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ARTICLE

# What men want: Results from a national survey on decision making for prostate cancer treatment and research participation

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## Abstract

Data comparing outcomes in prostate cancer and factors affecting treatment choice are sparse. To inform the design of a comparative effectiveness clinical trial, we engaged patients in developing a 28-question survey about decision making on treatment and research participation and dispersed it among men greater than or equal to 50 years of age. The 1046 respondents ranked long-term clinical outcomes as most important in making treatment decisions, specific functional outcomes as slightly less important, and duration, location, and cost of treatment as least important. Treatment choice was strongly impacted by side effect profile. Responses to whether the subject would agree to participation in a randomized trial between two types of radiation with minimal differences in outcomes were "yes" in 15%, "no" in 39%, and "undecided" in 46%. Responses to whether the subject would agree to participation in a randomized trial between two treatment durations with similar outcomes were yes in 36%, no in 24%, and undecided in 40%. Findings suggest many potential patients have strong treatment preferences and are averse to randomization, particularly when outcomes of importance may be affected. Patient engagement in study design and novel nonrandomized trial designs may offer a path to increase clinical trial success.

## Study Highlights

### WHAT IS THE CURRENT KNOWLEDGE ON THE TOPIC?

For the past 3 decades, there has been increasing emphasis on evidence-based decision making,[1–3] yet, there remains a paucity of comparative effectiveness data on which to base treatment decisions with localized prostate cancer.

### WHAT QUESTION DID THIS STUDY ADDRESS?

We engaged patients with prostate cancer and advocates in developing a national survey to ask men about preferences and priorities in decision making related to both treatment and participation in clinical trials for prostate cancer.

### WHAT DOES THIS STUDY ADD TO OUR KNOWLEDGE?

Our survey suggests that men will be more concerned with long-term outcomes—specifically survival, quality of life, freedom from disease recurrence, and remaining active and specific functional outcomes—than with short-term inconvenience, such

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as treatment cost, duration, or even location, when making prostate cancer treatment decisions and many men will be averse to trials randomizing between treatment options that may affect important outcomes.

**HOW MIGHT THIS CHANGE CLINICAL PHARMACOLOGY OR TRANSLATIONAL SCIENCE?**

These data have implications for research trial design, successful recruitment, clinical care, and insurance coverage.

## INTRODUCTION

Prostate cancer is the most common malignancy and is anticipated to be the second leading cause of cancer-related death for men living in the United States in 2021.[4] As a result of early detection through prostate-specific antigen screening and therapeutic advances, most patients are diagnosed with localized disease and have choices among various types of surgery and radiation therapy. For the past 3 decades, there has been increasing emphasis on evidence-based decision making,[1–3] yet, there remains a paucity of comparative effectiveness data on which to base treatment decisions for localized prostate cancer. There appears to be little difference in survival among the localized treatment options but significant differences in side effect profiles and cost; thus, decision making regarding treatment can be difficult for patients with prostate cancer and insurers.[5] Although the recent ProtecT trial has shed light on differences in side effect profiles between surgery and radiation,[6,7] there is a paucity of information comparing side effect profiles between different forms of radiation therapy, the treatment chosen by many men under 65 years old, most men over 65, and most men with high-risk disease.[8] Proton therapy is a type of radiation therapy that is gaining popularity but has generated some controversy. It has been utilized for the treatment of prostate cancer for over 30 years,[9] but, until recently, there were few facilities providing it and, to date, it represents only 1%–2% of radiation therapy treatments across the United States.[10] Compared with conventional photon-based radiation, proton therapy offers the theoretic benefit of placing a higher proportion of the radiation dose in the targeted cancer, rather than in nontargeted tissues, and has been shown to yield excellent outcomes including potential improvements in bowel frequency and urgency,[11] urinary irritative symptoms,[12] and the risk of secondary malignancies[10] compared with conventional photon-based radiation. However, proton therapy is more expensive than alternative radiation approaches and there is no level I evidence confirming improved outcomes. Although many patients self-refer for proton therapy, some commercial insurance companies do not approve proton therapy citing the lack of level I evidence from randomized clinical trials (RCTs) and their policies to cover only the least costly alternative. There is a potential for conflicts of interest both in coverage decisions on the part of insurance companies and treatment recommendations from for-profit radiation treatment facilities. Clearly, a comparative effectiveness trial is needed to provide patients with high-level evidence on which to base decisions.

Comparative clinical trials provide high-level, granular data that would aid in decision making, but low participation rates among adults in the United States have often resulted in premature trial closure or prolonged accrual and delayed, potentially nonrelevant results. The reasons for low trial participation are multifactorial, but include trial availability, eligibility requirements, insurance coverage, and patient refusal.[13] Some thought leaders have expressed concerns with the ethics and feasibility of RCTs comparing proton therapy with photon-based radiation.[14,15] In preparation for the now ongoing COMPPARE trial (ClinTrial.gov NCT 03561220), a prospective comparative study of outcomes of proton and photon irradiation in prostate cancer sponsored by the Patient Centered Outcomes Research Institute (PCORI), we engaged patients with prostate cancer and advocates in developing a national survey to ask men at risk for prostate cancer about preferences and priorities in decision making related to both treatment and participation in clinical trials for prostate cancer. Our goal was to learn what specific outcomes were of most importance to men, and thus should be compared, and whether recruitment to an RCT would be feasible. The survey also explored potential patient interest in filling an additional evidence gap of whether proton therapy can be delivered as safely and effectively in a shorter, more convenient, and less expensive treatment course.

We describe the results of this survey below and discuss its implications for clinical trial design.

## METHODS

From March through November of 2014, under institutional review board approval, a team comprised of radiation oncology prostate cancer specialists, investigators, and a cancer psychologist used a stepwise engagement approach to develop a 28-item survey on patient preferences and decision making

for prostate cancer treatment.[16,17] First, opinions were gathered from experienced prostate cancer physicians on factors their patients identified as being important in treatment decision making. Second, prostate cancer physicians at our institution identified prostate cancer survivors who provided recorded interviews with a health outcomes researcher on factors affecting their treatment choices (UFJ-2014-63) and a four-question open-ended survey was distributed to prostate cancer survivors returning for follow-up (UFJ2014-62). Third, a group of patient stakeholders comprised of prostate cancer survivors treated with surgery, conventional radiation therapy, or proton therapy, and prostate cancer advocates was created to review the qualitative data from interviews and expert opinions and to recommend questions for a national survey. The resulting 28-question survey covering both treatment decision making and research participation decision making was tested with the patient stakeholders and providers. With institutional review board approval (UFJ-2014-115 and UFJ 2014-150), the anonymous survey was distributed in three ways: (1) nationally through the cloud-based software Survey Monkey (San Mateo, CA) from July through November of 2014, which targeted responses from American men between 50 and 99 years old, (2) as a weblink on fliers placed in local clinics, and (3) as paper surveys distributed to two focus groups on September 26 and 30, 2014. The two focus groups were comprised of patients randomly selected from a large local safety net hospital using zip codes from economically challenged parts of the city. Simple explanations of the survey and basic concepts of randomization and ranking were given to the participants, and they were provided with refreshments and a $20 gift certificate. The purpose of the focus groups was to gather responses from minority and underinsured patients who might be less likely to be represented through an online survey. Because of concern that prostate cancer treatment outcomes, treatment preferences, and clinical trial participation rates might differ for certain minority groups, the survey asked respondents to self-identify ethnicity as Hispanic or non-Hispanic and race as one of four options: White or Caucasian, Black or African American, Asian, American Indian or Alaskan native, or Other.

Instructions explained that the survey was about individual preferences for prostate cancer treatment and research participation. The survey included 19 demographic and medical history questions, five decision making questions regarding treatment, and four decision making questions regarding research participation (Supplementary Material S1). See Table 1 for respondent demographics and prostate cancer history.

The five questions regarding treatment decisions asked respondents to rate the importance of several outcomes (such as survival, recurrence, disease symptoms, and treatment side effects) and parameters of convenience (such as cost, logistics, and treatment duration) in choosing a prostate cancer treatment. Responses were structured with a Likert scale (17 factors), relative ranking (8 factors), and discrete choices (2 questions with 2 options each). The first question included only a brief written description of treatment choices and minimal likely outcome information. The second question included the same two treatment choices but provided expanded side-effect profile information and explanatory radiation dose-distribution images (Figure 1). Additionally, respondents were asked to rate the expected relative life impact of seven different prostate cancer treatment-related symptoms with a 10-point scale (0, no bother; 10, worst possible bother). See Table 2 for each symptom and its rating.

The four questions regarding research participation asked respondents about their willingness to participate in a clinical research trial. Possible responses were "yes," "no," "maybe," and "I don't know"; for the purpose of analysis, the latter two responses were combined and treated as "undecided." After providing a lay definition of randomization and randomized trials, the first three questions asked respondents if they would (1) participate in a randomized study under any circumstances, (2) participate in a study that randomized two different types of radiation therapy, and (3) participate in a study that randomized two different radiation therapy treatment lengths (20 vs. 40 treatments) likely to produce the same outcome. The second research-related question was asked twice: first with a simple narrative description of the treatment arms and minimal information on likely outcomes and then with an expanded side effect profile, supplemental explanatory radiation dose-distribution images (Figure 1), and a more extensive description of side effects. The hypothetical radiation treatment options were consistent with standard conventional photon-based radiation therapy identified only as treatment A and proton therapy identified only as treatment B.

SAS and JMP software were used for statistical analyses (SAS Institute). The likelihood ratio $\chi^1$ test statistic assessed binary outcome differences in contingency tables. A different $\chi^2$ test statistic, the Cochran-Mantel-Haenszel row mean score, was utilized to assess shifts in Likert scores and rankings between strata of selected prognostic factors. The row mean score test statistic is optimal for ranked outcomes with multiple levels; a significant $p$ value indicates that the proportion of patients with generally more favorable scores is higher in one group relative to another. Not all patients provided responses to all questions. The tables include the number of respondents who did not answer specific questions; denominators for tabulation, and statistical analyses of specific responses included only respondents providing a response. Raw data and analyses for Tables 2 and 3 are shown in the first worksheet of Supplementary Material S2.

## RESULTS

A total of 1046 surveys were completed, including 93 on paper from the local focus groups. Respondents self-identified

**TABLE 1** Demographics and self-health rating

| Demographics | All respondents *N* = 1046 | Black respondents *n* = 37 (4%) | History of prostate cancer *n* = 160 (15%) | History of radiation therapy treatment *n* = 108 (10%) | Online survey completion *n* = 953 (91%) | Paper survey completion *n* = 93 (9%) |
|---|---|---|---|---|---|---|
| Age | | | | | | |
| <60 years | 386 (37%) | 19 (51%) | 19 (12%) | 9 (8%) | 373 (39%) | 13 (14%) |
| 60+ years | 628 (60%) | 16 (43%) | 137 (86%) | 97 (90%) | 553 (58%) | 75 (81%) |
| Missing | 32 (3%) | 2 (5%) | 4 (3%) | 2 (2%) | 27 (3%) | 5 (5%) |
| Ethnicity | | | | | | |
| Hispanic | 27 (3%) | 2 (5%) | 0 (0%) | 97 (90%) | 25 (3%) | 2 (2%) |
| Non-Hispanic | 951 (91%) | 27 (73%) | 142 (89%) | 11 (10%) | 869 (91%) | 82 (88%) |
| Missing | 68 (7%) | 8 (22%) | 18 (11%) | 0 (0%) | 59 (6%) | 9 (10%) |
| Race | | | | | | |
| White or Caucasian | 936 (89%) | 0 (0%) | 143 (89%) | 96 (89%) | 863 (91%) | 73 (78%) |
| Black or African American | 37 (4%) | 37 (100%) | 7 (4%) | 5 (5%) | 24 (3%) | 13 (14%) |
| Asian | 17 (2%) | 0 (0%) | 1 (1%) | 1 (1%) | 14 (1%) | 3 (3%) |
| American Indian or Alaskan Native | 8 (1%) | 0 (0%) | 2 (1%) | 2 (2%) | 6 (1%) | 2 (2%) |
| Other | 40 (4%) | 0 (0%) | 6 (4%) | 4 (4%) | 38 (4%) | 2 (2%) |
| Missing | 8 (1%) | 0 (0%) | 1 (1%) | 0 (0%) | 8 (1%) | 0 (0%) |
| Occupational status | | | | | | |
| Employed | 525 (50%) | 26 (70%) | 46 (29%) | 28 (26%) | 492 (52%) | 33 (35%) |
| Unemployed | 33 (3%) | 1 (3%) | 1 (1%) | 1 (1%) | 32 (3%) | 1 (1%) |
| Retired | 434 (41%) | 9 (24%) | 110 (69%) | 77 (71%) | 377 (40%) | 57 (61%) |
| Disabled | 40 (4%) | 0 (0%) | 2 (1%) | 1 (1%) | 39 (4%) | 1 (1%) |
| Student | 2 (<1%) | 0 (0%) | 0 (0%) | 0 (0%) | 2 (<1%) | 0 (0%) |
| Homemaker | 3 (<1%) | 0 (0%) | 0 (0%) | 0 (0%) | 3 (<1%) | 0 (0%) |
| Missing | 9 (1%) | 1 (3%) | 1 (1%) | 1 (1%) | 8 (1%) | 1 (1%) |
| Marital status | | | | | | |
| Married/living as married | 830 (79%) | 25 (68%) | 139 (87%) | 97 (90%) | 748 (78%) | 82 (88%) |
| Divorced/ separated | 94 (9%) | 4 (11%) | 5 (3%) | 2 (2%) | 90 (9%) | 4 (4%) |
| Widowed | 31 (3%) | 2 (5%) | 3 (2%) | 2 (2%) | 29 (3%) | 2 (2%) |
| Single | 89 (9%) | 6 (16%) | 12 (8%) | 6 (6%) | 85 (9%) | 4 (4%) |
| Missing | 2 (<1%) | 0 (0%) | 1 (1%) | 1 (1%) | 1 (<1%) | 1 (1%) |
| Insurance | | | | | | |
| Medicaid | 31 (3%) | 1 (3%) | 8 (5%) | 6 (6%) | 26 (3%) | 5 (5%) |
| Medicare | 369 (35%) | 9 (24%) | 97 (61%) | 68 (63%) | 319 (33%) | 50 (54%) |
| Uninsured | 23 (2%) | 1 (3%) | 0 (0%) | 0 (0%) | 22 (2%) | 1 (1%) |
| Private | 568 (54%) | 23 (62%) | 45 (28%) | 27 (25%) | 537 (56%) | 31 (33%) |
| VA/Tri-care | 43 (4%) | 3 (8%) | 8 (5%) | 1 (1%) | 8 (1%) | 1 (1%) |
| Other/unsure | 9 (1%) | 0 (0%) | 1 (1%) | 5 (5%) | 39 (4%) | 4 (4%) |
| Missing | 3 (<1%) | 0 (0%) | 1 (1%) | 1 (1%) | 2 (<1%) | 1 (1%) |

(Continues)

**TABLE 1** (Continued)

| Demographics | All respondents *N* = 1046 | Black respondents *n* = 37 (4%) | History of prostate cancer *n* = 160 (15%) | History of radiation therapy treatment *n* = 108 (10%) | Online survey completion *n* = 953 (91%) | Paper survey completion *n* = 93 (9%) |
|---|---|---|---|---|---|---|
| Education | | | | | | |
| <High school | 4 (<1%) | 1 (3%) | 1 (1%) | 1 (1%) | 3 (<1%) | 1 (1%) |
| High school | 52 (5%) | 1 (3%) | 5 (3%) | 4 (4%) | 49 (5%) | 3 (3%) |
| Some college | 196 (19%) | 6 (16%) | 25 (16%) | 17 (16%) | 312 (33%) | 32 (34%) |
| Vocational/ Technical | 42 (4%) | 2 (5%) | 5 (3%) | 5 (5%) | 39 (4%) | 3 (3%) |
| College graduate | 344 (33%) | 12 (32%) | 49 (31%) | 38 (35%) | 180 (19%) | 16 (17%) |
| Postgrad | 400 (38%) | 13 (35%) | 73 (46%) | 43 (40%) | 362 (38%) | 38 (41%) |
| Missing | 8 (1%) | 2 (5%) | 2 (1%) | 0 (0%) | 8 (1%) | 0 (0%) |
| Pre-tax income | | | | | | |
| $0–9999 | 17 (2%) | 1 (3%) | 1 (1%) | 1 (1%) | 16 (2%) | 1 (1%) |
| $15,000–34,999 | 105 (10%) | 2 (5%) | 8 (5%) | 5 (5%) | 102 (11%) | 3 (3%) |
| $35,000–49,999 | 89 (9%) | 5 (14%) | 12 (8%) | 6 (6%) | 86 (9%) | 3 (3%) |
| $50,000–99,999 | 365 (35%) | 13 (35%) | 57 (36%) | 37 (34%) | 327 (34%) | 38 (41%) |
| $100,000–199,999 | 348 (33%) | 13 (35%) | 52 (33%) | 35 (32%) | 321 (34%) | 27 (29%) |
| $200,000+ | 91 (9%) | 2 (5%) | 12 (8%) | 13 (12%) | 79 (8%) | 12 (13%) |
| Missing | 31 (3%) | 1 (3%) | 18 (11%) | 11 (10%) | 22 (2%) | 9 (10%) |
| Residential setting | | | | | | |
| City | 356 (34%) | 17 (46%) | 62 (39%) | 46 (43%) | 316 (33%) | 40 (43%) |
| Rural | 250 (24%) | 8 (22%) | 40 (25%) | 25 (23%) | 224 (24%) | 26 (28%) |
| Suburb | 430 (41%) | 12 (32%) | 55 (34%) | 35 (32%) | 404 (42%) | 26 (28%) |
| Other | 3 (<1%) | 0 (0%) | 1 (1%) | 1 (1%) | 2 (<1%) | 1 (1%) |
| Missing | 7 (1%) | 0 (0%) | 2 (1%) | 1 (1%) | 7 (1%) | 0 (0%) |
| Self-health rating | | | | | | |
| Excellent | 159 (15%) | 2 (5%) | 42 (26%) | 30 (28%) | 135 (14%) | 24 (26%) |
| Very good | 447 (43%) | 19 (51%) | 71 (44%) | 52 (48%) | 397 (42%) | 50 (54%) |
| Good | 304 (29%) | 12 (32%) | 28 (18%) | 14 (13%) | 291 (31%) | 13 (14%) |
| Fair | 96 (9%) | 4 (11%) | 13 (8%) | 7 (7%) | 91 (10%) | 5 (5%) |
| Poor | 34 (3%) | 0 (0%) | 5 (3%) | 4 (4%) | 34 (4%) | 0 (0%) |
| Missing | 6 (1%) | 0 (0%) | 1 (1%) | 1 (1%) | 5 (1%) | 1 (1%) |

Abbreviation: VA, Veterans Affairs.

primarily as White (89%), age 60+ years (60%), employed (50%), and married or living as married (79%); 94% were formally educated beyond high school and 71% were college graduates. Only 37 (4%) respondents identified as Black or African American, but this was the largest self-identified minority group and therefore analyzed separately. One hundred sixty (15%) respondents had a history of prostate cancer and 10% ($n$ = 108) had received radiation therapy for prostate cancer. Respondents reported incomes as follows: less than $50,000, 20%; $50,000 to less than $100,000, 35%; $100,000 to less than $200,000, 33%; greater than or equal to $200,000, 9%; and no answer, 3%. See Table 1 for additional respondent demographics.

## Decision making regarding treatment

Table 2 shows respondent mean rankings for how important 17 factors would be in deciding on a prostate cancer treatment. A score of one on the Likert scale meant not at all important and five meant most important. Overall, respondents ranked survival (4.4) as most important followed by quality of life (QOL; 4.3), likelihood of cancer recurrence (4.1), and remaining active (4.1), which were all ranked as more important than quantity of life (4.0). There were slight differences in ranking among subgroups. For example, Black or African American men ranked QOL (4.7) as more important than survival (4.5). Overall, remaining active was ranked as

**TABLE 2** Mean ratings of responses to how important the following factors would be in determining choice of prostate cancer treatment

| Symptom | All respondents (maximum $n = 1046$) | Black respondents (maximum $n = 37$) | History of prostate cancer (maximum $n = 160$) | History of radiation therapy treatment (maximum $n = 108$) | Online survey completion (maximum $n = 953$) | Paper survey completion (maximum $n = 93$) |
|---|---|---|---|---|---|---|
| 1. Survival | 4.4 ($n = 1039$) | 4.5 ($n = 37$) | 4.6 ($n = 160$) | 4.7 ($n = 108$) | 4.4 ($n = 946$) | 4.7 ($n = 93$) |
| 2. Quality of life | 4.3 ($n = 1032$) | 4.7 ($n = 36$) | 4.4 ($n = 158$) | 4.5 ($n = 106$) | 4.3 ($n = 941$) | 4.5 ($n = 91$) |
| 3. Likelihood of recurrence | 4.1 ($n = 1035$) | 4.4 ($n = 37$) | 4.4 ($n = 160$) | 4.5 ($n = 108$) | 4.0 ($n = 942$) | 4.5 ($n = 93$) |
| 4. Remaining active | 4.1 ($n = 1031$) | 4.4 ($n = 37$) | 4.4 ($n = 159$) | 4.4 ($n = 107$) | 4.0 ($n = 939$) | 4.5 ($n = 92$) |
| 5. Quantity of life | 4.0 ($n = 1027$) | 4.4 ($n = 37$) | 4.3 ($n = 159$) | 4.4 ($n = 108$) | 4.0 ($n = 934$) | 4.4 ($n = 93$) |
| 6. Urinary leakage requiring regular pads | 3.9 ($n = 1033$) | 4.1 ($n = 37$) | 4.1 ($n = 160$) | 4.3 ($n = 108$) | 3.8 ($n = 940$) | 4.3 ($n = 93$) |
| 7. Rectal bleeding | 3.6 ($n = 1036$) | 4.1 ($n = 36$) | 3.8 ($n = 159$) | 3.9 ($n = 107$) | 3.5 ($n = 944$) | 3.9 ($n = 92$) |
| 8. Bowel urgency | 3.5 ($n = 1027$) | 4.0 ($n = 37$) | 3.8 ($n = 156$) | 3.9 ($n = 104$) | 3.5 ($n = 936$) | 4.0 ($n = 91$) |
| 9. Urinary leakage (occasional) | 3.5 ($n = 1031$) | 4.0 ($n = 37$) | 3.9 ($n = 158$) | 4.0 ($n = 106$) | 3.5 ($n = 939$) | 4.1 ($n = 92$) |
| 10. Urinary frequency | 3.4 ($n = 1025$) | 3.9 ($n = 37$) | 3.7 ($n = 156$) | 3.8 ($n = 106$) | 3.3 ($n = 934$) | 3.9 ($n = 91$) |
| 11. Sexual function | 3.3 ($n = 1028$) | 4.2 ($n = 36$) | 3.6 ($n = 158$) | 3.7 ($n = 107$) | 3.2 ($n = 936$) | 3.8 ($n = 92$) |
| 12. Cost of treatments | 3.3 ($n = 1028$) | 4.1 ($n = 37$) | 3.0 ($n = 159$) | 3.0 ($n = 107$) | 3.3 ($n = 935$) | 3.1 ($n = 93$) |
| 13. Fatigue from treatments | 3.2 ($n = 1027$) | 3.9 ($n = 36$) | 3.3 ($n = 159$) | 3.4 ($n = 107$) | 3.2 ($n = 935$) | 3.4 ($n = 92$) |
| 14. Avoiding hospitalization | 3.2 ($n = 1025$) | 3.9 ($n = 35$) | 3.3 ($n = 158$) | 3.6 ($n = 107$) | 3.1 ($n = 932$) | 3.7 ($n = 93$) |
| 15. Treatment location (hometown or elsewhere) | 3.0 ($n = 1034$) | 4.0 ($n = 37$) | 2.8 ($n = 160$) | 2.7 ($n = 108$) | 3.1 ($n = 941$) | 2.6 ($n = 93$) |
| 16. Having to take pills long term | 2.8 ($n = 1035$) | 3.5 ($n = 37$) | 3.2 ($n = 160$) | 3.4 ($n = 108$) | 2.7 ($n = 942$) | 3.6 ($n = 93$) |
| 17. Treatment time (days) | 2.8 ($n = 1027$) | 3.8 ($n = 36$) | 2.9 ($n = 158$) | 2.9 ($n = 106$) | 2.8 ($n = 936$) | 2.9 ($n = 91$) |

*Note:* Answers ranged from 1 (not at all important) to 5 (most important).

**TABLE 3** Mean ratings for how significantly each treatment-related symptom would impact respondents

| Symptom | All respondents (maximum $n = 1046$) | Black respondents (maximum $n = 37$) | History of prostate cancer (maximum $n = 160$) | History of radiation therapy treatment (maximum $n = 108$) | Online survey completion (maximum $n = 953$) | Paper survey completion (maximum $n = 93$) |
|---|---|---|---|---|---|---|
| 1. Living with bowel dysfunction (wear pad) | 8.2 ($n = 964$) | 8.0 ($n = 36$) | 8.6 ($n = 153$) | 8.6 ($n = 104$) | 8.2 ($n = 876$) | 8.6 ($n = 88$) |
| 2. Living with rectal urgency and frequency | 7.4 ($n = 965$) | 7.7 ($n = 36$) | 7.4 ($n = 153$) | 7.5 ($n = 104$) | 7.4 ($n = 877$) | 7.4 ($n = 88$) |
| 3. Urinary dysfunction (wear pad) | 7.2 ($n = 965$) | 7.3 ($n = 36$) | 7.7 ($n = 153$) | 8.0 ($n = 104$) | 7.1 ($n = 877$) | 8.2 ($n = 88$) |
| 4. Fatigue | 6.1 ($n = 958$) | 6.2 ($n = 35$) | 6.1 ($n = 151$) | 6.0 ($n = 103$) | 6.1 ($n = 871$) | 6.2 ($n = 87$) |
| 5. Sexual dysfunction | 5.4 ($n = 960$) | 7.2 ($n = 35$) | 5.9 ($n = 153$) | 6.0 ($n = 104$) | 5.3 ($n = 872$) | 6.4 ($n = 88$) |
| 6. Urinary frequency and getting up at night | 5.4 ($n = 968$) | 6.1 ($n = 36$) | 5.8 ($n = 153$) | 6.0 ($n = 104$) | 5.4 ($n = 880$) | 6.2 ($n = 88$) |
| 7. Living with temporary rectal bleeding | 5.1 ($n = 963$) | 6.7 ($n = 35$) | 5.2 ($n = 152$) | 5.2 ($n = 104$) | 5.1 ($n = 876$) | 5.2 ($n = 87$) |

*Note:* Ratings were from 0 (no bother at all) to 10 (worst possible).

more important than specific functional outcomes, such as urinary, bowel, and sexual function. With respect to functional outcomes, the overall group ranked sexual function (3.3), urinary frequency (3.4), occasional urinary leakage (3.5), bowel urgency (3.5), and urinary leakage requiring regular pads (3.9) in increasing importance. Black or African American respondents ranked urinary frequency (3.9), bowel urgency (4.0), occasional urinary leakage (4.0), urinary leakage requiring regular pads (4.1), and sexual function (4.2) in increasing importance. Overall, respondents ranked functional outcomes as more important than treatment duration, location, or cost; however, Black or African American respondents ranked cost, location, and duration of treatment as of similar importance to functional outcomes.

Some of the differences in ranking among subgroups were statistically significant (as shown in the Table 2 data of Supplementary Material S2). Men with a history of prostate cancer rated clinical outcomes, such as survival ($p = 0.0015$), likelihood of recurrence ($p < 0.0001$), QOL ($p < 0.0001$), remaining active ($p < 0.0001$), sexual function ($p = 0.0026$), urinary leakage with occasional pads ($p < 0.0001$), urinary leakage with multiple pads or diaper ($p = 0.0004$), urinary frequency/urgency ($p < 0.0001$), bowel frequency/urgency ($p < 0.0001$), rectal bleeding ($p = 0.0070$), and having to take pills for long-term side effects ($p = 0.0001$), as more important than respondents without a history of prostate cancer. Respondents completing paper surveys ranked all clinical outcomes of higher importance, location and cost of treatment of lower importance, and duration of treatment of similar importance compared with respondents completing online surveys (Supplementary Material S2). Cost of treatment ($p = 0.0028$) and treatment location ($p = 0.0038$) were significantly less important among men with a history of prostate cancer compared to those without it. There was no difference in the ranking for survival and urinary leakage according to race; however, Black or African American respondents ranked the importance of all other outcomes as more important than Caucasian or White respondents. Contingency analyses of educational and income levels and concern about costs showed that increasing educational level was associated with increasing income level ($p = 0.001$), and that lower concern about treatment cost was associated with both increasing educational level ($p = 0.0001$) and increasing income level ($p = 0.0001$). There was no association between race and either income or educational level.

Ratings for how bothersome living long-term with seven prostate cancer treatment-related symptoms are shown in Table 3. With a scale from zero (no bother at all) to 10 (most bothersome), respondents rated bowel dysfunction requiring pads (mean = 8.2), rectal urgency and frequency (mean = 7.4), and urinary dysfunction requiring pads (mean = 7.2) as the most bothersome. Although both the overall group and each subset identified bowel dysfunction

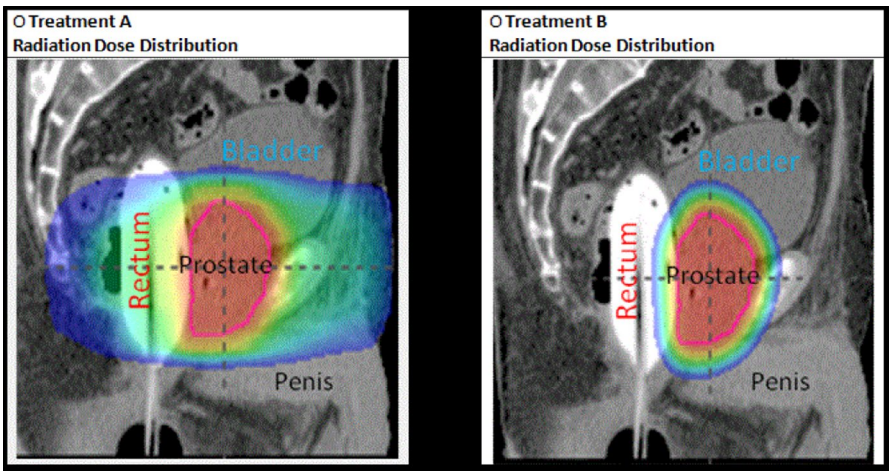


**FIGURE 1** Dosimetry images used in the survey for both treatment and research participation decision-making questions. The following short description was provided: "Below are pictures of radiation treatment plans using two different types of radiation. The colors indicate tissue exposed to radiation: red (high dose), yellow and green (moderate dose), and blue (low dose)"

as the most bothersome potential side effect, there were slight differences in the relative ranking of the bother associated with urinary incontinence and rectal urgency and frequency.

Respondents were asked twice to choose between two types of radiation treatments identified as treatment A and treatment B (Table 4). In the first question, treatment A was described as carrying a 15% risk of moderate or big problems with rectal urgency or frequency and as being available in all cities. Treatment B was described as carrying a 5% risk of moderate or big problems with rectal urgency or frequency and as being available in only some cities, potentially necessitating travel. As shown in section A of Table 4, despite the inconvenience of treatment B and relatively low differential risk of side effects, 67% of all respondents, 80% of respondents with a history of prostate cancer, 85% of respondents with a history of radiation therapy for prostate cancer, and 92% of paper respondents selected B, appearing to prioritize a 10% difference in the probability of moderate bowel urgency and frequency over treatment convenience. In this first choice of treatment, $\chi^2$ tests revealed significant differences in responses between paper versus online respondents (<0.0001) and based on history of prostate cancer ($p < 0.0001$), history of radiation therapy ($p < 0.0001$), race ($p = 0.0122$), marital status ($p = 0.0025$), education ($p = 0.0104$), and income ($p < 0.001$); paper respondents and those with a history of prostate cancer, those with a history of radiation therapy for prostate cancer, and those who were Caucasian or White, married, and of higher educational or income levels were more likely to choose treatment B.

Section B of Table 4 shows responses to the same choice between treatment A and treatment B with additional information provided on side effects and cost. Treatment B is now additionally described as carrying a second malignancy risk of 0.5% compared to 1.0% with treatment A, a 6% risk of urinary side effects compared to 10% with treatment A, and costing 30% more than treatment A. Images of radiation dose distributions for the two treatments are also provided (Figure 1). Despite the increased expense and inconvenience of treatment B, the proportion of respondents choosing treatment B rose from 67% to 75% presumably because of the increase in differential side effects. Again, there were some differences in subset responses. Treatment B was preferred over treatment A by a higher proportion of paper respondents ($p < 0.0001$) and those with a history of prostate cancer ($p = 0.0006$) or radiation for prostate cancer ($p = 0.0003$), and patients over 70 ($p = 0.0465$), married (0.0279), of higher education ($p = 0.0481$), or income ($p = 0.0001$), and those who lived in rural or suburban settings ($p = 0.0201$). Men who chose treatment A were more likely to be uninsured ($p = 0.0086$); the small subset ($n = 21$) of uninsured respondents was the only subset whose majority did not favor treatment B with 52.4% choosing A versus 47.6% choosing B (Supplementary Material S2).

Section C of Table 4 includes only patients who provided answers to both question 4 A and 4 B, so that the impact of additional information on choice could be assessed. As shown in section C of Table 4, 158 (49%) of the 323 respondents who initially chose treatment A continued with their choice of A when given the additional information in section B of Table 4, whereas 165 (51%) changed to treatment B, including 41% of Black or African American respondents, 51% of other respondents, 48% with and 51% without a history of prostate cancer, and 33% with and 52% without a history of radiation for prostate cancer. The apparent rationale for this change in treatment choice was additional side effect information that favored treatment B. In contrast, 564 (87%) of the 651 respondents initially choosing treatment B continued with their choice of treatment B and only 87 (13%) changed their choice to treatment A. Within the group of 651 patients who initially chose B, two of 16 (13%) Black or African American respondents and 85 of 635 (13%) non-Black or African American respondents ($p = 0.9999$), 80 of 529 (15%) respondents without a history of prostate cancer versus seven of 122 (6%) with a history of prostate cancer ($p = 0.0047$), and two of 88 (2%) with a history of radiation for prostate cancer versus 85 of 563 (15%) without a history of prostate

**TABLE 4** Responses to a discrete choice of two prostate cancer treatment options as described below: *People choose different types of prostate cancer radiation treatments for different reasons. Given these following two prostate cancer treatment options, which treatment would you choose?*

| Responses | All responders ($n = 1046$) | Black respondents ($n = 37$) | History of prostate cancer ($n = 160$) | History of radiation therapy treatment ($n = 108$) | Online survey completion ($n = 953$) | Paper survey completion ($n = 93$) |
|---|---|---|---|---|---|---|
| **A. Limited information provided about differential side effects and convenience** | | | | | | |
| Treatment A:<br>• Risk of moderate or big problems with rectal urgency/frequency is 15%<br>• Risk of temporary rectal bleeding is 30%<br>• Treatment is available in all cities | 338 (33%) | 19 (53%) | 31 (20%) | 16 (15%) | 331 (35%) | 7 (8%) |
| Treatment B:<br>• Risk of moderate or big problems with rectal urgency/frequency is 5%<br>• Risk of temporary rectal bleeding is 30%<br>• Treatment available only in some cities, so travel might be necessary | 691 (67%) | 17 (47%) | 126 (80%) | 90 (85%) | 609 (65%) | 82 (92%) |
| Total respondents | 1029 | 36 | 157 | 106 | 940 | 89 |
| No response | 17 | 1 | 3 | 2 | 13 | 4 |
| **B. Responses when additional information was provided on differential side effects, convenience, and cost of treatment with image of the radiation dose distributions[1]** | | | | | | |
| Treatment A:<br>• 5% risk of rectal bleeding requiring minor cautery (burning)<br>• 50% risk of erectile dysfunction<br>• 15% risk of significant rectal urgency/frequency<br>• 10% risk of urinary problems<br>• 1% risk of radiation induced cancer<br>• 30% less expensive than treatment B<br>• Treatment is available in most cities | 247 (25%) | 12 (36%) | 22 (15%) | 12 (12%) | 242 (27%) | 5 (6%) |
| Treatment B:<br>• Same risk of rectal bleeding as treatment A<br>• Same risk of erectile dysfunction as treatment A<br>• 5% risk of rectal urgency/frequency<br>• 6% risk of urinary problems<br>• 0.5% risk of radiation induced cancer<br>• 30% more expensive than treatment A<br>• Travel might be necessary to receive this treatment | 731 (75%) | 21 (64%) | 129 (85%) | 91 (88%) | 647 (73%) | 84 (94%) |
| Total respondents | 978 | 33 | 151 | 103 | 889 | 89 |
| No response | 68 | 4 | 9 | 5 | 64 | 4 |

**C. Impact of additional information on treatment choice[2]**

| Initial response with minimal information n (%) | Second response with additional Information *n* (%) | | |
|---|---|---|---|
| | Treatment A | Treatment B | Total |
| Treatment A | 158 (49%) | 165 (51%) | 323 |
| Treatment B | 87 (11%) | 564 (87%) | 651 (27%) |
| Total | 245 | 729 | 974 |

*Note:* [1]See Figure 1 for dose distribution.

[2]Only the 974 respondents who answered both questions are included in the comparison.

**TABLE 5** Responses to, *Would you be willing to be randomized to a study that used one of two different types of radiation therapy?*

| Responses | All respondents ($n = 1046$) | Black respondents ($n = 37$) | History of prostate cancer ($n = 160$) | History of radiation therapy treatment ($n = 108$) | Online survey completion ($n = 953$) | Paper survey completion ($n = 93$) |
|---|---|---|---|---|---|---|
| **A. Limited information provided about differential side effects and convenience**[a] | | | | | | |
| Yes | 148 (15%) | 11 (31%) | 20 (13%) | 13 (12%) | 136 (15%) | 12 (13%) |
| No | 393 (39%) | 10 (28%) | 91 (58%) | 67 (63%) | 337 (37%) | 56 (62%) |
| Undecided | 456 (46%) | 15 (42%) | 46 (29%) | 26 (25%) | 433 (48%) | 23 (25%) |
| Total respondent | 997 | 36 | 157 | 106 | 906 | 91 |
| No response | 49 | 1 | 3 | 2 | 47 | 2 |
| **B. Additional information provided on differential side effects, convenience, and cost of treatment including images of radiation dose distributions**[b] | | | | | | |
| Yes | 136 (14%) | 9 (24%) | 13 (9%) | 7 (7%) | 125 (14%) | 11 (12%) |
| No | 420 (44%) | 10 (27%) | 99 (66%) | 74 (73%) | 351 (41%) | 69 (76%) |
| Undecided | 400 (42%) | 18 (49%) | 37 (25%) | 20 (20%) | 389 (45%) | 11 (12%) |
| Total respondent | 956 | 37 | 149 | 101 | 865 | 91 |
| No response | 90 | 0 | 11 | 7 | 88 | 2 |

**C. Impact of additional information on decision to participate in RCT**[c]

| Initial response with minimal information *n* (%) | Second response with additional information, *n* (%) | | | |
|---|---|---|---|---|
| | Yes | Undecided | No | Total |
| Yes | 67 (47%) | 51 (36%) | 22 (16%) | 140 |
| Maybe | 48 (11%) | 269 (62%) | 119 (27%) | 436 |
| No | 20 (5%) | 79 (21%) | 278 (74%) | 377 |
| Total | 135 | 399 | 419 | 953 |

Abbreviation: RCT, randomized controlled trial.

[a]Treatment A has 15% risk of moderate or big problems with rectal urgency or frequency and is available in all cities; treatment B has 5% risk of moderate or big problems with rectal urgency or frequency and is available in only some cities, potentially necessitating travel.

[b]Treatment has 5% risk of rectal bleeding, 50% risk of erectile dysfunction, 15% risk of significant rectal urgency and frequency, 10% of urinary problems, 1% risk of radiation induced cancer, is 30% less expensive than treatment B and available in most cities. Treatment B has 5% risk of rectal bleeding, 50% risk of erectile dysfunction, 5% risk of rectal urgency and frequency, 6% risk of urinary problems, 0.5% risk of radiation induced cancer, is 30% more expensive than treatment A, and travel might be necessary to receive this treatment. Images of the radiation treatment plans (Figure 1) are included with an explanation.

[c]Only the 953 respondents who answered both questions are included.

cancer ($p = 0.0003$) revised their choice to A. The only apparent rationale for this change in treatment preference was added knowledge of differential cost. Interestingly, patients with the experience of prostate cancer or radiation treatment for prostate cancer were less likely to revise their treatment choice based on cost.

## Decision making regarding research participation

Respondents were asked whether they would ever participate in an RCT. Overall, 15% of respondents said yes, 42% said no (including 36% of Black or African American respondents, 58% of men with a history of prostate cancer, and 65% of men with a history of radiation), and 43% were undecided. When asked if they would participate in an RCT comparing two types of radiation therapy (section A of Table 5), 15% said yes, 39% said no, and 46% were undecided. When provided with additional information about an RCT comparing the two types of radiation, including a written description of treatments A and B with accompanying images of radiation dose distributions and potential side effects, differential costs, and convenience factors (as described in the questions for section B of Table 4), 14% said yes to participation, 44% said no, and 42% were undecided (section B of Table 5). With the additional information about the two types of radiation to be compared and the image of the radiation dose distributions, there was a significant change in the pattern of response ($p < 0.0001$). Although the proportion agreeing to participate remained constant at ~ 14%, the proportion of undecided decreased from 46% to 42%, and the proportion refusing increased from 40% to 44%.

As shown in Table 2, patient responses indicated that duration of treatment was the least important factor in choosing a treatment. Table 6 depicts responses to the question of whether respondents would be willing to participate in an RCT of two different lengths of radiation therapy likely to produce the same outcomes. Compared to an RCT randomizing between types of radiation likely to impact outcomes of importance (bowel function), a much higher proportion of respondents (36%) said yes, only 24% said no, and 40% were undecided.

## DISCUSSION

As described in the Introduction, this survey informed an application to the Patient-Centered Outcomes Research Institute for funding of the now ongoing COMPPARE trial (ClinTrial.gov NCT 03561220). The survey explores which outcomes men prioritize when choosing a treatment option and indicates that most men rank survival, QOL, disease control, and remaining active as most important. It also indicates that long-term functional outcomes are more important than factors of convenience, such as cost, duration, and location of treatment, with one exception: Black or African American patients ranked cost, duration, and location of treatment of similar importance to some functional outcomes. Our sample of Black or African American respondents was quite small; therefore, it is unclear whether this differential prioritization reflects differences in cultural values, differences in resources that make choices feasible, or may not be representative of the larger Black or African American population. With minimal information, most patients chose the radiation treatment described as causing less bowel dysfunction even though the treatment was less convenient. When presented with information describing additional differences in side effect profiles and differential costs, an even higher percentage of patients selected the more costly and inconvenient treatment because of the improved side effect profile. Our survey was comprised primarily of Caucasian or White educated men, but contingency analyses did show associations between less concern about increased cost and both increasing educational and income levels (Supplementary Material S2, second worksheet). The only subset of respondents for whom the choice between treatment A and treatment B was nearly equal when all information was provided was the very small uninsured subset; it is possible that most other groups assumed their insurer would provide their chosen treatment so that personal cost of treatment was of less concern.

Although the RCT design is the preferred study design for evaluating the comparative effectiveness of medical interventions,[1,2] recruitment is often lower than anticipated. In fact, only 3%–10% of all adult patients with cancer enroll in clinical trials, with even lower estimates in prostate cancer trials.[18–20] Minority participation in clinical trials is especially low.[19,21–23] Some reports indicate growing interest and willingness to participate in clinical research[24,25]; however, multiple reports indicate that patient preference is a strong factor in choice of treatment and research participation.[26,27] Our survey suggests that a significant proportion of men (~ 40%) are averse to randomization under any circumstance. In questions about hypothetical trials between types of radiation described as producing minor differences in side effects, the proportion of respondents unwilling to be randomized remained fairly constant at 39% to 44%. Although only a small proportion (13%–15%) was agreeable to participating in an RCT under any circumstance or trials comparing two forms of radiation with differing side effect profiles, a substantial proportion was undecided, suggesting that under the right circumstances these respondents might participate in a randomized study. When asked about participating in an RCT comparing two lengths of radiation treatments not expected to result in different outcomes, 36% of respondents agreed to randomization—more than double the rate when randomization was between two radiation regimens that were expected to produce some differences in outcomes that had been identified as important by the respondents. This finding suggests that consent to randomization may depend on whether the randomization would likely

**TABLE 6** Responses to, *If survival and side effects are expected to be the same, would you be willing to be randomized to a study that used one of two different lengths of radiation therapy? (e.g., 20 treatments vs. 40 treatments)*

| Responses | All respondents ($n = 1046$) | Black respondents ($n = 37$) | History of prostate cancer ($n = 160$) | History of radiation therapy treatment ($n = 108$) | Online survey completion ($n = 953$) | Paper survey completion ($n = 93$) |
|---|---|---|---|---|---|---|
| Yes | 363 (36%) | 16 (44%) | 62 (39%) | 49 (46%) | 316 (35%) | 47 (52%) |
| No | 237 (24%) | 9 (25%) | 47 (30%) | 25 (24%) | 219 (24%) | 18 (20%) |
| Undecided | 397 (40%) | 11(31%) | 48 (31%) | 32 (30%) | 371 (41%) | 26 (29%) |
| Total | 997 | 36 | 157 | 106 | 906 | 91 |
| Missing | 49 | 1 | 3 | 2 | 47 | 2 |

impact an outcome that mattered a great deal to the patient in contrast to a randomization impacting outcomes of less importance. Even in the setting where randomization impacted only the factor of least importance (duration of treatment), only approximately one-third said they would participate. It is also of interest that respondents with a history of prostate cancer were more definitive in their answers, more likely to say they would not agree to randomization between types of radiation, but also more likely to agree to randomization between two radiation regimens differing in duration but not in side effects. These findings suggest that men faced with actual research decisions may be less likely than hypothetical patients to accept randomization for factors that could impact outcomes important to them and more likely to accept randomization for factors that were not of importance to them; or it may simply suggest that the men in our survey who previously received radiation were better informed, had already considered such decisions, and thus found the questions easier to answer. Finally, as explored in contrasting responses within Tables 4 and 5, increasing information about side effect profiles significantly impacted decision making for both treatment choice and research participation. The Belmont Principle relating to patient autonomy in clinical research suggests that it is incumbent on researchers to fully inform patients of the nature of the study and all potential differences between treatment arms as more complete information impacts patient decisions. The relatively small proportion of respondents agreeable to randomization to treatments likely to produce different outcomes suggests that novel designs for comparative trials are needed to ensure rapid and representative comparative trial accrual and generalizable trial results.

## Limitations

This study has several limitations. Although we were able to obtain responses from a large unselected national sample, we primarily utilized an online survey that queried respondents who had access to a computer and were also computer literate. Our sample was comprised primarily of Caucasian or White educated males with relatively high incomes, and so the findings may not be generalizable to men of lower socioeconomic status or minorities. Despite efforts to enrich the survey with minority responses by providing paper surveys and fliers with web links to the survey to local clinics serving minority patients, there were few minority respondents, and the small sample of Black or African American respondents may not be representative of the overall population of Black or African American men. The survey respondents also, largely, had no personal experience with prostate cancer, and data within this study suggest that hypothetical responses might not adequately predict the decisions men make when faced with actual treatment and research decision making. It is also likely that other factors not addressed in this type of study could strongly influence both research participation and treatment decisions, such as extent of disease, family history, social context, and geographic proximity to large research-oriented facilities.

# CONCLUSIONS

In summary, our survey suggests that men will be more concerned with long-term outcomes—specifically survival, QOL, freedom from disease recurrence, and remaining active and specific functional outcomes—than with short-term inconvenience, such as treatment cost, duration, or even location, when making prostate cancer treatment decisions. These long-term outcomes, then, are the end points of most importance to patients and those which should be addressed in comparative clinical trials. Furthermore, our survey suggests that only a relatively small proportion of men are likely to agree to randomization between treatments hypothesized to produce differences in these outcomes of importance. These data have implications for research trial design, recruitment to clinical trials, clinical care, and insurance coverage. To fill evidence gaps with generalizable data that will inform patient, physician, insurer, and policymaker decisions, it is imperative to undertake not only the best research design for the highest level of evidence but also to consider what design is ethical and most feasible and will ultimately result in generalizable findings. The findings from this survey challenge clinical investigators to move beyond the traditional RCT to create more novel comparative trial designs that respect patient preference yet remain scientifically sound.

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### CONFLICT OF INTEREST

All authors declared no competing interests for this work.

### AUTHOR CONTRIBUTIONS

N.P.M., S.O., and B.H. designed the research. N.P.M. and S.O. performed the research. N.P.M., S.O., C.B., and C.M. analyzed the data. N.P.M., S.O., C.B., B.H., and C.M. wrote the manuscript.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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