# Interventions to Improve Decision Making and Reduce Racial and Ethnic Disparities in the Management of Prostate Cancer: A Systematic Review

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**OBJECTIVES:** Ethnic minorities are disproportionately impacted by prostate cancer (PCa) and are at risk for not receiving informed decision making (IDM). We conducted a systematic literature review on interventions to improve: (1) IDM about PCa in screening-eligible minority men, and (2) quality of life (QOL) in minority PCa survivors.

**DATA SOURCES:** MeSH headings for PCa, ethnic minorities, and interventions were searched in MED-LINE, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, CINAHL, and PsycINFO.

**SUBJECT ELIGIBILITY CRITERIA:** We identified U.S.-based, English-language articles (1985–2010) on interventions to improve PCa IDM and QOL that included 50 % or more minority patients or analyses stratified by race/ethnicity.

**STUDY APPRAISAL AND SYNTHESIS METHODS:** Articles (n=19) were evaluated and scored for quality using a Downs and Black (DB) system. Interventions were organized by those enhancing 1) IDM about PCa screening and 2) improving QOL and symptom among PCa survivors. Outcomes were reported by intervention type (educational seminar, printed material, telephone-based, video and web-based).

**RESULTS:** Fourteen studies evaluated interventions for enhancing IDM about PCa screening and five evaluated programs to improve outcomes for PCa survivors. Knowledge scores were statistically significantly increased in 12 of 13 screening studies that measured knowledge, with ranges of effect varying across intervention types: educational programs (13 %–48 % increase), print (11 %–18 %), videotape/DVD (16 %), and web-based (7 %–20 %). In the final screening study, an intervention to improve decision-making about screening increased decisional self-efficacy by 9 %. Five cognitive-behavioral interventions improved QOL among minority men being treated for localized PCa through enhancing problem solving and coping skills.

**LIMITATIONS:** Weak study designs, small sample sizes, selection biases, and variation in follow-up intervals across studies.

**CONCLUSIONS:** Educational programs were the most effective intervention for improving knowledge among

screening-eligible minority men. Cognitive behavioral strategies improved QOL for minority men treated for localized PCa.

KEY WORDS: prostate cancer; interventions; informed decision making; disparities; African American.

J Gen Intern Med 27(8):1068–78 DOI: 10.1007/s11606-012-2086-5

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#### INTRODUCTION

Prostate cancer (PCa) is a major cause of morbidity and mortality for men in the United States. In 2010, an estimated 217,730 new cases were diagnosed and over 30,000 men died of prostate cancer. African American (AA) men have lower rates of early detection and increased mortality compared to non-Hispanic whites. These stark statistics led to increased PCa screening for all men with the introduction of serum prostate specific antigen (PSA) testing in the late 1980s. However, screening with PSA has been controversial since its introduction, due to uncertainty about the impact of PSA screening in reducing mortality, its non-specificity for PCa, and its inability to gauge PCa aggressiveness. Recommendations have shifted from encouraging PSA screening to discouraging it as the standard of care.

Over the past 25 years, shared decision making between patient and physician has been increasingly emphasized, especially for PCa. In 1992, the American Cancer Society recommended that all men ≥50 undergo PSA testing annually.<sup>5</sup> In contrast, in 1989, the United States Preventive Services Task Force (USPSTF) recommended routine PCa screening for men with a life expectancy >10 years and encouraged patients who requested screening to be given objective information about the benefits and harms of early detection and treatment.<sup>7</sup> Recently updated USPSTF guidelines now recommend against routine PSA screening in all age groups, giving it a grade D recommendation, and concluding with "moderate certainty" that the harms of PCa screening outweigh the benefits.<sup>6</sup> However, USPSTF guide-

lines do not directly address racial and ethnic disparities in PCa, possibly underestimating the lost benefits of discontinuing testing in high-risk ethnic groups, specifically in AA men.<sup>8,9</sup> Despite these shifting guidelines, the call for informed decision making (IDM) for all men, including ethnic minorities, has remained a constant.<sup>10</sup>

IDM is important for minorities, such as AA men, who are disproportionately affected by PCa. AA men are nearly 60 % more likely to be diagnosed with PCa and more than twice as likely to die from it compared to white men.<sup>11</sup> Physicians are less likely to discuss treatments with AA men compared to white men, 12 and cultural barriers may prevent AA men from seeking emotional support regarding their PCa. 13 This suboptimal communication can lead to increased decisional conflict, increased anxiety, and poorer quality of life (QOL). Tillman has argued that reducing racial-ethnic disparities should focus on instituting a wellcoordinated system of care that provides high quality interventions focused on culturally-sensitive shared decision making, defined by recognizing ethnicity and culture as a central structure of the intervention. 14 In addition, psychological interventions focusing on cancer-related stress and QOL could help narrow the racial disparities in PCa management. 15

To better understand what is known about the management of PCa for minorities, we conducted a systematic review of the literature summarizing interventions to improve informed decision making about PCa detection among screening-eligible minorities, and QOL among minority PCa survivors.

#### **METHODS**

We followed the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement.<sup>16</sup>

### **Initial Search**

We searched MEDLINE via Ovid using specific Medical Subject Heading (MeSH) terms. We combined MeSH terms referring to PCa, racial/ethnic minorities, and healthcare disparities. The specific terms included in the search strategy were: [(Prostatic neoplasms/prostate cancer or prostate specific antigen or psa or digital rectal examination or dre) AND [(Race or racial or minority or African Americans or Hispanic Americans or Asian Americans or Indians, North American or Continental Population Groups or African continental ancestry group or American native continental ancestry group or Asian continental ancestry group or oceanic ancestry group or brazil [United States] or Portugal [United States] or Arabs[United State, or Inuits)] OR [(Healthcare disparities or health status disparities, or minority health or health\*adj3disparit\* or underserved)]

AND [(Intervention or intervention studies or health interventions or health knowledge)] limited to English language, humans and adults. We conducted parallel searches in the Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and PsycInfo. We then combined search results from all databases and removed duplicate articles.

# Inclusion/Exclusion Criteria

We included studies on humans, in English language that were conducted in the US and published between 1985 and 2010. Articles had to include at least one ethnic minority group (overall patient population more than 50 % minority or, if less than 50 % minority, include specific analysis by race/ethnicity) and an IDM or QOL-affecting intervention taking place within an identified health care setting. Community-based interventions linked to a consistent source of health care delivery were included. The initial search yielded 2,815 articles (Fig. 1). In light of current recommendations, studies that assessed only screening behavior, without consideration of IDM or QOL, were excluded.

# **Article Selection (Figure 1)**

Two primary reviewers (SS, AK) independently evaluated each article for inclusion. Disagreements in articles selected were discussed between the reviewers, with input from a third reviewer (WD) as necessary for adjudication. Only articles that explicitly included interventions were selected for further review (n=76). From these articles, abstracts were blindly and independently reviewed by SS and AK; full articles were reviewed in the event of disagreements. "Pre-intervention" studies, in which interventions were being developed or tested only for feasibility, were excluded. Articles exclusively studying screening behavior (e.g. changes in PSA screening rates) without inclusion of some aspect of IDM or QOL as an outcome were removed (n=3). Following selection (n=12), each full article was independently evaluated by the primary reviewers. Review of references of these articles added 7 more studies to the total (n=19).

#### **Quality and Bias Assessment**

All papers were evaluated for methodological quality using the Downs and Black (DB) scoring algorithm (0 to 28), which allows assessment of articles across various study designs.<sup>17</sup> Methods are described in detail elsewhere.<sup>18</sup> In brief, DB scoring rates each study based on external validity, bias, confounding, and power. We also added one

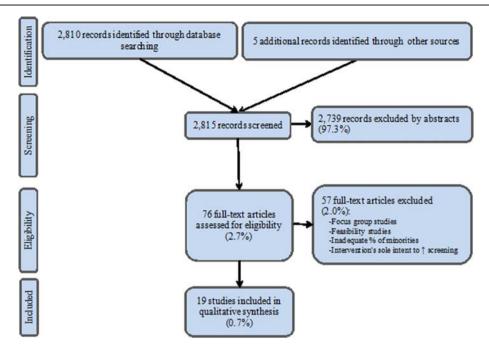


Figure 1. Flow diagram of the inclusion/exclusion of studies for review.

item from the Cochrane tool for bias<sup>19</sup> that was not captured with the DB tool, for a total maximum modified DB score of 29. DB score ranges were grouped for randomized studies into the following four quality levels: very good ( $\geq$ 20), good (15 to 19), fair (11 to 14) and poor (10 or less).<sup>20</sup> We did not assess for a risk of publication bias.

# Data Extraction and Synthesis (Tables 1, 2)

The results are organized slightly differently between the tables and text. To prevent multiple listing of studies, the tables are organized as follows. First, the 19 studies are divided into screening studies (Table 1) and PCa survivor studies (Table 2). Second, within each type of study, papers are grouped by intervention type: 1) educational program, 2) printed-material/booklets, 3) telephone/videotape/DVD, and 4) web-based. Some studies have multiple types of interventions, but they are listed in the area that is the dominant intervention. Third, the specific outcome measures (e.g.-knowledge and self-efficacy for IDM in screening-eligible men; QOL and symptom management self-efficacy among PCa survivors) are described in the "outcomes" column. To complete the tables, studies are compared based on study design, sample size, ethnicity of population, study duration, follow-up period, content of intervention, results, and Cochrane-modified DB quality score.

To report the findings in a way that is most clinically meaningful, the text is organized as follows.

First, as in the table, we discuss screening studies and survivorship studies separately. Second, we discuss outcomes associated with each type of study. For screening studies, we describe knowledge about PCa and screening self-efficacy. For survivorship studies, we report QOL and self-efficacy about symptom management. Third, we discuss the results, within each outcome, based on the intervention used (e.g. educational program or printed materials).

Finally, in order to compare results across different intervention types for the same outcome such as "knowledge", we calculated a "percent change" value for that outcome. That is, for studies that found statistically significant differences in that outcome across intervention groups, we calculated and reported a "percent change/difference" in the relevant score. While we cannot report p-values of significance for these percentages, they provide a range of values that can be considered for assessing the impact of interventions across studies for specific outcomes. The final set of articles varied significantly in outcome reporting, use of controls, and risk adjustment, so a meta-analysis was not possible.

# **RESULTS**

Overall, 14 of the 19 studies were of screening-eligible men being evaluated for IDM (Table 1), and the remaining 5 were on improving outcomes for PCa survivors (Table 2). The Cochrane-modified DB scores for studies varied across intervention types as follows: (1) educational seminar interventions, 19.3±SD 3.5; (2) printed material/booklet

Table 1. Interventions to Improve Informed Decision Making About Prostate Cancer Screening

Reference Design	Design	Sample Size (N), Ethnicity	Duration, Follow- up	Content*	Outcome(s)	Results	DB Score
EDUCATI Boehm et al. 1995 <sup>20</sup>	IONAL I Pre- test/ Post- test	EDUCATIONAL PROGRAM INTERVENTIONS Boehm Pre- N=123 Same day ES: E et al. test/ AA: 100 % PCa 1995 20 Post- knov	NTERVENT Same day	ES: Educational session using AA PCa survivors to teach PCa knowledge and self-efficacy. Focus group used for development of	<b>K:</b> 11-item scale (anatomy, physiology, PCa risks, benefits of early detction, methods of screening, signs of PCa).	<b>K:</b> 13 % PCa screening knowledge score increase pre vs. post (p<0.01) with mean test score improving from 8.7 to 10.1	19
Collins et al. 1997	Pre- test/ Post-	N=75 AA: 100 %	Same day	messures  ES: Pretest questionnaire, followed by an educational session, then a post-test questionnaire	K: 7-item PCa Knowledge Scale (Developed from American Cancer Society [1992] "For Men Only" Pamphlet)	<b>K:</b> 46 % increase in knowledge scores pre vs. post (21 % to 67 %, no CI or p-value provided)	41
Powell et al. 1997	Cohort	N=1,105 AA: 100 %	Same day	ES: Education and recruitment intervention for effective communication on PCa screening in	K: 11-item PCa knowledge inventory.	<b>K:</b> PCa knowledge score on 11-item questionnaire increased from 8.7 to 10.1 (p< 0.001)	41
Wilkinson et al. 2003	Ъ	N=900 AA: 100 %	Same day	ES: I hour culturally-sensitive education seminar with audiovisual materials to promote informed	K: 12-item PCa scale (PCa symptoms, incidence, screening beliefs, detection, treatment, mortality, side effects from treatment, foods, Responses:	<b>K:</b> 47 % increase in post-seminar PCa knowledge score over pre (26 %±17.7 % to 73 %±22.1 %, p <0.01)	19
Husaini et al. 2008 <sup>31</sup>	RCT	N=430 (At 3-mo follow up, N=350), AA: 100	Same day	E.S., V, PM: Culturally-tailored educational intervention, including a video, pamphlet, and Q&A sessions. Early (intervention) vs. late (control)	K. Chien P. Carloned Scale (True/false, 0-6 Score), O. Patient Physician P. Screening discussion (at 3 months)	K: No significant differences. O: Intervention group relatively more likely to talk to physician about PCa screening than control (OR=2.01, p<0.05)	25
Holt et al. 2009 <sup>25</sup>	RCT	N=49 AA: 100 %	Same day	ES, PM: Spiritual vs. Non-spiritual, educational IDM intervention—print materials and 1-hour class	K: 9-item scale (PCa risk factors and knowledge, previously validated scale), 4-item scale (knowledge of PSA controversy), Single-item (Awareness of if screening can prevent PCa mortality). SE-D: 2-item IDM about screening, 8-item screening barrier scale, 10-item preparation for decision-making scale	K: Relative increase in PCa knowledge in both groups over control: spiritual post-test M=2.15 (SD=1.75), p<0.05, non-spiritual post-test M= 1.82 (SD=1.08), p<0.05; <b>SE-D:</b> relatively increased decision making self-efficacy for PSA screening in spiritual group over control [mean=0.55 (SD=1.18) vs. mean=0.44 (SD=1.46); p<0.051	21
Carter et al. 2010	Pre- test/ Post- test	N=405 (At 3-mo follow-up, N=204), AA: 100	Same day, Follow- up at 3 months	ES: Educational session with focus groups, 13 modules focused on PCa knowledge, screening, treatment, empowerment, and health insurance	K: 15 item PCa scale (total score not reported).	K. Increase in PCa knowledge (by 85 %-total score change not available) in questions on PCa incidence, ethnic disparity, PSA and DRE use, sexual function side effects mortality, causes, and insurance over control (p<0.01, CI not provided)	17
Drake et al. 2010	Pre- test/ Post- test	N=73	Same day	ES: Education session on IDM SE-D, and control of decision process	K: 17-item PCa knowledge scale (validated, 0–100 % score), SE-D: 11-item Decision Self-Efficacy Scale (standardized scores of 0–100), D-C: 9-item validated decisional conflict scale, (standardized 0–100 score), O: Control Preference Scale	K: 25.7 % increase pre vs. post (p<0.01); SE-D: 8.9 point average relative increase (83.6 to 92.5, p = 0.025). D-C: no significant difference. O: men wanted to be more involved in screening decision making post-intervention compared to control (16.4 %, p<0.01)	20
Taylor et al. 2006	RCT	KINTED MATERIALS/BOOKLETS Taylor RCT N=238 Bas et al. AA: 100 % 11 2006 28	Baseline, 1 month, 1 year	V, PM: Videotape or booklet to inform men of PCa screening controversy. Three groups: video, booklet, and control	<ul> <li>K: 11 item scale from NCI Cancer Fact Sheet on PCa (Questions on symptoms, controversy risk factors, test limitations, and PCa treatment course.</li> <li>D-C: 10-item decisional conflict scale</li> </ul>	K: Print—11.8 % relative increase in total score compared to control [p<0.001], <b>D-C</b> : relatively reduced D-C in Print (OR=0.098, 95 % CI: 0.04–0.26) compared to control. Print more successful than Video (OR:0.21, CI: 0.09–0.52)	22

Table 1. (continued)

DB Score	25	25 h	18	- 22	19	21 n
Results	SE-D: Increased discussion rates in Cue handout (58 %; OR=2.39, CI=1.26–4.52) and PtEd handout (50.0 %; OR=1.92, CI=1.01–3.65) vs. control 37.3 %; patient-initiated discussion increased at 6 months (47.6 % PtEd: 40 % Cue, or 27.0 %).	K: 24-item scale based on previous work and content of decision aid. Knowledge improved with DA use in AA (17.5 to 20.6; p<0.001). <b>D-C:</b> Decision aid lowered decisional conflict (indirectly through improved knowledge).	K: 26.7 % increase in overall score in AA and whites pre vs. post [mean increase from 4.61 to 5.84 (p<0.01)]	K: Video—18.1 % increase in total score compared to control [p<0.001]; D=C: relatively reduced D-C in Video (OR=0.46, 95 % CI:0.21-0.99) compared to control. O: No difference in satisfaction about screening decision.	K: 3.8 point increase pre vs. post (47.7 to 51.5, p <0.01) with CAI intervention; D-C: No statistically significant results, O: No statistically significant differences.	K: 7.4 % relative increase (p<0.01) in knowledge score for enhanced web-based decision aid [mean=7.67, 63.9 % score (SE=0.25)] vs. usual care [mean=6, 78, 56.5 % score (SE=0.23)]
Outcome(s)	SE-D: Patient-Physician PCa Discussion	K: 24-item scale based on previous work and content of decision aid. D-C: Decsional Conflict Scale, 5 sub-scales—uncertainty, feeling uninformed, feeling unclear, feeling unsupported, quality of the decision.	<b>K:</b> questionnaire (unclear number of questions, on PCa knowledge, attitudes on screening. Responses: True/False or multiple choice. Max score 7)	K: 11 item scale from NCI Cancer Fact Sheet on PCa (Questions on symptoms, controversy risk factors, test limitations, and PCa treatment course.)  D-C: 10-item Decisional Conflict Scale; O: Satisfaction with decision	K: 21-item PCa knowledge scale (risk, racial disparities, treatment options, screening risks and benefits, intention), D-C: 16-item Decisional Conflict Scale (5 subscales—certainty, feeling informed, clear values, support, quality of decision), 11-item Screening Benefits, Risks, and Congruence Scale, O: Patient-Physician discussion of appropriate screening (validated 4-	item cognitive approach scale)  K: 12-item PCa screening scale (PCa symptoms, treatment side effects, screening age guidelines. Responses: true/false/don't know)
Content*	PM: Patients given 1) a neutral educational PCa handout (PtEd), 2) a simple handout encouraging PCa discussion (Cue), or 3) a control handout	PM: Patient given printed decision aid designed by CDC. Information on PCa, mortality from PCa, PCa screening risks and benefits, and importance of MD discussion	V: Videotape educational intervention stressing importance of PSA & DRE screenings, free screenings provided	V, PM: Videotape or booklet to inform men of PCa screening controversy. Three groups: video, booklet, and control	W: Computer assisted instructional (CAI) model to increase PCa knowledge and awareness. Focus groups for education provision	Same day W: Enhanced or usual care (control) neutral web-decision aids related to PCa screening
Duration, Content* Follow- up	6 months	Same day	Same Day	Baseline, 1 month, 1 year	Same day	Same day
Reference Design Sample Size (N), Ethnicity	N=250, AA: 90.4 %, White: 8.0 %, Other: 1.6 %	N=400; AA: Same day 50 %	TELEPHONE/VIDEOTAPE/DVD  Barber Pre- N=944, S  et al. test/ White: 1998 19 Post- 51.6 %, test AA: 43.6  7.0, Hisp:	N=238 AA: 100 %	N=43 AA: 100 %	N=87 AA: 100 %
Design	RCT	RCT	ONE/VID Pre- test/ Post- test	RCT	Pre- test/ Post- test	RCT
Reference	Kripalani et al. 2007 18	Stephens et al. 2008	TELEPHC Barber et al. 1998 19	Taylor et al. 2006	WEB-BASED Weston Pre et al. 2007 29 P. te	Ellison et al. 2008

\*Intervention type: ES=educational seminar, V=video or dvd, PM=print materials, T=telephone, W=web

"" Quality score is based on a 28 point scale combining the Downs and Black criteria and Cochrane bias criteria.

Abbreviations: PCa—Prostate Caneer, AA—African American, RCT—Randomized Controlled Trial, DRE—digital rectal examination, HS—high school, yr—year, QOL—quality of life, DM-decision making, Absolute change: measure over time within intervention group, Relative effect: measure at one time point vs. control. Outcomes: K—Knowledge, D-C—Decisional Conflict, SE-D=Self-Efficacy for Decision Making, SE-S—Self-Efficacy for Symptom Management, QOL—Quality of Life, O - Other

Table 2. Interventions to Improve Outcomes for Prostate Cancer Survivors

Reference Design	Design	Sample Size (N), Ethnicity	Duration, Follow-up	Intervention Content*	Outcome(s)	Results	DB Score
EDUCATION Penedo et al. 2004 34	ONAL I	EDUCATIONAL INTERVENTIONS Penedo RCT N=92, Non- 10 w et al. Hispanic white: 35 %, Hispanic: 35 %,	ONS 10 weeks	ES: Random assignment to either 10-week cognitive behavioral stress management (CBSM) or 1 day seminar (control)	QOL: 27 item Functional Assessment of Cancer Therapy—General (FACT-G) Scale (4 domains—physical, social, emotional, functional, 5 pt Likert scale, validated, Max score 135), 17 item Measure of Current Status	QOL: 3 point post-intervention increase in FACT-G (87.3 to 90.5, p<0.01); 3.7 point increase in stress-management skills in intervention group compared to control (63.3 to 67.0, p<0.01)	23
Penedo et al. 2007 <sup>44</sup>	RCT	22 % N=71, Hispanic: 100 %	10 weeks	ES: Random assignment to either a 10-week cognitive behavioral stress management (CBSM) with psychosocial batteries, workbooks or a seminar (control)	(MOCS) Scale (Stress-management skill) (QOL: 27 item Functional Assessment of Cancer Therapy—General (FACT-G) Scale (4 domains—physical, social, emotional, functional, 5 pt Likert scale, validated, Max score 135; Expanded Prostate Cancer Index Composite (EPIC) 3-item sexual function subscale (0–12),	QOL: CBSM group with absolute increases in total well-being $(\beta=-0.23, p<0.01)$ ; physical well-being $(\beta=0.408, p<0.01)$ ; emotional well-being $(\beta=-2.44, p<0.03)$ ; sexual functioning $(\beta=-0.014, p=0.05)$ compared	24
TELEPHO Mishel et al. 37 2002 37	RCT RCT	TELEPHONE/DVD/VIDEOTAPE INTERVENTIONS  Mishel RCT N=239, AA: 8 weeks, T: Nurse- et al. 44 %, Follow up interven 2002 37 White: at 4 symptor 56 % months men wit and 7 surgery months patient control.	E INTERVE  8 weeks, Follow up at 4 months and 7 months	T: Nurse-delivered psychoeducational intervention to improve uncertainty and symptom control by weekly phone calls to men with localized PCa shortly after surgery or radiation therapy. Three groups: patient alone, patient and family, and control.	K: 21-item Cancer Knowledge Scale (True/False), SE-S: 26-item Uncertainty in Illness Scale (validated, 1–5 Likert scale), 10-item problem solving scale (define concerns and generate solutions, 1–10 scale), 9-item Cognitive reframing (view concerns as manageable, 1–10 scale) 15-item Symptom Distress Scale (total symptoms and intensity of symptoms on 1–5 scale), O: 5-item Patient-Provider communication scale (Degree of communication with provider, 1–5 scale)	K: No change. SE-S: Uncertainty—relatively improved management in intervention groups (p=0.01), Problem solving—relatively improved at 4 month in intervention (p<0.05); Cognitive reframing -relatively improved in intervention group at 4 month (P=0.009). Symptom distress: relative decrease in overall symptoms reported at 8 weeks (p=0.05), but no difference at 4 months or 7 months; improved incontinence (p<0.03); improved sexual satisfaction at 4 months (P<0.02) for AA intervention compared to AA control. O:	20
Campbell et al. 2007 35	RCT	N=40; A=100%	6 weeks	T: Telephone-based sessions of coping skills training (CST) for AA PCa survivors and spouses	QOL: 50-item Expanded Prostate Cancer Index (EPIC) Scale (4 symptom domains—urinary, bowel, sexual, hormonal). Domain scores on 1–100 scale), Short Form—36 (SF-36) Health Survey general health scale. SE-S: Self-efficacy for Symptom Control Inventory (3 sub-scales: symptom management, physical function, coping)	No change. <b>QOL:</b> EPIC Scale—compared to control, relatively improved QOL related bowel symptoms [p<0.05], hormonal symptoms [p<0.05] (relative effect); SF-36 Scale—no statistically significant differences. <b>SE-S:</b> improved physical function self-efficacy compared with control	23
Mishel et al. 2009 <sup>38</sup>	RCT	N=256; AA:28.5%, White:71.5r %	8 weeks, Follow up at 4 month and 7 months	V, T, PM: Decision-making uncertainty management intervention (DMUMI) for early stage PCa patients, with DVDs, telephone calls, and booklets. Three intervention groups; direct (TD), supplemental (TS), and control.	K: 20-item Cancer Knowledge Scale. SE-S: 10-item problem solving scale; 35-item Profile of Mood States, short form. O: 5-item Patient-Provider Communication Scale; Medical Communication Competence Scale; 3-item Decisional Regret Scale.	[p<0.05], no other differences. <b>K:</b> Improved at 1 months (p=0.001). At 3 mo: 3.5 % improvement in TD vs. control and 4.0 % improvement in TS vs. control. <b>SE-S:</b> improved at 3 months (p=0.05). <b>O:</b> Communication competence improved in TD and TS vs. control@ 3 months (p=0.01).	20

\*Intervention Type: ES= educational seminar, V= video or dvd, PM= print materials, T= telephone, W= web

\*\* Quality score is based on a 28 point scale combining the Downs and Black criteria and Cochrane bias criteria. Abbreviations: PCa—Prostate Cancer, pp—percentage point, A4—African American, RCT—
\*\* Quality of life, DM-decision making, IDM—Informed Decision Making, A8—African American, RCT—
Randomized Controlled Trial, DRE—digital rectal examination, HS—high school, yr—year, QOL—quality of life, DM-decisional Making, IDM—Informed Decision Making, SE-S—Self-Efficacy for Symptom Management, Sc—PSA Screening, QOL—Quality of Life, O—Other

interventions,  $22.6\pm SD$  1.9; (3) telephone-based interventions,  $21.0\pm SD$  1.7; (4) video-tape/DVD interventions,  $20.3\pm SD$  1.7; and (5) web-based interventions,  $20.0\pm SD$  1.4, consistent with "good" to "very good" scores.

# Interventions to Enhance Informed Decision Making for Prostate Cancer Screening (Table 1)

**Prostate Cancer Knowledge (n=13 Across Intervention Types).** Of the 14 studies of PCa screening, 13 assessed knowledge changes, most using same day assessments. An additional screening study did not evaluate changes in knowledge at all and is described in the next section. PCa knowledge scores increased in 12 studies 19–30 and did not change in 1. Five were RCTs, 24,25,27,28,31 7 were pre-/post-test studies, 19–23,29,30 and 1 a cohort study. Eight assessed the effects of educational programs, 20–23,25,26,30,31 2 printed materials/booklets, 27,28 1 a videotape/DVD, 19 and 2 web-based interventions. Overall, AA men represented 84 % of the study population across the studies.

Educational Programs (n=8). PCa knowledge increased in 7 of these studies. Educational programs included combinations of lectures provided by trained experts, primarily people in the community trained by specialists, and/or didactic seminars. Regardless of the source for the questions asked, men were typically provided a basic understanding of PCa risk factors, and they were explained the risk, benefits and limitations of available screening and treatment modalities.

Two RCTs tested educational programs. Holt et al built on prior work with AA women (in which a spirituality-based approach was used to encourage mammography), randomly assigning one of two interventions at the church level, one "spiritual" and one "non-spiritual", then measuring change in knowledge between baseline and immediately after.<sup>25</sup> PCa knowledge increased 21 % (from 71 % to 92 %) in the spiritual arm, and increased 26 % (from 72 % to 98 %) in the non-spiritual arm. In the second RCT, "early" and "delayed" intervention groups received a culturally-tailored, multipart intervention including a videotape, printed pamphlet, and question answering session.<sup>31</sup> The "early" intervention group attended an educational seminar at baseline, while the "delayed" intervention group attended the seminar at 3 months. The "early" intervention showed no difference from the "delayed" intervention on PCa knowledge at 3 months.

The remaining studies were pre-/post-assessments or cohort studies. Drake et al. designed an intervention based on the Ottawa Decision Support Framework and Health Belief Model.<sup>23</sup> Knowledge increased on a 0-100 scale by 25.7 points (p<0.001).<sup>23</sup> Collins et al. found that, following a one-on-one counseling intervention, PCa knowledge increased by 41 % from pre- to post-test, from 23 to 64 %

correct. Boehm et al. assessed the impact of an education session with AA speakers, one of whom was a physician and one a PCa survivor on PCa knowledge.<sup>20</sup> Knowledge increased by 13 %, from 8.7 to 10.1 (p< 0.001). Wilkinson et al. assessed a one-hour seminar using a 12-item questionnaire assessing knowledge of PCa, and found that knowledge increased by 47 %, (26 % to 73 %, p<0.0001).<sup>30</sup> Powell et al. utilized an educational program with an outreach coordinator; an 11-item knowledge inventory score increased from 8.7 to 10.1 (p<0.0005), a 13 % increase.<sup>32</sup> Carter et al assessed a 13-module intervention taught by trained men to AA men; knowledge was statistically-significantly higher in 13 of 17 areas, but percentage increases are not calculable.<sup>21</sup>

**Printed Materials/Booklets (n=2).** Taylor et al. conducted a 3-arm RCT comparing 1) a booklet intervention, 2) a videotape intervention, and 3) control.<sup>28</sup> The primary outcome was PCa knowledge differences, measured using an 11-item scale developed from the NCI Cancer Facts Sheet on PCa testing. PCa knowledge scores in the booklet arm increased from 7.2 to 9.2 (p<0.0001), an increase of 18 % in the proportion correct (from 66 % to 84 %). Similarly, in the videotape arm, knowledge scores increased relative to the control arm from 7.2 to 8.5 (p<0.0001), an 11 % improvement in the proportion correct (from 66 % to 77 %). Stephens et al. used an RCT to assess a printed decision aid for PCa screening.<sup>27</sup> On a 24-item PCa knowledge scale, scores for AA increased from 17.5 to 20.6 (p<0.001), an increase of 13 % in the proportion correct (from 73 % to 86 %), with unchanged scores in the control arm (17.0 pre-test vs. 17.5 post-test; p-value "not significant").<sup>27</sup>

*Telephone/Videotape/DVD Interventions (n=1).* Barber et al. reported results from their existing PCa Early Detection Program surveying knowledge and attitudes about PCa before and after the program was implemented. <sup>19</sup> Knowledge scores for the group increased from 4.6 to 5.8, p<0.01), a 16 % increase in the proportion correct (from 66 % to 83 %).

Web-based Interventions (n=2). Weston et al. evaluated a computer-assisted intervention by measuring pre-/post-test knowledge using an 18-item questionnaire from the National Cancer Institute (2002).<sup>29</sup> PCa knowledge scores increased from 11.2 to 14.8 (p<0.001), a 20 % increase in the proportion correct (from 62 % to 82 %). Ellison et al. conducted an RCT of a web-based decision aid and measured knowledge with a validated 12-item PCa knowledge test.<sup>24</sup> PCa knowledge scores were 6.78 for the usual care group and 7.67 for the decision aid group, a difference of 7.4 % (p=0.0017).

Self-efficacy for Decision Making (n=3). Of the 14 studies of PCa screening, there were 2 papers assessing changes in

self-efficacy for decision making in addition to knowledge changes, <sup>23,25</sup> all using educational interventions. There was an additional study that evaluated self-efficacy for decision making alone. <sup>18</sup>

Educational Programs (n=2). Drake et al. created a theory-driven "road map" educational intervention for improving comfort, control and knowledge for PCa screening, and assessed outcomes immediately after.<sup>23</sup> It was assessed with an 11-item decision self-efficacy scale, with scores ranging from 0 to 100. The self-efficacy score increased from 84 to 93 (p=0.025), a 9 % overall increase. Holt investigated a spirituality-based intervention (as described above) and found that self-efficacy for IDM significantly increased (mean=0.55 in the intervention arm versus mean=0.44 in the control arm; p<0.05).<sup>25</sup>

**Printed Materials/Booklets** (*n*=1). Kripalani et al. investigated the likelihood of a discussion about PCa in screening-eligible men, 90 % of whom were AA. <sup>18</sup> Patients were randomized to receive a patient education handout, a "cue" handout to ask about PCa, or a generic handout (control), and the likelihood of a discussion with the physician was recorded. Compared with the control group's likelihood of a conversation (37.3 %), the "cue" handout increased the likelihood the most (58.0 %; OR: 2.39[1.26–4.52]), but the education handout also significantly increased the likelihood (50.0 %; OR: 1.92[1.01–3.65]).

# Interventions to Improve Outcomes for Prostate Cancer Survivors

**Quality of Life (QOL) (n=3).** The interventions designed to improve QOL in minority cancer survivors all showed statistically significant improvements.  $^{33-35}$ 

Educational Programs (n=2). Two studies, both by Penedo et al., focused on Hispanic men following treatment for localized PCa. 21,22 One study captured a racially/ethnically diverse group (34 % Hispanic, 22 % AA, 35 % white), <sup>33</sup> and the other was conducted in Hispanic men only.<sup>34</sup> In both, a 10-week Cognitive-Behavioral Stress Management course<sup>36</sup> was compared to a 1 day seminar with a control condition. QOL was measured using the 27item Functional Assessment of Cancer Therapy-General (FACT-G) Scale, assessing QOL across 4 domains (physical, social/family, emotional and functional). In the mixed ethnicity study, the intervention significantly improved mean QOL in the intervention group (87.31± 12.41 vs.  $90.48\pm11.27$ ; p<0.01), but not in the control group  $(89.37\pm14.30 \text{ vs. } 88.65\pm13.19; \text{ p}>0.10)$  In the Hispanic-only study, several domains of QOL improved including: total QOL (82.35±14.02 vs.87.22±13.21; p=

0.05); physical well-being (23.98 $\pm$ 4.51 vs. 25.51 $\pm$ 3.80; p= 0.002); emotional well-being (19.24 $\pm$ 4.04 vs. 20.73 $\pm$ 3.31; p=0.04); and sexual functioning (5.61 $\pm$ 6.35 vs. 7.78 $\pm$ 6.79; p=0.002).

Telephone/Videotape/DVD Interventions (n=1). In a third QOL study, Campbell et al. conducted an RCT of a telephone-based coping skills intervention and evaluated QOL in AA men and their partners.<sup>35</sup> QOL was measured using the SF-36 for general QOL and a disease-specific symptom assessment, the Expanded Prostate Cancer Index Composite (EPIC). The intervention group scored higher than the control group on the SF-36 on the Mental Health sub-scale (24.8 vs. 25.2; p<0.08) but not on the Physical Health sub-scale (27.5 vs. 26.1; p=0.34). At 6 weeks, patients reported improved QOL related to bowel symptoms (p<0.05) and hormonal symptoms (p<0.05) on the EPIC. However, the overall SF-36 scale showed no significant change.

**Symptom Management Self-efficacy (n=2).** Mishel et al. conducted two related RCTs assessing symptom management in both AA and white men, focused on improving self-efficacy for symptom management in men receiving treatment for localized PCa using a DVD/booklet/telephone intervention.<sup>37,38</sup>

*Telephone/Videotape/DVD Interventions (n=2).* The effect of an "uncertainty management" invention on symptom control, using weekly telephone conversations with nurses for 8 weeks, was assessed at baseline, 3 months, and 7 months.<sup>37</sup> A 26-item, "Uncertainty in Illness" scale measured emotional distress in AA men with localized PCa. In the intervention arm, they found improvement for managing uncertainty using problem solving (8.02±1.28 vs.  $8.32\pm1.28$ ; p<0.05) and cognitive reframing  $(7.70\pm1.37)$ vs.  $8.20\pm1.37$ ; p<0.005) at 4 months, but no additional improvement at 7 months. In a second study also led by Michel, the authors used a similar uncertainty management intervention to assess self-efficacy for PCa and treatmentrelated symptoms.<sup>38</sup> The intervention improved problemsolving ability (p=0.05). This effect persisted at 1 month, but disappeared at 3 months. No other differences were found.

### **DISCUSSION**

The majority of interventions for ethnic/racial minority men, including both screening-eligible and treatment populations, improved some aspect of IDM or QOL for PCa. We draw the following conclusions from the studies: First, all but one relevant intervention for screening-eligible ethnic minority men increased PCa knowledge. Second, all relevant interventions improved self-efficacy for decision making about screening or symptom manage-

ment. Third, educational programs showed the greatest percentage increase in knowledge across studies. Fourth, all culturally-sensitive psychosocial interventions in ethnic minorities successfully improved post-PCa treatment QOL and symptom management, at least in the short term. However, the overall magnitude of effect of one intervention compared with another was difficult to ascertain because of differences in interventions, differences in outcome measures, variations in patient populations and variations in study design, study duration, and analytical methods.

As hypothesized, shared decision making programs in ethnic minorities significantly increased PCa knowledge, at least in the short term. Interventions to improve knowledge about PCa in predominantly white, low-risk populations decrease PSA testing. 39-42 It is unclear what effect knowledge interventions have on rates of PSA testing in minority populations. Educational materials in multiple formats—including educational programs, printed materials, telephone, DVD and web-based presentations—all facilitate IDM. Educational programs had the largest increases in PCa knowledge scores compared with printed materials/booklets, telephone/videotape/ DVD, and web-based interventions. Only one study reported the effect of specific, competing interventions on PCa knowledge; printed materials were shown to be slightly more effective than videotapes for improving and retaining PCa knowledge at 1 month.<sup>28</sup> Studies generally assessed changes in PCa knowledge on the same day the intervention ended. Long term effects of interventions in screening-eligible populations are unknown.

Only 5 studies tested interventions to improve PCa treatments to reduce disparities. This lack of research is a major concern, particularly with a likely future decrease in PCa screening rates and a renewed emphasis on treatment only for symptomatic PCa. In the studies we identified, all culturally-sensitive cognitive behavioral interventions targeting treatment-related complications in ethnic minorities improved QOL. Most men treated for PCa survive many years and suffer from treatment-related complications. 43 Managing the disease and its treatments long-term is even more crucial for ethnic minorities as they are less likely to discuss treatment-related complications with their physicians, 44 potentially leading to poorer QOL outcomes following treatment for PCa. 33-35 In addition, ethnic minority men, who are more likely to be in lower socioeconomic categories, typically have worse OOL outcomes and longer recovery periods from PCa treatments. For instance, Litwin et al. found that compared with whites, non-whites were much less likely to return to pretreatment level of physical (55 % vs. 90 %) and social (72 % vs. 91 %) functioning 1 year post-prostatectomy. 45 In advanced PCa, men in underserved populations had faster QOL declines on SF-36 scores. 46 Given the high prevalence of PCa in these men, it is critical to develop interventions that improve their QOL related to treatment.<sup>47</sup>

#### **LIMITATIONS**

Our review has several limitations. For historical reasons, most interventions were targeted to increasing PSA screening rates, which was an accepted goal during the time of most of these studies. However, we focused on the impact on IDM, which remains the central tenant of PCa management. Further, we did not assess for a risk of publication bias. A meta-analysis of the studies was not feasible given the lack of consistency in interventions, variability in follow-up intervals and outcomes across studies. Analysis of which intervention yielded the most improvement in PCa knowledge score is hampered by use of different knowledge scales across studies, lack of validity of several PCa knowledge scales, variability in study quality as assessed by Cochrane-modified DB scores, variation in the type of PCa knowledge provided within specific interventions, and lack of information on the effect of individual components of multi-faceted interventions on a specific outcome. Also, almost all of the studies assessed these outcomes on the same day as the interventions, and it is not clear that such knowledge would be retained after longer periods of time.

# CONCLUSIONS

Overall, despite the increased risk of high-risk PCa in minority men, we found disappointingly few articles in the last 25 years on interventions to reduce those disparities. While screening for PCa has fallen out of favor, the core management strategy for PCa remains IDM. Appropriate interventions have consistently improved knowledge, increased self-efficacy, and raised QOL—all core components of IDM. Educational programs were the most effective intervention for improving knowledge among screening-eligible minority men. Cognitive behavioral strategies improved QOL for minority men treated for localized PCa. Going forward, it is essential that we create a much stronger evidence base for the use of such interventions to improve IDM across the clinical spectrum for PCa. 49

**Funding Source:** Support for this publication was provided by a grant from the Robert Wood Johnson Foundation's Finding Answers: Disparities Research for Change program.

**Prior Presentation:** Poster presented at Presidential Poster Session, American Geriatrics Society, Annual Meeting, 2011.

**Conflict of Interest:** The authors declare that they do not have a conflict of interest.

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