Title

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Journal

JNCI Cancer Spectrum, 8(5)

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Publication Date

2024-09-02

DOI

10.1093/jncics/pkae079

Peer reviewed

JNCI Cancer Spectrum, 2024, **8(5),** pkae079
https://doi.org/10.1093/jncics/pkae079
Advance Access Publication Date: September 10, 2024
Brief Communications

Germline testing for veterans with advanced prostate cancer: concerns about service-connected benefits

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Abstract

To better understand veterans' decisions about germline testing, we conducted a single-site, qualitative study of 32 veterans with advanced prostate cancer. Seven days after oncologist-patient discussions about germline testing, we conducted semistructured interviews with patients to explore their decision-making process using an interview guide. Four of 14 veterans with service-connected disability benefits for prostate cancer declined germline testing for fear of losing benefits because their livelihood depended on these benefits. All 18 veterans without service-connected benefits agreed to testing. Veterans declining germline testing based on this concern can lead to suboptimal cancer care because targeted treatments that could improve their outcomes may go unrecognized. Our findings contributed to new language in the Veterans Benefits Administration Compensation and Pension Manual clarifying that genetic testing showing hereditary predisposition is insufficient to deny service-connected benefits for conditions presumed to be caused by military exposures. Clinicians should communicate this protection when counseling veterans about genetic testing.

To tailor care to tumor biology, guidelines recommend germline testing for patients with advanced prostate cancer (1). Many oncologists directly offer testing, also known as *mainstreaming*, to increase timely access to testing (2,3). It is crucial that oncologists discuss the potential advantages and disadvantages of germline testing (1,4). Informed consent is particularly important for veterans who receive service-connected disability benefits because their prostate cancer is presumed to have been caused by a military exposure, such as to Agent Orange (5-7). Such veterans may fear losing their service-connected benefits if tests reveal a hereditary predisposition for their cancer (8,9) in addition to other concerns about genetic discrimination and psychological impact (10). Many Veterans Health Administration (VHA) clinicians, however, do not feel prepared to discuss the elements of informed consent (11). Our objective was to understand veterans' decision-making process about germline testing for prostate cancer, including whether potential risks of service-connected benefits communicated by oncologists influence veterans' germline testing decisions.

We conducted a prospective qualitative study of veterans with advanced prostate cancer who were going to be offered germline testing at a hematology/oncology appointment at the San Francisco Veterans Affairs Medical Center. Potentially eligible patients were consecutively recruited 7 to 21 days before appointments scheduled between November 17, 2022, and November 15, 2023.

For veterans who provided consent, we audio recorded the oncologist-patient germline testing conversation because variability in oncologist communication may influence veterans' decisions. For in-person appointments, we hid a live digital recorder on the desk before patient arrival and removed it upon their exit. For telephone and video appointments, we attended the appointment remotely and recorded the germline testing conversation. During the study period, VHA clinicians had access to a frequently asked questions document in the electronic health record that included a description of the potential advantages, disadvantages, and limitations of germline testing for veterans with cancer. Regarding potential disadvantages, the document acknowledged the concerns of some veterans regarding loss of or reductions in service-connected benefits, but the document implied that a positive genetic test result would not reduce these benefits: "Some VA [US Department of Veterans Affairs] patients have concerns that they will lose or have reduced service-connected benefits if genetic testing shows an inherited cancer predisposition. There is no evidence that links inherited gene variants with military exposures in causing cancer. As a result, a

Received: July 29, 2024. **Revised:** August 13, 2024. **Accepted:** August 30, 2024
Published by Oxford University Press 2024.

genetic test result showing an inherited cancer predisposition should not reduce the connection between your cancer and a service-connected exposure."

Seven days after the appointment, we conducted a 30- to 45-minute semistructured telephone interview exploring veterans' decision-making process for germline testing, including how they considered the potential advantages and disadvantages (Supplementary Box 1, available online). Interviewers followed pilot-tested interview guides that were developed using the Ottawa Decision Support Framework and the critical incident technique to understand veterans' decision-making process for germline testing and identify barriers and facilitators to well-informed, preference-based decision making (12,13). Interviews were recorded and transcribed verbatim. Two authors inductively coded transcripts using the critical incident technique; discrepancies were discussed and negotiated to consensus. We recruited patients until qualitative data saturation was met, defined as no new major emergent themes after 2 consecutive interviews. The study was approved by the institutional review board governing San Francisco Veterans Affairs Medical Center. All participants provided informed consent and received a $50 gift card for participating. Further methodological details are in the Consolidated Criteria for Reporting Qualitative Research checklist (Supplementary Table 1, available online).

Of 63 veterans approached, 32 (51%) completed interviews after their germline testing discussion with 7 oncologists. Median patient age was 76 years; for self-reported race, 1 patient (3%) was American Indian or Alaskan Native, 8 (25%) were Black, 1 (3%) was Pacific Islander, and 22 (69%) were White (Table 1). For 14 patients (44%), their prostate cancer was service connected.

According to the audio-recorded germline testing conversations, oncologists in 12 (38%) of the 32 conversations brought up the potential loss of service-connected benefits. In interviews, 28 veterans (88%) agreed to germline testing; the primary reasons were altruistic (eg, to help family and contribute to knowledge). When stratified by service connection for prostate cancer status, none of the 18 (0%) veterans with non–service-connected prostate cancer declined testing, while 4 of the 14 (29%) veterans with service-connected prostate cancer declined testing. The 4 veterans who declined testing did so based on fear of potential loss of or reductions in service-connected disability benefits. None of the 18 veterans with non–service-connected prostate cancer expressed similar fears. In the qualitative analysis (Table 2), the veterans who declined testing understood the health-related advantages and disadvantages of testing but were concerned that testing may lead to a life-changing loss of income received from service-connected benefits.

> I could lose my VA benefits. And then I would lose my life. My way of life. I would be standing in the soup kitchen, and I'm not willing to subject my life to that. —Patient 10

Prior experiences affected the decision to decline germline testing: 1 patient described that the VHA had previously denied a request to increase service-connected benefits for an injury because of the injury's genetic association. Two patients reported that they would reconsider their decision if service-connected benefits could be protected.

These findings illustrate the importance of informed consent for germline testing to ensure that decisions are concordant with patient preferences. Moreover, we identified a potential barrier to the VHA health care priority of serving veterans who have military environmental exposures (14): 4 patients declined germline testing due to fear of losing service-connected disability benefits.

The use of genetic information by insurance providers to deny high-risk individuals coverage has been a public concern since the 1970s (15). Though federal law currently prohibits health

Table 1. Patient characteristics

Characteristic	Responders (n = 32) No. (%)	Nonresponders (n = 31)[a,b] No. (%)
Age, y		
<70	5 (16)	6 (19)
≥70	27 (84)	25 (81)
Race and ethnicity		
Black, Non-Hispanic	8 (25)	12 (39)
White, Non-Hispanic	22 (69)	7 (23)
Other	2 (6)[c]	5 (16)
Declined to answer or unknown	0	7 (23)
Stage of prostate cancer		
Locally advanced (pelvic lymph nodes only)	9 (28)	—
Metastatic, castration sensitive	15 (47)	—
Metastatic, castration resistant	8 (25)	—
Education		
Did not complete high school	1 (3)	—
Completed high school	5 (16)	—
Completed undergraduate or graduate school	25 (78)	—
Unanswered	1 (3)	—
Income		
<$50 000	13 (41)	—
$50 000 to $99 999	13 (41)	—
≥$100 000	5 (16)	—
Unanswered	1 (3)	—
Service-connected for prostate cancer		
Yes	14 (44)	—
No	18 (56)	—

[a] Reasons for not consenting were Unable to reach (n = 13), Too busy or Study would be too much work (n = 6), Lack capacity to consent (n = 4), Not interested in research (n = 2), Cancer is depressing topic (n = 1), Already had germline test discussion (n = 1), Focused on symptoms (n = 1), Need more time to think (n = 1), Low energy (n = 1), and Unable come in person or use the internet to consent (n = 1).
[b] Empty cells have no value because the study team was not permitted to access these data for nonresponders.
[c] One participant self-identified as American Indian or Alaskan Native, and the other self-identified as Other Pacific Islander and Hispanic.

Table 2. Themes of service-connected benefits and germline testing decision making in veterans with prostate cancer[a]

Theme	Quote
Declined germline testing because of risk of losing service-connected benefits	It was hard because I really want to take [germline testing], but the practicality came down to simply monetary. . . . I'm not going to take the test because it may end up costing me $150 000. I agree with every reason to do the test and I know it could help my family. It's just that when it comes down to the decision . . . it's what better for the family because it helps them also. —Service-connected Patient 6, declined testing
	I just don't like the idea of it may be used against me for benefits. . . . If you're getting benefits for, say, damage from Agent Orange, which I am, but the ailment you have shows up in your genes and they say, well, you didn't get it from this Agent Orange. You were gonna get it anyway. So bye. We'll drop you from our medical plan. . . . Other veterans have also worried about service connection. —Service-connected Patient 9, declined testing
	The VA has taken responsibility for my cancers because of the chemicals that I was subjected to in my line of work in the military. . . . I've got stage 4 prostate cancer and I've got bladder cancer, and I'm unable to work because I have treatment from 2 different types of cancer leaves you stripped of any energy or abilities. So my greatest concern is that I do not lose the benefits that I am currently receiving from the VA. . . . There's no guarantee [VA benefits won't be affected], and [germline testing] would show the link between either chemical exposure or genetic variants? Then I could lose my VA benefits. And then I would lose my life. My way of life. I would be standing in the soup kitchen, and I'm not willing to subject my life to that. I'm not willing to go down that road. —Service-connected Patient 10, declined testing
	I was OK with taking the test until I found out that it could affect me and my children and insurance wise, and you know, be denied. I'm a disabled vet. I'm trying to upgrade my disability, and [germline testing] might affect their decision to upgrade my service connection. I'm not in that. That doesn't sit well. —Service-connected Patient 30, declined testing
Decision influenced by prior VA benefits denial due to genetic association	I know how the VA works and they're always looking. When I hurt my back in 1962, they claimed that it was genetic, that I came in the military with a back injury, which I didn't. They tried to say that I came in the military with a genetic back injury which I didn't have. And so in my mind, every time from then on, if I try to do anything to upgrade [service-connected benefits], if I took that genetic test, they're gonna say "well you were predisposed to this and that's a genetic thing. We can't upgrade you because you know that's your family history." —Service-connected Patient 30, declined testing
Open to reconsider germline testing if service-connected benefits are protected	I think if there was a guarantee that my benefits weren't affected then that would be great. But as of right now, that'll be the only thing but I think I would change. —Service-connected Patient 6, declined testing
	[I would get genetic testing] if it ever got to where it wouldn't affect the decision on insurance issues and in my case, getting upgrades for disability for my service connection. —Service-connected Patient 30, declined testing
Not worried about potential effect on service-connected benefits	I had a little bit of hesitation about what if this affected my benefits but that was gone. That was fleeting. . . . I don't really believe that [genetic testing would could interrupt my service connection]. I'm not worried about it. If I was really worried about it I wouldn't go through with [germline testing]. —Service-connected Patient 23, consented to testing

[a] VA = US Department of Veterans Affairs.

insurers from using genetic information to make certain decisions, such laws do not apply to long-term care, life, and disability insurance—a gap particularly relevant to the 4.9 million (27%) veterans with a service-connected disability (16). For veterans with prostate cancer, service-connected disability benefits typically are established when the Veterans Benefits Administration (VBA) determines their prostate cancer is a "presumptive condition" caused by contact with military exposures such as Agent Orange (6,7). To estimate the prevalence of veterans with metastatic prostate cancer who receive service-connected benefits for that cancer, we conducted a secondary analysis of a cohort of all 21 563 VHA patients with metastatic prostate cancer alive any time between May 2021 and November 2022. In this cohort, 6609 (31%) patients had prostate cancer that was service connected.

Veterans who have or are applying for service-connected benefits for prostate cancer may have concerns that a positive result can cause loss of or render them ineligible for benefits because in the absence of explicit protections, VBA may deny benefits if it identifies separate evidence that makes the presumptive service-related cause of the prostate cancer medically unlikely (17). Surveys have shown that veterans submitting online family history information to the VHA fear insurance discrimination, including fear related to loss of service-connected disability benefits (18). Also, veterans with service-connected benefits are more likely to report that genomic privacy protections are very important compared with veterans without benefits (19). To our knowledge, we are the first to describe first-hand reports of veterans declining germline testing because of such fears, although second-hand reports have been described (8). Although oncologists counseled that this risk is low, patients perceived the ramifications of losing benefits as considerable. Patients did weigh this potential disadvantage against the potential health-related advantages of germline testing. Some reported that they would reconsider their decision should there be guaranteed protection of their financial benefits.

Hereditary forms of prostate cancer have incomplete penetrance and variable expressivity, meaning that for any given patient, germline test results cannot reveal the degree to which a pathogenic genetic variant contributed to the development or severity of prostate cancer (5,6). We presented this argument to the VBA and VA Office of General Counsel in September 2023, along with this study's findings and testimonials from VHA clinicians describing missed opportunities for optimal care because of veterans' concerns about germline test results influencing their benefits. Consequently, the VBA inserted new language in the Compensation and Pension Manual in December 2023,

stating that "genetic test results showing predisposition to a disease are not sufficient to rebut the evidentiary presumption of service connection or to sever service connection that has already been granted" (20).

This language change alone will not necessarily change veterans' decisions. The VHA Genomic Medicine Field Advisory Board has created a workgroup of key VA stakeholders to develop a comprehensive dissemination plan about this update to VBA claim processing procedures and its implications. The target audience includes internal (veterans, clinicians, VBA staff, etc) and external (oncology and genetics professional societies, veterans organizations, US Congress, etc) audiences. This plan will include tailored recommendations, such as revising the aforementioned frequently asked questions document, informing clinicians and patients (eg, using patient-facing decision aids), and increasing public awareness through print and lay media. Although this plan is in development, VHA clinicians should communicate this protection.

Outside the VHA, patient-targeted and insurer-targeted media have colored the implications of genetic testing on insurance decisions in an uncertain or negative light (21-23). For example, a 2018 National Public Radio article was titled, "Genetic Tests Can Hurt Your Chances of Getting Some Types of Insurance" (21). We could not find any documented reports of non-VHA patient concerns surrounding germline testing and insurance, but these concerns may be underreported and warrant investigation in future studies.

Our study is limited by the single site and a small sample size from a quantitative perspective, limiting inferences surrounding the precise prevalence of veterans' fear of losing service-connected benefits. This qualitative study, however, enabled in-depth characterization of critical incidents that have never been reported first-hand, contributing to a new protection. In addition, our results are subject to recall bias, which we mitigated in interviews by "anchoring" participants to their oncologist appointment, and social desirability bias between participants and interviewers.

In conclusion, some veterans have declined germline testing because of concerns about losing service-connected disability benefits. This decision can lead to suboptimal cancer care because targeted treatments that could improve patient outcomes may go unrecognized. The VBA has added language to its Compensation and Pension Manual that should mitigate this concern. Although a dissemination plan is being developed, VHA clinicians should communicate this protective language when offering germline testing to veterans with cancer or other conditions that are or may be presumed to be caused by a military exposure. Future directions for research include understanding how the language change affects veterans' decisions about germline testing and exploring similar concerns about disability, life, and long-term care insurance for patients outside the VHA.

Data availability

The data underlying this article cannot be shared due to the sensitive nature of the data and patients not consenting to their deidentified data being shared outside the research team. Summary-level data may be shared upon reasonable request.

Author contributions

Daniel Kwon, MD (Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Writing—original draft; Writing—review & editing); Maren T. Scheuner, MD, MPH (Data curation; Writing—review & editing); Marissa McPhaul, BS (Data curation; Formal analysis; Project administration; Writing—review & editing); Eliza Hearst, BA (Data curation; Project administration; Writing—review & editing); Saffanat Sumra, BA (Data curation; Formal analysis; Project administration; Writing—review & editing); Carling Ursem, MD (Data curation; Writing—review & editing); Evan Walker, MD (Data curation; Writing—review & editing); Sunny Wang, MD (Data curation; Project administration; Resources; Supervision; Writing—review & editing); Franklin Huang, MD, PhD (Data curation; Supervision; Writing—review & editing); Rahul Aggarwal, MD (Conceptualization; Resources; Supervision; Writing—review & editing); Jeff Belkora, PhD (Conceptualization; Methodology; Resources; Supervision; Writing—review & editing).

Funding

This work was supported by the US Department of Defense (W81XWH-21-PCRP-PRA).

Conflicts of interest

The authors report no relevant conflicts of interest.

Acknowledgements

From the VHA: Shweta Dhar, Sharyl Martini, Gina McWhirter, Carolyn S. Menendez, Robert Pinter, and Deepak Voora

From the VBA: Deana E. Chase

The funder did not play a role in the design of the study; the collection, analysis, and interpretation of the data; the writing of the manuscript; or the decision to submit the manuscript for publication.

The opinions expressed in this manuscript are those of the authors and do not represent official positions of the VA.

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Published by Oxford University Press 2024.

JNCI Cancer Spectrum, 2024, 8, 1–5
https://doi.org/10.1093/jncics/pkae079
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