

Race and Outcomes Following Radical Prostatectomy: Can Patient Reported Outcomes Improve Equity in Prostate Cancer?

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Words: 1319/1500

Figures: 1

References: 10/10

Conflict of interest statements:

Alexander P Cole: reports research founding from the American Cancer Society and Pfizer Global Medical Grants.

Caroline M Moore: reports funding from Prostate Cancer UK, Movember, the Medical Research Council, Cancer Research UK, and the National Institute of Health Research (NIHR); receives fees for HIFU proctoring from SonaCare; has received speaker fees from Astellas and Janssen; and receives research support for photodynamic therapy from Spectracure.

Black men with prostate cancer experience worse outcomes and lower quality care compared to those of other ethnicities. While much research on racial disparities in prostate cancer outcomes has been performed in the United States, race-based differences in care are present throughout the world and in equal-access health systems such as the UK—with black men in the UK being 5% less likely to receive definitive treatment compared to white men.¹ The reasons for this phenomenon are complex, and include structural racism as manifested by geographic, community and hospital factors as well as patient-level factors (e.g. culture, values, health literacy, and access to care). These may influence and reinforce discriminatory beliefs, values and distribution of resources which may further entrench inequities in care.

Radical treatment for localised prostate cancer includes radical prostatectomy (RP) and radical radiotherapy (RR). Each of these can have a significant impact on quality of life, particularly due to the effect of treatment in functional outcomes such as urinary, sexual and bowel function. Studies that report differences in racial outcomes in prostate cancer have largely focused on endpoints such as readmissions, length of stay, and survival (as well as process measures such as receipt of definitive treatment and time to treatment). Although these are comparatively easy to measure, the mortality of modern RP is low and endpoints such as readmissions rates and length of stay may ultimately be less meaningful to the majority of men having RP than lifelong preservation of erectile function and urinary continence.

There is a small but growing evidence that urinary and sexual functional outcomes also differ based on race. In their 2008 paper, which prospectively compared outcomes of over 1200 patients treated for localised prostate cancer, Sanda et al showed that Black men treated with radiation or surgery experience overall lower satisfaction with quality of life outcomes compared to other racial and ethnic groups—despite receiving care at the same high volume academic centers.² More recently, our team at Brigham and Women's Hospital, USA showed that Non-Hispanic Black men had significantly lower quality of life scores at 3 and 6 months after RP (despite having care performed by the same group of high-volume RP surgeons).³ The reasons for this difference are unclear and may relate to absolute differences in function, related to baseline differences or differences in care, or differences in expectation or reporting of functional outcomes.

Although race and ethnicity are social constructs with no biological basis, the concept of race provide a useful lens through which to examine the ways in which historically disenfranchised groups experience inequities in health care, education and research.⁴ In diagnosing the cause of worse functional outcomes, a focus access and quality of care is an obvious starting point: For example, we know that non-Hispanic Black men receiving radical prostatectomy in the US are less often treated in high-volume centers, less likely to receive pre-surgical magnetic resonance imaging (MRI), and less likely to undergo minimally invasive surgery.^{5 6}

But these process measures doesn't fully account for why these race-based differences in functional outcomes persist even in equal access systems (e.g. in nationalized health

care systems such as the UK) and amongst groups of men treated by the same, high-volume surgeons (such as the men treated at Brigham and Women's Hospital).

Functional outcomes—the subjective experience of post-operative recovery—are closely linked to both patient expectations and lifestyle in ways that many traditional cancer outcomes are not. Approaches that provide a more personalized approach to treatment counselling are one potential strategy to address differences in functional outcomes.

A survey by the 'Brother to Brother , Man 2 Man' prostate cancer support group in South London in 2019 found suggestions that might increase engagement with prostate cancer cancer support services included 'don't hold it in the hospital' , 'more men that look like me running it', 'do not call it a cancer group' and 'need to feel free to discuss alternatives (eg herbal treatments) without being shut down.' A more general comment was 'we don't feel anyone has our best interests at heart'.

Stacy Loeb led a randomised study of 2904 US adults, using videos to explain prostate cancer screening or clinical trials, where the same transcript was read by a black or white patient, or a black or white doctor. They found that health information is considered more trustworthy when delivered by a doctor, and that racial concordance is significantly associated with trust in prostate cancer information amongst Black adults.⁷

Alongside the technical aspects of surgical care— these results highlight how factors such as health literacy, (justified) medical mistrust and access to survivorship care all may

change the way that a man experiences his recovery after radical prostatectomy. Regarding health literacy, one study of men seen in two low-income, predominantly African American (91%) general medical clinics in Virginia found that fewer than 50% understood the words "erection" or "impotent" and only 5% of patients understood the term "incontinence." ⁸ Add to this the fact that physicians may provide overly optimistic appraisals of the quantity and severity of undesirable side-effects⁹ –there is likely a gap in patient counselling among these communities with lower health literacy. Differences in cultural expectations around sexual performance almost certainly affect the way in which a man may experience the changes in potency after prostatectomy. If providers struggle to translate standardised incontinence and sexual domain scores into more readily accessible terms such as the likelihood of post-operative urine leakage, need to wear incontinence pads, the ability to have an erection, and the need for tablets or devices to have an erection, then expecting patients to translate these outcomes is unrealistic.

Further compounding these disparities there are likely to be differences in access to many of the tools available for addressing survivorship concerns: appointments in dedicated clinics require time off from work and or even something as mundane as obtaining verbal or written instructions for performing pelvic floor exercises to improve continence and potency can be impeded by language and literacy barriers.

The concepts of “personalized or precision medicine” are useful here. Just as the promise of ‘precision oncology’ is to use patients’ unique genetic code and tumor mutations to predict their response to treatment, we may one day have tools to predict ways in which

the unique anatomic and pathological pre-treatment condition of a patient, as well as the specific geographic, cultural, and sociopolitical forces in men's lives affect their subjective experience of cancer care. Incorporating 'patient reported outcomes' has been termed 'PRO-cision medicine', to capture the goal of adapting and modifying treatment to address patient's own subjective experience of their cancer care.¹⁰ This goes beyond simply collecting and reporting quality of life outcomes in the scientific literature—patient reported outcomes should be collected in ways that aid treatment decisions and (when relevant), which are readily interpreted by patients (e.g. by using plain language terminology) and which can be fed forward to both modify treatment and survivorship plans and to help patients to make decisions about cancer care that fit their own values and preferences **(Figure)**.

In earlier years, collecting formal PROMs required the hiring of many data managers and research assistants to collect the data in Excel spreadsheets, correct and curate the information, as well as prompt patients to answers handwritten surveys sent through the post.⁹ Nowadays, cloud computing platforms connected to mobile data collection solutions can make this process much more seamless and pain-free. PROMs should ideally be collected at set treatment related time intervals from patients using a combination of web surveys, point of care mobile devices, and phone/in-person questionnaires. These should use plain-language terminology, give real-time information which can feed-forward to care and survivorship plans, and should do so in ways that are culturally sensitive, and which minimize linguistic barriers to comprehension.

To see how this might work, one only needs to log in to popular online shopping website or streaming service: we receive personalized, curated suggestion for online purchases, music, or movie viewing. These suggestions consider our preferences, tastes, geography and other pertinent information. While choosing a prostate cancer treatment is a far cry from picking a Friday night movie, the way that personalized recommendations can be made in these other realms illustrate the possibilities for prostate cancer treatment. Decision support tools tend to focus on clinical variables, but racial differences in quality-of-life measures after RP clearly underscore the ways in which men's unique life circumstances as well as cultural, demographic and political factors play a key role in the subjective experience of prostate cancer recovery. Simplistic views of racial justice in prostate cancer care may emphasize equal outcomes. But a one size fits all approach fails to recognize that true fairness goes beyond "equal access" and instead provides men the tools to choose the treatment and the sort of outcomes that prioritizes their own values and priorities.

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Figure: Model of Using Patient Reported Outcomes to Inform Personalized Prostate Cancer Care

