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ORIGINAL ARTICLE

Experience with the US health care system for Black and White patients with advanced prostate cancer

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Abstract

Objective: The purpose of this study was to assess differences in reported information about treatment, integration into care, and respect by self-identified Black and White individuals with advanced prostate cancer in the United States.

Patients and Methods: This is a prospective cohort study of 701 participants (20% identifying as Black) enrolled in the International Registry for Men with Advanced Prostate Cancer at 37 US sites from 2017 to 2022. Participants were asked six questions from the Cancer Australia National Cancer Control Indicators about their experience with care at study enrollment. Prevalence differences by self-reported race were estimated using marginal standardization of logistic-normal mixed

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See editorial on pages 000–000, this issue.

effects models (adjusted for age at enrollment and disease state at enrollment), and 95% CIs were estimated using parametric bootstrapping.

Results: Most participants reported a high quality of care for each question. Black participants generally reported higher care quality compared with White participants. Black participants reported more frequently that they were offered a written assessment and care plan (71%) compared with White participants (58%; adjusted difference, 13 percentage points; 95% CI, 4–23). Black participants also reported more frequently being given the name of nonphysician personnel who would support them (64%) than White participants (52%; adjusted difference, 10; 95% CI, 1–20). Prevalence differences did not differ by disease state at enrollment.

Conclusions: Black participants generally reported a higher quality of care compared with White participants. This study calls attention to the need to study potential mediating factors and interpersonal aspects of care in this population to improve survivorship.

KEYWORDS
information about treatment, integration into care, patient experience, patient preference, prostate cancer, racial disparities

INTRODUCTION

In the United States, Black individuals have a 1.7 times higher incidence of a prostate cancer diagnosis and 2.1 times higher mortality from prostate cancer compared with White individuals.[1] Patients with advanced disease experience the highest prostate cancer morbidity and mortality compared with those with localized disease and the incidence of advanced disease is highest among Black patients.[2] There are two major categories of advanced prostate cancer: metastatic hormone-sensitive prostate cancer (mHSPC) and castration-resistant prostate cancer (CRPC).[3]

Patient-reported experience with the health care system offers a potential point of intervention for improving equity in survivorship in patients with advanced prostate cancer.[4] Racial disparities persist across a variety of illnesses and health care services as a result of patient-level, health care systems-level, and care process-level variables.[5] Numerous interventions to move toward equity in treatment have been suggested, such as increasing the diversity of the health care workforce, bolstering interpretation services, and using multidisciplinary care teams, among others; many of these interventions have started to be implemented at health care sites across the country and have shown improved quality of care as a result.[6–8]

Patient experience is a multidimensional construct encapsulating many of these systems- and process-level variables of care as an indicator of health care quality, most often including the areas of information provided about treatment, process of making an appointment, interactions with health care professionals, and waiting times.[9] Patient experience is distinct from patient satisfaction: whereas patient experience is typically measured via patient report of what happened (e.g., did you receive information about your treatment?), patient satisfaction is typically measured via patient evaluation and is more influenced by expectations and preferences (e.g., how would you rate the information you received about your treatment?).

Patients undergoing biopsy for suspected prostate cancer want to be thoroughly informed about and have an active role in their care[10]; however, health care professionals often either do not provide full treatment options or side effect profiles to their patients or do not explain them in a way the patient can understand.[11,12] Because domains of patient experience and quality of care have been associated with quality of life and survival in prostate cancer,[4,13,14] research into these patient-reported measures could lead to enhanced prostate cancer survivorship.

Studies on racial disparities in experiences with the health care system among localized prostate cancer survivors are sparse and have shown poorer or similar ratings of communication and involvement in care for Black individuals compared with White individuals.[15,16] There is a need to describe the experience of individuals with advanced prostate cancer to gather insight into ways to improve care for this population and identify unmet needs.

This study used patient-reported experience measures to examine racial differences in patient experience among people newly diagnosed with advanced prostate cancer in the International Registry for Men with Advanced Prostate Cancer (IRONMAN) study. In this study, we consider race a social construct that serves as a proxy marker for a range of social experiences shaped by structural racism, and racism is the driver of potential racial disparities, not race itself.[17] We described overall group differences in reported information about treatment, integration into care, and respect for patient preference among IRONMAN participants identifying as Black or White in the United States.

PATIENTS AND METHODS

Study participants

Study participants included individuals with advanced prostate cancer enrolled in the IRONMAN study (NCT 03151629) between July 21, 2017, and October 3, 2022. IRONMAN is a global prospective cohort of individuals newly diagnosed with advanced prostate cancer (within the past 6 weeks for patients with mHSPC or 3 months for CRPC without a prior diagnosis of mHSPC). Participants are recruited through IRONMAN-affiliated clinicians in 17 countries, and detailed data are collected at study enrollment and throughout a follow-up period of at least 5 years. Because race has different social and historical contexts and categories depending on the country/region and non-US countries in IRONMAN currently have relatively small sample sizes, this analysis focuses on individuals enrolled in the United States.

Outcome measure: Patient experience

Patient experience was measured using the Cancer Australia National Cancer Control Indicator (NCCI) patient experience items completed by participants at study enrollment via a web-based platform (TrueNth) or paper questionnaires.[18] The NCCI items were adapted from the National Health Service National Cancer Patient Experience Survey, the model for further development and refinement of other patient experience measures in countries across the world.[19] IRONMAN includes six of the eight NCCI questions, with two questions on diagnosis removed because of potential confusion between localized and advanced prostate cancer diagnoses among the participants. The six questions are rated on a yes/no scale and fall into three categories: patient information and communication regarding treatment (questions 1 and 2); patient coordination and integration of care (questions 3 and 4); and respect for patient preference (questions 5 and 6).

Demographic and clinical characteristics

Demographic variables (i.e., age at initial prostate cancer diagnosis, age at study enrollment, highest level of education, employment status, marital status, military status, race, ethnicity) were collected through a patient-reported questionnaire at study enrollment. Clinical variables (i.e., disease state at enrollment, Gleason score, prostate-specific antigen [PSA] level, type of health center, baseline treatment) were drawn from patient medical records and entered by study sites.

Race was self-reported by participants at study enrollment, allowing multiple selection from the following categories: White/Caucasian, African/African American/Black/Black British/Caribbean, Asian/Asian American/Asian British, Native Hawaiian or Other Pacific Islander, American Indian/Alaska Native, Middle Eastern, and other. Ethnicity was self-reported by participants choosing between Hispanic/Latino and not Hispanic/Latino categories. Because the IRONMAN population is overwhelmingly not of Hispanic/Latino ethnicity, this study focuses specifically on individuals self-identifying as only White or only Black.

Age at study enrollment (years) was included as a continuous variable. Disease state at enrollment was collected at the clinical sites and categorized as mHSPC (do novo metastatic disease at diagnosis or progressed to metastasis during follow-up after localized prostate cancer diagnosis) and CRPC (progression of disease while on androgen deprivation therapy or with castrate level of testosterone as determined by the investigator).

Statistical analysis

We summarized demographic and clinical participant characteristics, stratified by self-reported race. We then summarized the proportion of participants, stratified by self-reported race, answering yes or no to each of the six NCCI items.

We fit logistic-normal mixed effects models in the overall population for each NCCI question (both crude models and models adjusted for age at study enrollment and disease state at enrollment) and conducted marginal standardization over the self-reported race variable to obtain adjusted prevalence differences.[20] The outcome for each model was a "yes" response to that NCCI question, and the prevalence difference obtained represents the percent of higher prevalence of answering yes to the question for Black participants compared with White participants (controlling for any other variables included in the model). Because we were interested in overall differences by self-reported race, we controlled for time-invariant variables (age at study enrollment and disease state at enrollment). We did not control for variables that may mediate the association between self-reported race and care experiences (e.g., education, employment, insurance status) in the statistical models.[21] Participants were clustered by study site for each of the models. We then fit the same models stratified by disease state at enrollment (both crude models and models adjusted for age at study enrollment) and by type of health center (National Cancer Institute [NCI]-designated center vs. other, crude model only).

To obtain valid standard errors and CIs for our estimates, we used the parametric bootstrap to preserve clustering at study sites.[22] Briefly, rather than resampling observations as in nonparametric bootstrapping, we used the initially fit model to simulate new cluster-specific random effects from the estimated parametric distribution of cluster-specific random effects, and, subsequently, simulated a new binary outcome for each participant. These simulated outcomes and observed covariates were then used in the analysis procedure described previously to obtain a bootstrap estimates of prevalence differences. This process was repeated 1000 times, and 95% CIs were normally approximated by 1.96 SDs above and below the prevalence difference estimated from the marginal standardization procedure.

Finally, as an exploratory secondary analysis, we conducted a confirmatory factor analysis using a two-factor and three-factor solution stratified by self-reported race. Additional methods information regarding choice of adjustment variables, the marginal standardization procedure, and the confirmatory factor analysis is available as supplementary material accompanying the online article. All analyses were completed using R version 4.1.0.

Patient involvement

An advanced prostate cancer survivor and participant in the IRONMAN study was involved in setting the research question and study design. This individual, along with another prostate cancer survivor who directs a cancer patient advocacy nonprofit organization, was also involved in the interpretation of the research findings and review of the manuscript. With the goal of increasing the accessibility of this manuscript to patients and individuals outside of academia, we have included a glossary of technical terms in the supplementary material accompanying this manuscript.

RESULTS

Participant characteristics

This study included 701 participants from IRONMAN self-identifying as White or Black and receiving care at 38 study sites across the United States (Figure 1, Table 1). These study sites span academic, private practice, and government health centers and are primarily located in urban centers in regions with high prostate cancer mortality. Demographic and clinical characteristics for the population stratified by self-reported race are shown in Table 2. The study included 137 participants (20%) identifying as Black and 564 participants (80%) identifying as White. The mean age at enrollment was 69.1 years, and most of the sample (64%) had mHSPC compared with CRPC (36%). Most of the participants attended at least some college (76%), were married at study enrollment (72%), and were retired at study enrollment (57%). One-third of participants reported current or previous service in the national military (32%). More than one-half of participants had a prostatectomy or biopsy Gleason score of at least 8 (67%) and mean first on-study PSA level was 98.0 ng/mL.

Differences by self-reported race were noted across many of the demographic and clinical characteristics (Table 2). Black participants were diagnosed with advanced prostate cancer at a younger age, reported considerably lower education, were less likely to be married, were more likely to be disabled, and had higher first on-study PSA levels compared with White participants. No differences by race were noted for disease state at enrollment, military service, or Gleason score.

NCCI responses by race

The proportion of participants answering yes or no to each of the six NCCI items is shown in Table 3 stratified by self-reported race.

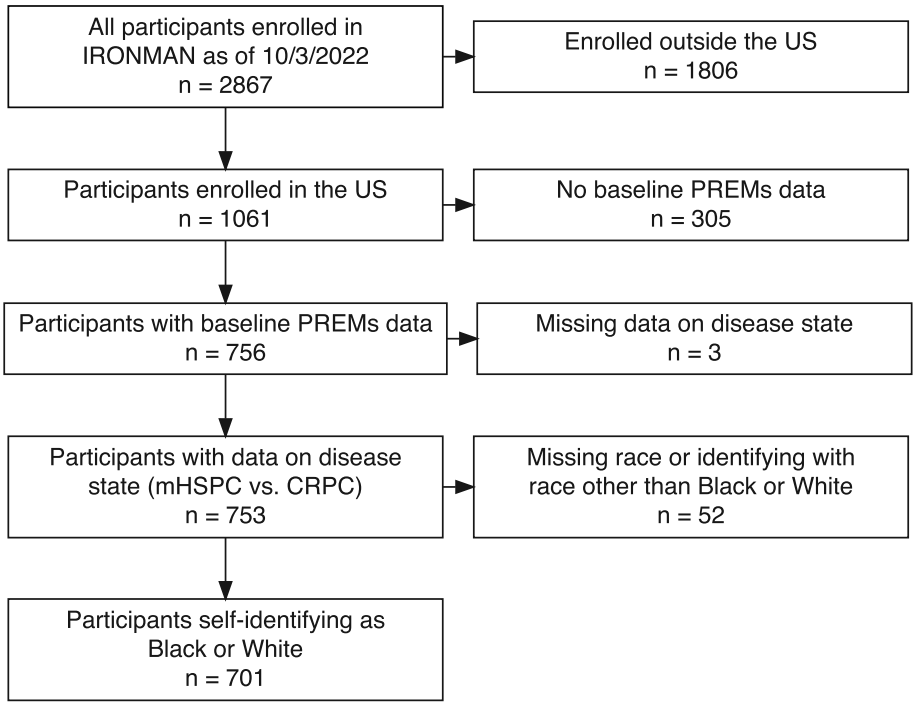

FIGURE 1 Selection of IRONMAN study participants for analysis of patient-reported experience measures. IRONMAN indicates International Registry for Men with Advanced Prostate Cancer.

TABLE 1 Study sites for US participants in IRONMAN by self-reported race (N = 38 sites).

	White (N = 564)	Black (N = 137)
Baylor College of Medicine	6 (1%)	6 (4%)
Chesapeake Urology Associates	5 (1%)	4 (3%)
Columbia University	4 (1%)	2 (1%)
Dana-Farber Cancer Institute	40 (7%)	3 (2%)
Delnor Cancer Center	16 (3%)	1 (1%)
Doylestown Health	14 (2%)	0 (0%)
Duke Cancer Network	5 (1%)	6 (4%)
Duke Comprehensive Cancer Center	44 (8%)	9 (7%)
Durham VA Medical Center	0 (0%)	3 (2%)
Fox Chase Cancer Center - Temple Health	0 (0%)	1 (1%)
Kishwaukee Cancer Center	1 (0%)	0 (0%)
Memorial Sloan Kettering Cancer Center	41 (7%)	7 (5%)
Memphis VA Medical Center	3 (1%)	4 (3%)
Moffitt Cancer Center	2 (0%)	0 (0%)
New York-Presbyterian Brooklyn Methodist Hospital	0 (0%)	1 (1%)
Oregon Health and Sciences Cancer Center	19 (3%)	0 (0%)
Ralph H. Johnson VA Medical Center	9 (2%)	4 (3%)
Reading Health System	9 (2%)	2 (1%)
Robert H. Lurie Comprehensive Cancer Center Northwestern University	4 (1%)	0 (0%)
Roswell Park Cancer Institute	5 (1%)	1 (1%)
Sidney Kimmel Comprehensive Cancer Center	3 (1%)	4 (3%)
Thomas Jefferson University	3 (1%)	1 (1%)
Tulane University	45 (8%)	8 (6%)
University of Alabama-Birmingham	3 (1%)	1 (1%)
University of California Los Angeles	6 (1%)	0 (0%)
University of California San Diego	25 (4%)	0 (0%)
University of Chicago	9 (2%)	7 (5%)
University of Illinois at Chicago	1 (0%)	1 (1%)
University of Michigan	27 (5%)	4 (3%)
University of Mississippi Medical Center	2 (0%)	1 (1%)
University of North Carolina	30 (5%)	7 (5%)
University of Virginia	86 (15%)	12 (9%)
University of Washington	30 (5%)	1 (1%)
University of Wisconsin	8 (1%)	0 (0%)
Warrenville Cancer Center	1 (0%)	0 (0%)
Wayne St. University Karmanos Cancer Institute	21 (4%)	27 (20%)
Weill Cornell Medical Center	30 (5%)	2 (1%)
Winship Cancer Institute Emory University	7 (1%)	7 (5%)

Abbreviations: IRONMAN, International Registry for Men with Advanced Prostate Cancer; VA, Veterans Administration.

Overall, this population reported receiving high levels of information about their treatments and side effects as well as high levels of involvement in decision-making about their care, with the majority of participants answering yes to each of the questions. For example, more than 95% of participants were involved as much as they wanted in decisions about their care and had their views taken into account when deciding their treatment plan. For five of the six questions, Black participants had a better experience with care compared with White participants (with minimal difference in the other question).

Differences between Black and White participants

In the overall population of advanced prostate cancer, when adjusted for age at study enrollment and disease state at enrollment, Black participants reported more frequently that they were offered a written assessment and care plan (71%) compared with White participants (58%; adjusted difference 13 percentage points; 95% CI, 4–23) (Table 3). Black participants also reported more frequently being given the name of nonphysician personnel who would support them (64%) than White participants (52%; adjusted difference 10; 95% CI, 1–20). Black participants in this population also tended to have slightly higher prevalences of being involved as much as they wanted to be in decisions about their care, feeling like their views were taken into account, and receiving written information about side effects compared with White participants, though the differences were small and imprecisely estimated.

In models stratified by disease state at enrollment (mHSPC vs. CRPC, Table 4) and adjusted for age at study enrollment, Black participants with mHSPC had higher prevalences of being offered a written assessment and care plan (15%; 95% CI, 4–27) and having nonphysician personnel supporting them (21%; 95% CI, 9–33) compared with White participants with mHSPC. Among participants with CRPC, no questions reached statistical significance because of there being a smaller sample size and less variation in the outcomes. In models stratified by type of health center (NCI-designated health center vs. other; Table S1), prevalence differences for each question were larger among non–NCI-designated centers with Black participants again reporting better quality of care.

TABLE 2 Cohort demographics of US participants in IRONMAN by self-reported race (*N* = 701), 2017-2022.

	White (*N* = 564)	Black (*N* = 137)
Age at study entry, years		
Mean (SD)	69.6 (8.9)	67.4 (9.0)
Hispanic/Latino		
No	527 (97%)	121 (96%)
Yes	17 (3%)	5 (4%)
Missing	*n* = 20	*n* = 11
Disease state at enrollment		
CRPC	197 (35%)	56 (41%)
mHSPC	367 (65%)	81 (59%)
Highest education level at baseline		
Less than college	29 (16%)	16 (44%)
Some college or bachelor's degree	65 (36%)	11 (31%)
Vocational school/program	2 (1%)	1 (3%)
Graduate degree	82 (45%)	7 (19%)
Other	3 (2%)	1 (3%)
Missing	*n* = 383	*n* = 101
Marital status at baseline		
Married	436 (78%)	66 (49%)
In a civil partnership	15 (3%)	2 (1%)
Widowed	24 (4%)	11 (8%)
Divorced/separated	65 (12%)	36 (27%)
Never married	20 (4%)	19 (14%)
Missing	*n* = 4	*n* = 3
Employment status at baseline		
Retired	332 (59%)	68 (50%)
Working full-time	156 (28%)	35 (26%)
Working part-time	46 (8%)	8 (6%)
Unemployed	9 (2%)	11 (8%)
Disabled	19 (3%)	13 (10%)
Missing	*n* = 2	*n* = 2
Member of national military at baseline		
Yes, currently or previously	139 (33%)	30 (29%)
No, I have never served in the national military	286 (67%)	73 (71%)
Missing	*n* = 139	*n* = 34
Prostatectomy or biopsy Gleason score		
6 or lower	22 (5%)	3 (3%)
7	127 (28%)	35 (33%)
8	85 (19%)	14 (13%)
9-10	222 (49%)	54 (51%)
Missing	*n* = 108	*n* = 31
First on-study PSA, ng/mL		
Mean (SD)	78.7 (441.0)	176.7 (430.7)
Missing	*n* = 21	*n* = 4
Type of health center		
NCI-designated	428 (76%)	106 (77%)
Other academic hospital	95 (17%)	14 (10%)
VA hospital	12 (2%)	11 (8%)
Outpatient clinic	29 (5%)	6 (4%)
Type of therapy at enrollment		
ADT only	329 (58%)	85 (62%)
ARSI only	9 (2%)	5 (4%)
ADT + ARSI only	136 (24%)	25 (18%)
Other	39 (7%)	7 (1%)
No therapy within 30 days before enrollment	51 (9%)	15 (11%)

Abbreviations: ADT, androgen deprivation therapy; ARSI, androgen receptor signaling inhibitor; CRPC, castration-resistant prostate cancer; IRONMAN, International Registry for Men with Advanced Prostate Cancer; mHSPC, metastatic hormone sensitive prostate cancer; NCI, National Cancer Institute; PSA, prostate-specific antigen; VA, Veterans Administration.

DISCUSSION

Our study expands the understanding of patient experience with the health care system among individuals with advanced prostate cancer who experience the highest morbidity and mortality compared with those with localized disease. In a nationwide population of 701 individuals with advanced prostate cancer in the United States, we found that this group reports high levels of information about their treatment and potential side effects and that they were involved in decision-making processes around their care.

For most questions, participants identifying as Black reported higher prevalences of information about treatment, integration in care, and respect for patient preference compared with White participants. Participants in our study received care at 38 institutions in the United States, and we did not find evidence to suggest that large differences at only a few institutions are driving these results.

Compared with previous literature, these results were unexpected. The existing literature focused on individuals with localized disease receiving care from surgeons and urologists; because medical oncologists are the primary physicians caring for IRONMAN

TABLE 3 Absolute prevalence and prevalence differences (in %) for answering yes to each patient experience measure comparing Black participants with White participants in the IRONMAN cohort.

	Absolute prevalence		Prevalence difference (95% CI)	
	White (*N* = 564)	Black (*N* = 137)	Model 1	Model 2
Q1: Have you been offered a written assessment and care plan?	327 (58%)	95 (71%)	13 (4–23)	13 (4–23)
Missing	*n* = 3	*n* = 3		
Q2: Were you given the name of nonphysician personnel who would support you?	292 (52%)	84 (64%)	12 (2–21)	10 (1–20)
Missing	*n* = 4	*n* = 5		
Q3: Were you involved as much as you wanted to be in decisions about your care?	527 (94%)	129 (96%)	2 (−2 to 6)	2 (−2 to 6)
Missing	*n* = 4	*n* = 3		
Q4: Do you think your views were taken into account when deciding on your treatment plan?	533 (95%)	132 (99%)	2 (0–5)	2 (0–5)
Missing	*n* = 5	*n* = 3		
Q5: Were treatment side effects explained in a way you could understand?	537 (96%)	127 (94%)	−2 (−6 to 2)	−2 (−6 to 2)
Missing	*n* = 5	*n* = 2		
Q6: Before you started treatment, were you given written information about possible side effects?	483 (86%)	118 (87%)	2 (−5 to 8)	1 (−5 to 8)
Missing	n = 5	n = 2		

Note: Model 1 is the unadjusted model. Model 2 is adjusted for age at study enrollment (years) and disease state at enrollment (metastatic hormone sensitive prostate cancer vs. castration-resistant prostate cancer). Interpretation: Prevalence difference represents the percent higher prevalence of answering yes to the question for Black participants compared with White participants.

Abbreviation: IRONMAN, International Registry for Men with Advanced Prostate Cancer.

TABLE 4 Prevalence differences (in %) for answering yes to each patient experience measure comparing Black participants with White participants in the IRONMAN cohort, stratified by disease state at enrollment.

Question	mHSPC Model 1 PD (95% CI)	mHSPC Model 2 PD (95% CI)	CRPC Model 1 PD (95% CI)	CRPC Model 2 PD (95% CI)
Question 1 (N_m = 447, N_c = 248)	16 (4–27)	15 (4–27)	11 (−4 to 26)	11 (−4 to 26)
Question 2 (N_m = 443, N_c = 249)	22 (10–33)	21 (9–33)	−6 (−23 to 11)	−6 (−23 to 11)
Question 3 (N_m = 442, N_c = 252)	5 (0–9)	4 (0–9)	−1 (−6 to 4)	−1 (−6 to 4)
Question 4 (N_m = 441, N_c = 252)	2 (−2 to 6)	2 (−2 to 6)	---[a]	---[a]
Question 5 (N_m = 443, N_c = 251)	0 (−4 to 4)	0 (−5 to 4)	−5 (−13 to 3)	−5 (−13 to 3)
Question 6 (N_m = 443, N_c = 251)	5 (−2 to 12)	5 (−3 to 12)	−4 (−15 to 6)	−5 (−16 to 7)

Note: Model 1 is the unadjusted model. Model 2 is adjusted for age at study enrollment (years). N_m is the *N* for that question in the subset of patients with mHSPC. N_c is the *N* for that question in the subset of patients with CRPC. Interpretation: PD represents the percent higher prevalence of answering yes to the question for Black participants compared with White participants.

Abbreviations: CRPC, castration-resistant prostate cancer; IRONMAN, International Registry for Men with Advanced Prostate Cancer; mHSPC, metastatic hormone sensitive prostate cancer; PD, prevalence difference.

[a]PD could not be estimated because some simulated outcomes had no variability and models could not be fit.

participants, it is possible that this discrepancy with previous literature results from different care practices and patterns by physician specialty. Additionally, previous literature used different and more narrow outcome measures, restricting the domains of patient experience that could be explored.

The reasons why Black participants reported being provided more information about treatment and nonphysician care personnel compared with White participants in our study are unclear. Some explanations could include IRONMAN study sites intentionally implementing interventions to decrease racial disparities in care in line with recent recommendations,[23] that higher education in White participants allows for more careful scrutiny of provided paperwork and the care team, or that individuals who are eligible to enrolled in IRONMAN but decline are different than

those who consent to the study. The type of health center likely plays a central role in mediating the relationship between race and patient experience, with White participants having poorer experience with care at non–NCI-designated centers in this population. Our results demonstrate that patient experience is a complex phenomenon; further investigation into potential mediating factors is needed to determine best practices for ensuring that all patients receive appropriate care.

The patient experience measures assessed in this study can be thought of as indicators of quality of care regarding provision of information and interactions with health care professionals. The measures in this study, however, do not assess the more humanistic perceptions and ratings of the patient's care. Although the responses to these questions are mostly "yes," this does not necessarily translate into experiences of being treated with courtesy and respect. Racism permeates through the US medical system, leading to poorer quality of care and ratings of interpersonal treatment for non-White individuals.[24] Patient satisfaction has been shown to be associated with long-term quality of life and survival in a variety of cancers including prostate cancer.[25,26] To better understand racial disparities in care experiences among patients with advanced prostate cancer, it will be important to study patient satisfaction and the more interpersonal aspects of care. Several instruments covering these aspects of care have been developed for this purpose.[27–29] Additionally, because race is a proxy for lived social experiences, it is important to note that these outcomes can change over a person's life course as a result of shifting social hierarchies.

In our analyses, we assessed each question individually. Because many patient experience and satisfaction instruments use a summary score, we conducted an exploratory analysis to determine if the NCCI instrument could be reduced and used in a similar way. We conducted two confirmatory factor analyses: one using the three domains outlined by Cancer Australia and one using two domains identified in a previous validation study[30] of the instrument in White patients (Table S2). We found that the two- and three-factor solutions both perform well in White participants; however, both models fit poorly in Black participants. Because there was so little variability in outcomes for Black participants, this was expected. The results of this factor analysis suggest against reducing this instrument from the individual six questions in Black patient populations; they also emphasize the importance of using additional measures (such as patient satisfaction as described previously) to identify issues not captured by this instrument that are more relevant to this population.

There are several potential limitations of this study. First, this study focuses specifically on participants self-identifying their race as either Black or White. Because a previous study has shown additional differences in patient experience for Asian Americans and Latinx populations,[16] it is important to expand this research among more diverse populations. Second, as mentioned previously, the instrument used in this study does not capture patient satisfaction and the more interpersonal aspects of care. Additional measures will need to be used in this population to obtain a fuller picture of the experience of patients with advanced prostate cancer. Finally, these results may not be generalizable to other health centers. Centers participating in IRONMAN tend to be highly resourced, which could lead to better experience with care; other health spaces with fewer resources (such as rural and primary health centers or urban centers with less clinical trial infrastructure) likely have different distributions of patient experience.

With 38 study sites across the United States, IRONMAN captures the major sites at which patients receive care for advanced prostate cancer, and our study expands the research of patient experience into this population that experiences high morbidity and mortality. Overall, our findings of disparate experiences of care call attention to the importance of studying patient experience with the health care system among patients with advanced prostate cancer. Our results also highlight the importance of considering additional metrics of patient experience within and outside of the health care system that may influence disease trajectories in this population to improve quality of care and increase prostate cancer survival.

CONCLUSIONS

Patients with prostate cancer desire an active role in their care.[10] Although it has been shown that health care professionals often do not engage patients in core shared decision-making processes for those with localized disease,[11] the results of this study show that participants with newly diagnosed advanced prostate cancer in the IRONMAN registry generally feel as though they have the information they need and are included appropriately in decisions about their care. In this population, participants identifying as Black have more positive experiences with information about treatments, integration into care, and respect for patient preference compared with White participants. This study provides novel information into the experience of patients with advanced prostate cancer in the United States and calls attention to the need to study potential mediating factors and interpersonal aspects of care in this population to improve survivorship.

AUTHOR CONTRIBUTIONS

Emily M. Rencsok: Conceptualization, data curation, formal analysis, funding acquisition, methodology, project administration, writing – original draft, and writing – review and editing. **Konrad H. Stopsack:** Formal analysis, methodology, software, visualization, and writing – review and editing. **Natalie Slopen:** Formal analysis, methodology, supervision, and writing – review and editing. **Folakemi T. Odedina:** Conceptualization, data curation, and writing – review and editing. **Camille Ragin:** Conceptualization, data curation, and writing – review and editing. **Joel Nowak:** Methodology and writing – review and editing. **Lawrence McSwain:** Conceptualization, data curation, and writing – review and editing. **Jan Manarite:** Methodology and writing – review and editing. **Elisabeth Heath:** Data curation, methodology, and writing – review and editing. **Daniel J. George:** Conceptualization, data curation, methodology, supervision, and writing – review

and editing. **Philip W. Kantoff:** Conceptualization, methodology, and writing – review and editing. **Jacob Vinson:** Conceptualization, methodology, and writing – review and editing. **Paul Villanti:** Conceptualization, methodology, and writing – review and editing. **Sebastien Haneuse:** Conceptualization, formal analysis, methodology, supervision, and writing – review and editing. **Lorelei A. Mucci:** Conceptualization, formal analysis, methodology, supervision, and writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

Folakemi T. Odedina reports consulting for Pfizer, Inc; board of directors for the American Cancer Society and Foundation for Carcinoma of the Prostate Transatlantic; and consultant on a University of Florida Health Equity project to advise on recruitment and dissemination in minority communities. Joel Nowak reports consulting for Janssen Pharma and that Cancer ABCs is funded by Foundation Medicine, AAA – Novartis, Bayer, Sanofi, Pfizer, Dendreon, Janssen Oncology, Blue Earth Diagnostics, Astellas, and Lantheus. Jan Manarite reports that Cancer ABCs is funded by Foundation Medicine, AAA – Novartis, Bayer, Sanofi, Pfizer, Dendreon, Janssen Oncology, Blue Earth Diagnostics, Astellas, and Lantheus. Elisabeth Heath reports a consulting/advisory role, paid travel, and research funding from Astellas Pharma; research funding from Arvinas, AstraZeneca, BioXcel Therapeutics, Bristol-Myers Squibb, Calibr, Calithera Biosciences Inc, Corcept Therapeutics, Corvis Pharmaceuticals, Daiichi Sankyo Inc, Eisai Inc, Exelixis, Five Prime Therapeutics, Fortis Therapeutics, GlaxoSmithKline, Gilead Sciences Inc, Harpoon Therapeutics, Hoffman-La Roche, Infinity Pharmaceuticals, iTeos Therapeutics, Merck Sharp & Dohme Merck, Mirati Therapeutics, Modra Pharmaceuticals, Oncolys BioPharma, Peloton Therapeutics Inc, Pfizer, Pharmacyclics LLC, and POINT Biopharma; honoraria from and Ad Board for Bayer; research funding and paid travel from Caris Life Sciences; research funding from and Steering Committee for Janssen Research & Development LLC; honoraria from, speakers' bureau, paid travel, and Ad Board for Sanofi; and honoraria, paid travel, research funding from Seattle Genetics. Daniel J. George reports serving as a contractor for Advanced Accelerator Applications SA/Novartis; serving as senior editor for the American Association for Cancer Research; serving as a consultant and participating in research and on an advisory board for Astellas and AstraZeneca; independent contractor for AVEO Pharmaceuticals; serving as a consultant and speaker and receiving honorarium and travel accommodations from Bayer H/C Pharmaceuticals; institutional research for BMS and Calithera; personal/financial from Eisai; research, consultant, and speaker and receiving honorarium and travel accommodations from Exelixis, Inc; consultant for IdeoOncology (formerly Nexus); research, consultant, and independent data monitoring committee for Janssen Pharmaceuticals; independent contractor for Medscape Education; consultant for Merck Sharp & Dohme; honorarium and consulting for Michael J Hennessey Associates; serving as co-editor-in-chief for *Clinical Advances in Hematology & Oncology*, Millennium Medical Publishing; consulting for Myovant Sciences, Inc; NCI Genitourinary Steering Committee member for Leidos Biomedical Research Inc; research for Novartis; research and consulting, Steering Committee, and Honorarium from Pfizer; consulting for Propella TX (formerly Vizuri) and RevHealth, LLC (David Winkler); researcher, consultant, speaker, and honorarium and travel accommodations from Sanofi; consulting for Seattle Genetics; honorarium from UroGPO; honorarium and travel accommodations from UroToday (Digital Science Press); consulting for WebMD; expert witness for WilmerHale Attorneys; and consulting for Xcures. Philip W. Kantoff reports that he has investment interest in Cogent Biosciences, Context Therapeutics LLC, DRGT, Mirati, Placon, PrognomIQ, Seer Biosciences, SnyDevRx and XLink; is a company board member for Context Therapeutics LLC; is a company founder for XLink; is cofounder and CEO of Convergent Therapeutics; was a consultant/scientific advisory board member for Anji, Candel, Immunis, AI Janssen, Progenity, PrognomIQ, Seer Biosciences, SynDevRX, Tarveda Therapeutics, and Veru; served on data safety monitoring boards for Genentech/Roche and Merck; and reports spousal association with Bayer. Lorelei A. Mucci is a consultant to Bayer Pharmaceuticals; receives research funding from Astra Zeneca and Janssen; and serves on the Scientific Advisory Board for Convergent Therapeutics. The other authors declare no conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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