all be informed by patient preferences. DAs in these clinical areas might ensure that all relevant information regarding the risks and benefits of treatment options are fully considered and that the preferences of individual patients are registered by the clinician. Many of the studies we excluded were interventions designed to modify health behaviors without an SDM framework. Most of these studies did not offer patients an evaluation of the treatment options or elicit patient preference. For some medical situations (e.g., quarantine in the face of an infectious epidemic), the SDM model may not be appropriate. However, we believe that almost all decisions can be viewed through the lens of SDM and can be a way to improve treatment adherence.⁴¹

Another opportunity for promoting SDM for minority patients is to consider making changes in the clinical environment.⁴² The reality is that DAs cannot be designed for every micro-decision that occurs in the life of a patient and it may be potentially more important to create a culture of SDM. DeMeester and colleagues explore the drivers and mechanisms required to impact care; the model contains six drivers: workflows, health information technology, organizational structure and culture, resources and clinic environment, training and education, and incentives and disincentives. These drivers work through four mechanisms that can impact care: continuity and coordination, the ease of SDM, knowledge and skills, and attitudes and beliefs. It is possible that even the best designed DAs and clinical interventions will not affect change unless these drivers and mechanisms are evaluated and changed to accommodate minority populations.

This review of DAs in minority populations is limited in that our sample size was very small, and it is difficult to provide recommendations for specific sub-populations based upon our results. However, this limitation highlights one of our primary findings: that more DAs need to be studied in minority populations.

In conclusion, DAs in minority populations have been similarly efficacious as DAs in majority populations. However, there is currently a lack of research on DAs in racial, ethnic, sexual, and gender minority populations and a lack of diversity of tools and study participants within existing literature. The lack of DA research in minority populations parallels a general lack of SDM in actual clinical practice for minority patients.^{9,10,43,44} The need to expand DA research experiences within minority populations is now more important than ever,

given the recent adoption and promotion of SDM by policymakers. This will help to ensure that DAs are optimally designed for the language, culture, and medical needs of all minority patients.

Corresponding Author: Aviva G. Nathan, MPH; Section of General Internal Medicine, University of Chicago, 5841 S. Maryland Avenue, MC 2007, Chicago, IL 60637, USA (e-mail: anathan@bsd.uchicago.edu).

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