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The lived experience of prostate cancer: 10-year survivor perspectives following contemporary treatment of localized prostate cancer

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Abstract

Purpose Studies relying on standardized instruments to measure patient-centered harms and benefits of cancer treatment may fail to capture important elements of the lived experience of cancer patients. Further, qualitative studies on the survivorship experience of men with localized prostate cancer (PCa) are limited. We sought to explore the early experience, long-term experience, and advice provided for others among long-term survivors of localized PCa.

Methods Semi-structured qualitative interviews with a subset ($n = 66$) of respondents to a survey of 10-year PCa survivors who underwent active surveillance, radical prostatectomy, or radiotherapy. Topics included early and long-term experiences and advice to other men and physicians.

Results Immediately after treatment, men were mostly satisfied with radiation and active surveillance due to remaining whole and avoiding surgical removal of the prostate. Meanwhile, men treated with surgery felt relieved by the removal of cancer. Some early negative perception was related to short-term anxiety, particularly among men who underwent active surveillance. Long-term experiences included accepting the trade-offs of urinary and sexual side effects with survival. Most men fared well financially, some had strengthened relationships, and many reported greater appreciation and compassion. Men provided essential advice to other men and physicians on the importance of gathering detailed information on treatments and establishing a strong relationship with physicians.

Conclusions Long-term survivors of localized PCa generally do well by accepting the long-term effects of contemporary treatments, experiencing strengthened relationships, and developing a better overall life approach.

Implications for Cancer Survivors We provide useful perspectives and insights for men opting to use current-day treatments for localized PCa.

Keywords Long-term cancer survivors · Prostate cancer · Quality of life · Qualitative research

Introduction

Prostate cancer is the most common non-cutaneous malignancy in men [1]. In 2022, it is estimated that almost 270,000 men will be diagnosed with prostate cancer in the USA [1]. When cancer is confined to the prostate without evidence of metastasis, treatment options, depending on clinical characteristics and patient preference, include surgery with radical prostatectomy, radiation therapy with or without hormonal treatment, or active surveillance, where indolent cancer is actively monitored and treated if it progresses to become higher risk [2].

Long-term studies comparing the effectiveness of these treatments have demonstrated comparable survival outcomes in favorable-risk cancers [3]. As such, the side effects of these treatments, and their impact on quality of life, play a significant role in decision-making [4]. The Comparative Effectiveness Analysis of Surgery and Radiation (CEASAR) study is a prospective population-based cohort study that uses validated questionnaires to compare patient-reported quality of life outcomes for men receiving different treatments for localized prostate cancer [5]. Compared to other

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studies that have evaluated the quality of life after prostate cancer treatment, the CEASAR study represents a more diverse cohort of men from five cancer registries in the USA who were treated with contemporary treatment strategies and is, therefore, a relevant and representative cohort [4, 6].

Contemporary qualitative studies assessing long-term prostate cancer survivors' lived experiences are limited. To illuminate the patient experience beyond the quantitative content of validated questionnaires, we conducted in-depth qualitative interviews with a subset of respondents from the CEASAR study, which originally accrued participants more than a decade ago. This study sought to explore the early experiences, long-term experiences, and advice for others among long-term prostate cancer survivors.

Methods

Participants

The CEASAR study included men younger than 80 years who were diagnosed with localized clinical stage T1-T2 prostate cancer between 2011 and 2012 from five Surveillance, Epidemiology and End Results (SEER) registries (Los Angeles [California], Louisiana, New Jersey, Utah, and Atlanta [Georgia]) in the USA. Surveys including validated instruments assessing common side effects of prostate cancer treatment were sent to patients for completion at time of enrollment, and at 6 months, 1, 3 and 5 and 10 years [5, 7]. To augment the quantitative survey results, we conducted qualitative interviews with a subset of respondents. Specifically, the survey concluded with a brief description of the interviews and invited those interested to provide contact information. Among those who did, we contacted prospective interviewees based on stratified purposive sampling with the goal of enrolling approximately 20 men in each of the three intervention groups (surgery, radiation, active surveillance)—a number expected to reach saturation, i.e., the point at which no new information or themes emerge [8–10]. Within each group, we endeavored to maximize diversity by demographics (e.g., race, education), age at diagnosis, geographic location, and whether or not the patient had experienced disease progression.

Instrument development

We developed a semi-structured interview guide to investigate a range of challenges and concerns, including an in-depth exploration of patients' lived experience of key quality-of-life issues and their reflections on the meaning and implications of their treatment choices. Questions were developed based on existing literature, first-hand knowledge of, and experience with clinical care of patients with prostate cancer. In particular, our experience with previous and current research of men in the CEASAR study informed some of our questions. The interview questions were not crafted to follow the specific quality of life items men filled in the quantitative study but to ask in an open-ended manner about larger conceptual areas raised in the surveys. After refinements based on three pilot interviews, the final instrument (Appendix A) comprised 14 main questions. Here we report on three key topics (1) early experience following treatment, (2) long-term experiences, and (3) advice to physicians and other patients. Data unrelated to long-term survivorship, including initial diagnosis and decision-making, will be reported elsewhere.

The larger CEASAR study, including these interviews, was reviewed and approved by the Institutional Review Boards at Vanderbilt University Medical Center and each participating SEER site. Participants provided written informed consent for the CEASAR study, including the option to participate in this qualitative interview study. Among participants who indicated in their survey willingness to be contacted about an interview, we purposively selected men based on maximizing diversity.

Data collection

Interviews were conducted by phone between November 2020 and August 2021 by one trained member of our research team. At the beginning of each interview, we reviewed a study information sheet and obtained the interviewee's verbal agreement to participate and for audio recording. The interviews were audio recorded and transcribed verbatim. Interviews averaged approximately 45 min, and participants were offered $50 for their time.

Data analysis

We uploaded professionally transcribed interviews into qualitative research software (MAXQDA 2020) and used an overarching grounded theory approach and constant comparison to code and analyze the data [11–13]. The topics and subtopics discussed were from the interview guide. The content of what the interviewees said, i.e., the themes and subthemes, arose from their answers and were not determined a priori. Specifically, the research team iteratively developed a codebook based on key domains reflected in the interview guide as well as themes emerging from a review of transcripts. Two trained team members independently applied broad structural codes to a starting set of transcripts, comparing the results and modifying code definitions in consultation with the team as needed until reaching $\geq 80\%$ inter-coder agreement. The remaining transcripts were structurally coded by one team member, with the second team member independently coding every tenth transcript to ensure inter-coder agreement was maintained. The second team member, who had expertise in qualitative research as well as community-based experience with men's health, then applied content codes to capture additional meaning (see Appendix B for additional methodologic details) [14, 15].

Narrative segments presented here are exemplary of frequently mentioned ideas, labeled with a participant ID; more examples can be found in Appendix C.

Results

Participant characteristics

Overall, our participants ($n = 66$) were diverse regarding geographic location, education, and race/ethnicity (Table 1). They were distributed roughly equally among the three intervention groups (surgery, radiation, active surveillance); approximately one-fifth were diagnosed before age 55, and a similar proportion experienced disease progression after the initial intervention.

The key topics and subtopics from the interview guide, as well as the emerging themes and subthemes that emerged from the answers of the interviews, are shown in Table 2.

Early experience following treatment

Perceptions of treatment

When asked about their experience with the approach they initially chose upon being diagnosed with prostate cancer, most interviewees responded positively: "I didn't like to get the cancer, but my experience was good" (S-57). Many said undergoing the intervention they chose was easy…

> I don't want to make it sound like it was going to Disneyland, but it just wasn't very painful or invasive or uncomfortable. (R-66)

…or easier than expected:

Table 1 Participant characteristics ($n = 66$)

	Atlanta		Los Angeles		Louisiana		New Jersey		Utah		Total	
	n	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*	*n*	*(%)*
Total participants	13	(20)	15	(23)	14	(21)	12	(18)	12	(18)	66	(100)
Age at diagnosis												
< 55 years	3	(23)	3	(20)	3	(21)	2	(17)	1	(8)	12	(18)
55 + years	10	(77)	12	(80)	11	(79)	10	(83)	11	(92)	54	(82)
Education												
Grade school or less	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)
Some high school or technical school	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)	0	(0)
High school or technical school graduate	0	(0)	0	(0)	4	(29)	0	(0)	1	(8)	5	(8)
Some college	2	(15)	7	(47)	2	(14)	1	(8)	6	(50)	18	(27)
College graduate	5	(38)	4	(27)	3	(21)	3	(25)	2	(17)	17	(26)
Graduate or professional school after college	6	(46)	4	(27)	4	(29)	8	(67)	3	(25)	25	(38)
Unavailable	0	(0)	0	(0)	1	(7)	0	(0)	0	(0)	1	(2)
Race/ethnicity												
White/Caucasian (not Latino/Hispanic)	10	(77)	7	(47)	9	(64)	12	(100)	12	(100)	50	(76)
Black/African-American (not Latino/Hispanic)	3	(23)	4	(27)	2	(14)	0	(0)	0	(0)	9	(14)
Latino/Hispanic/Mexican–American	0	(0)	1	(7)	0	(0)	0	(0)	0	(0)	1	(2)
Asian/Oriental/Pacific Islander	0	(0)	1	(7)	0	(0)	0	(0)	0	(0)	1	(2)
American Indian/Native Alaskan	0	(0)	0	(0)	1	(7)	0	(0)	0	(0)	1	(2)
Other	0	(0)	1	(7)	1	(7)	0	(0)	0	(0)	2	(3)
Unavailable	0	(0)	1	(7)	1	(7)	0	(0)	0	(0)	2	(3)
Initial treatment												
Active surveillance	5	(38)	7	(47)	4	(29)	3	(25)	3	(25)	22	(33)
Radiation	4	(31)	3	(20)	5	(36)	4	(33)	4	(33)	20	(30)
Surgery	4	(31)	5	(33)	5	(36)	5	(42)	5	(42)	24	(36)
Recurrence?												
No	11	(85)	12	(80)	10	(71)	9	(75)	11	(92)	53	(80)
Yes	2	(15)	3	(20)	4	(29)	3	(25)	1	(8)	13	(20)

Table 2 Topics with corresponding emerging main themes and subthemes[a]

Main topics	Subtopic	Main theme	Subtheme
Early experience	Perceptions of treatment	Positive	Easy and easier than expected
		Neutral	As expected, mild/tolerable discomfort
		Negative	Harder than expected, anxiety, pain, serious adverse events
	Satisfaction	Satisfied	Successful outcome, keep prostate or remain whole, and immediate removal
		Dissatisfied	Hindsight
Long-term experience	Side effects	Urinary	Frequency, urgency, and flow. Incontinence. Severity: mild and moderate, severe, and sleep. Acceptance: sleep, life stage and trade-offs
		Sexual	Severity: mild, severe. Interventions. Acceptance: general, life stage and trade-offs
	Relationships	No major impact	Relationships already strong, changes inconsequential and decreased over time
		Positive long-term effects	
		Negative long-term effects	Strain and anxiety, worries for others
	Life approach	Acceptance	General and acceptance of mortality
		Greater appreciation	General, better life and re-prioritize
		Compassion	
		Spirituality	No effect, positive effect, and negative effect
		Focus on health	
	Self-perception	Sexuality	Masculinity Role as life partner
		Aging and mortality	
		Vulnerability	
		Fortunate	
		Advocate role	
	Financial	Work and income	Retired, no major impact, had time off, recovered quickly, had impact and lost income
		Insurance	General, insurance-related concerns: high out-of-pocket costs and coverage. Able to manage costs, and declined procedures
Advice	For health care providers	Information	Options, reliability, details and statistics, information overload. Timeframe, level of urgency
		Information-related	Honesty, guidance and second opinions
		Provider-patient interactions	Time, compassion, reissuance, and connection
	For other men	Overall health	Regular check-ups, PSA screening and controversies. Early detection
		Decision-making	Take time Understand options Understand options: autonomy Info seeking: multiple sources Outcomes vary
		Providers	Skepticism, skepticism: COI, bias. Comfort, confidence, and expertise: seek out best
		Prostate cancer	Do not panic and do not ignore

[a] The topics and subtopics listed were from the interview guide, whereas the themes and subthemes emerged from the answers of the interviewees

> I would say that it was probably easier than I anticipated... I didn't mark it on my calendar and keep track of the days but it was a relatively short amount of time, from the time I'd gone in for the surgery until I started feeling like, gee, I'm 100%. I can go back to work. (S-35)

Some were more neutral, saying that their chosen intervention went as they expected: "[It was] what I had envisioned – not harder, not easier" (A-56). In some cases, healthcare providers or other patients helped set expectations appropriately:

> It was about what I expected, after I did all the reading and talking to previous patients about what you have to go through. (R-27)
> I think Dr. [Name's] team was very direct and honest about what would happen, how long it would take. So I was completely prepared for that. I can't say it was harder or easier than I was prepared for. It was right on point. (SR-09)

In addition, interviewees were familiar with some of the procedures, having experienced them as part of screening and/or diagnosis, such as this individual who describes getting repeat biopsies while on active surveillance:

> I had already been through a biopsy, so I knew what I was in for and how unpleasant they are… So, it really is pretty much what I expected, fortunately. (A-61)

Other "neutral" reactions included characterizing their initial approach as involving mild or tolerable discomfort, particularly relative to the alternatives:

> I didn't look forward to the biopsies, which was once a year. I had several days of discomfort from that… It's not something I was really excited about, but I just saw that as my best option at the time. (AR-65)

However, some interviewees had more negative reactions to their initial experience. A few found treatment harder than expected:

> I was in more pain than I thought I would be when I was in recovery… The catheter was uncomfortable and, what is the word I want, humiliating, embarrassing? I felt vulnerable. That's the word. (S-48)

Anxiety was another issue, particularly (but not exclusively) among those who chose active surveillance:

> Thinking about it all the time, that's it. Thinking about it all the time. Did I make the right decision? Should I have went on ahead and got it done, get it over with? (AR-51)

A few who chose radiation or surgery encountered serious adverse events:

> It radiated my bladder and my kidneys and it shut me down and it made me terribly sick… I was in intensive care for seven days. (R-02)
> I ended up having dual pulmonary embolism. (S-10)

Satisfaction

Despite negative experiences, a vast majority of interviewees indicated they were satisfied with the approach they took. Perhaps not surprisingly, many of these 10 + year survivors were satisfied because the course of action they selected was successful: "Yes, I would do it the same, because I'm still alive after 10 years" (A-37). Some who chose active surveillance or radiation said they were glad to "be whole":

> I get to keep my prostate. I don't know what it would be like if I did not have it. I know it's an organ that's used in going to the bathroom, and it's also used in the other, the sexual part. (A-59)
> It turned out to be much more of a speed bump than a brick wall… I had a relative who was diagnosed exactly the same time as me and actually opted to go through the surgery and six months later, he was still just miserable and I was whole and feeling good. (R-66)

In contrast, relief to be rid of the cancer from their bodies was a common sentiment among those who chose surgery:

> I tell a lot of people, I say I'm a walking miracle, that God blessed me… Being able to find it and then take care of it right then. (S-19)
> Getting rid of that disease—that's a good thing about it. (S-47)

Among the small number of interviewees who expressed dissatisfaction with the approach they took, hindsight was a common theme—potentially leading to a different treatment decision:

> I think, in reading some of the research, I might've delayed it, I don't know, even for 36 months. If you had 36 months more of a home life, sex life, live it. I might've done that. The minute you hear prostate cancer, "I got to go tomorrow. I got to go next week. I got to go. I got to go." So I think I would've gone slower on the whole thing. (SR-45)

Long-term experience

When asked about longer-term experience with prostate cancer and its treatment, interviewees described several areas in which it had an impact on their lives.

Side effects

Many interviewees had lasting side effects, primarily urinary and sexual. Urinary problems included issues with frequency, urgency, and flow, as well as incontinence.

Most who experienced these described the problem as mild or moderate:

> Having probably a little less control over urinating than I had, but I've developed ways to compensate for that, and it hasn't caused me any problems. The only thing, I tell my wife, I said, there's just not a good reason to pass by a perfectly good bathroom anymore. (R-44)

Although many reported that medical or surgical interventions had been helpful, a few continued to experience challenges that were more severe…

> For the rest of my life, I'll be looking at this big warehouse of incontinence supplies. That has been my most serious, worrisome problem in that … it affects where I go and when I go somewhere, or if I go somewhere…. I don't really go nowhere for one or two days, because I have to carry so much stuff with me. If I go visit, I visit and I come home back home. When I leave my house, I'm padded down. Sometimes I got on three different padded type items to catch my urination, you know what I mean? But I survive. (RR-23)

… including sleep disturbance:

> The incontinence has gotten worse, so I have gotten thicker and thicker diapers when I go to bed and I still need to change my sheets and pads and wash them when I get up in the morning. That's rather unpleasant and uncomfortable and sometimes I don't sleep very well as a consequence. (S-48)

Whether urinary side effects had a minor or more significant impact on their daily lives, acceptance was a common theme in interviewees' narratives. Some related this to their life stage:

> My wife and I like to walk, we take extended walks. But... now I don't dare take those long, long walks, unless there's some place that I can dodge into to relieve myself. I'm very, very cognizant of that. Now, is that a result of not having a prostate or is that just a result of being 72 years old? I don't know the answer to that. (AR-16)

Others framed their acceptance with reference to surviving cancer: "I guess I'm satisfied because I'm still here" (RR-23).

Problems with sexual function were also common. Again, some interviewees described these as relatively mild…

> I'm kind of used to everything the way it is, and so it doesn't seem like a big deal to me. One thing I noticed is your erections are not as firm as they were before. It's not that bad. (S-33)

…while others experienced them as more severe: "It bothers me that the sexual activity is pretty much over—or is over" (S-32). Success with interventions such as medications, injections, and devices varied:

> I've tried every type of [intervention for] erectile dysfunction except injection, and none of them have been successful. (S-10)
>
> There was some still side effects of ED. I can't say as for other men, but let's see, what was the one? [Drug A]. That had no effect on me after the surgery. [Drug B] was the one that helped me get back into the light. (S-19)

Similar to discussions of urinary side effects, acceptance of diminished sexual function was a common theme, including for reasons related to life stage and cancer survival:

> At 74-years-old, sexual activity is, I'm happy to say, somewhat in existence but nowhere near as important emotionally or otherwise as it has been earlier in my life. (A-14)
>
> The sexual part has turned out okay for me. I do take a small amount of [Drug A] and I have to do an injection for sexual activity. But in a lot of ways, I'm a lot more fortunate than other people that I know… Would I have rather not had it? Yeah. But ... considering all the alternatives, I think I'm pretty fortunate. (S-11)

Relationships

Many interviewees said their experience with prostate cancer did not have a major lasting impact on relationships. Some of these described their relationships as already strong—and an important source of support:

> The relationship with my wife is wonderful. My wife and I have been together since she was 17 and I was 19. and I worship the water that she walks on. She was the rock of Gibraltar when I was going through this. (S-54)

Others indicated that any changes were either inconsequential…

> My wife and I, we have been married going on 53 years, we've had a very close relationship and our relationship is not necessarily built around sex. Maybe it was the first few years of our marriage, but there's deeper things in our relationship now than the actual sex act. (R-40) or decreased over time:
>
> My kids, I don't know what they felt on the inside, but they adjusted pretty quickly to the fact that I was seeming to survive… My relationship with my wife, she's

> just relieved… She's gotten through it pretty well and she's I think happy to still have me. (R-36)

For some interviewees, their experiences had a positive impact on relationships:

> I think it makes you think about your mortality and so you try and do better in relationships and maintain relationships and seek out people. (A-39)

One described how sexual dysfunction served to enhance other areas of his relationship:

> That helped my marriage … because I became a better listener... I make love to you now outside the bed… When you get your hair fixed, I know it's fixed now. When you put on a new dress, I know that. Because I can't do nothing in the bedroom physically, so I'd better focus on the things that's external. (S-57)

Several interviewees, however, said their journey through prostate cancer had a negative impact on relationships. These included strained marriages and tested friendships:

> I put tremendous strain on my relationship with my wife. It didn't wreck the relationship, but it made it a bit choppy at times. And it's adjusted our behavior from that point onwards. So, it's something I would not want to go through again, but it happened. (AR-15)
>
> I found out to some degree who my friends are and who my friends are not. (R-02)

More generally, interviewees recognized the negative impact of anxieties and worries for those close to them:

> We made it a family trip out here, and I sat down with mom, and explained it to her. It was very shocking to her... It rattled her, I guess you could say, in the fact that she had lost her husband to prostate cancer, and now her only son is informing her. (A-62)
>
> Well, my wife... it's periodic, we'll get worried, and then we won't think about it anymore. But her feelings of life without her partner are intense. So … when this big scare came on and the periodic scares we've had since, that weighs on her mind. (SR-45)

Life approach

Many interviewees expressed acceptance of prostate cancer as a life event: "I kind of look at it like you just roll with the punches—you deal with it when it happens" (A-56). This included acceptance of death as a potential outcome of their diagnosis:

> I'm very comfortable with life. I'm very comfortable with death… Like I told the doctor, he says "Can we do anything to help you?" And I says, "No, doc." I says, "You know, having six children, and a wonderful wife that loves me regardless of my condition. It's just fine. I can live with it. It's not that big of a deal to me." (R-40)

Some described their experience with prostate cancer as giving them "a greater appreciation for life" (A-39), and a desire to "try to live a better life" (R-66) and to re-prioritize by discarding "the petty sort of worries that plague you as you go through life" (SR-09). As one interviewee put it:

> Sometimes I think to myself hey, I'm a cancer overcomer. Let's just take a day at a time and enjoy life and every day is a gift. (S-13)

Several mentioned their experiences had made them more compassionate toward others:

> In a weird way, it's made me a better person… It made me realize there's an end, an end to life. I'm not saying I was a bad person. I'm not saying that at all, but it made me a better person, more loving, caring, and empathetic. (SR-07)

Interviewees commonly indicated that having prostate cancer either did not affect their spiritual life…

> My spirituality has been the same. The prostate cancer's not lessen it, or give me any great new insights into life and death… But my spiritual life is, I would say fairly strong, but it hasn't changed because of the prostate cancer. (RR-63)

… or that it had a positive effect:

> Anything that makes you more aware that your future may be shorter than what you would like it to be, I think that it makes you more aware spiritually. I think it makes you more aware of trying to enjoy what you have left of your life. (SR-08)

A few, however, described a negative impact on spirituality:

> I became very bitter with God, if you will. Why did this happen to me? No one in my family had ever had cancer. I live a good Christian life. I'm a nice person. So, why would I be struck with something like this? (S-06)

Regarding their approach to life more generally, many interviewees mentioned focusing attention on their overall health—to which some gave credit for their successful outcomes:

> The things that I previously loved to eat, my wife cut it out. I began to start eating more green and leafy vegetables. The alcohol consumption went down… I get a lot of exercise and I stay mentally fit, as well as

> physically fit. So those things have contributed a great deal to my success, no doubt. (R-43)

Self-perception

Some interviewees described changes in how they perceived themselves as a result of their journey through prostate cancer. Some of those who experienced long-term impact on sexual function described feeling "a little less manly" (R-40) and reflected on their role as a life partner:

> We both liked sex, so it's difficult… She's been very generous about it, but I feel... what's the word? I don't feel very good about it, that's for sure. Makes me feel unworthy. Not fulfilling my role in life for not helping her. (AR-25)

More generally, awareness of their own aging and mortality were common themes:

> I feel older because I spend a lot of money and time in the adult incontinence section of CVS and Amazon. Every time I put on a pair of incontinence diapers, I go, huh, I didn't see this coming. (S-48)
>
> It has played a role in my unhappy recognition of the fact that I'm approaching end of life. As I say and as my actuarial tables would say, I've got 15 or 20 years likely left, but it could be over any time. Prostate cancer is somehow associated with that. (A-14)

For some, this extended to a feeling of vulnerability:

> You know how most people think they're bulletproof, and nothing's going to hurt them, and now you see where [if] you can get [prostate cancer] you can get other things, too, and you can also have a reoccurrence, so I'm always on the watch for things like that. I don't feel like I'm quite as bulletproof as I used to be. (S-33)

Recognition of human vulnerability to disease led some to perceive themselves as fortunate…

> It's highly visible or noticeable to me that a lot of people deal with a lot of health issues that I have never had to deal with. I'm very, very fortunate in that regard, very fortunate. (S-35)

… and to take on an advocate role: "It's just one more thing I've gone through in life and … hopefully be of help to other people going through it" (A-52).

Financial

Many interviewees were retired or near retirement at the time they were diagnosed. Among those still working, most described their experience with prostate cancer as having a minimal impact: "I missed a few days initially when I had the treatment, but other than that it doesn't affect my ability to do my job" (RR-63). Common reasons included having sufficient leave time ("I was very fortunate that I had plenty of leave time" (A-42)) and a quick recovery ("It had really no work impact, because other than the immediate time for treatment, and a couple days out to recover, that was about it" (R-60)). A few described more significant impact on work, including longer than expected recovery…

> For the second surgery, the recovery was much more difficult than they led me to believe. They were saying I can go back to work in like a week or two, that [ended up] being more like six weeks. (AR-65)

… and lost income:

> I have the type of job where I get paid a base salary and commission, so obviously during the period of time that I wasn't working, I wasn't selling anything, so the commission side of my income went down. (S-06)

Most interviewees said the financial impact of prostate cancer was relatively small in that costs were largely covered by insurance:

> Gratefully, I have had good insurance coverage the whole way, and I been able to cover any of the auxiliary expenses beyond that with no problem. So honestly, I've just been extremely fortunate. (SR-55)

A few noted insurance-related concerns, including out-of-pocket costs on high deductible plans, as well as questions about coverage:

> When we had to switch insurance companies, the surgeon who did my surgery was not on my insurance anymore. So I was trying to figure out what to do with a new insurance group. That was another confusing struggle, really stressful time… It's interesting—issues with the actual disease was not nearly as frustrating and stressful as just dealing with the health industry. (A-52)

In general, interviewees described being able to handle the costs—including in some cases with the help of patient and employee assistance programs—although one described declining procedures to contain costs:

> I'm kind of a tight person with finances, so I'm like, "Oh, come on. An MRI? Are you serious? We don't want to do that." (A-64)

Advice for others

Interviewees offered a wide range of advice for health care providers and for other men.

Health care providers

Interviewees emphasized the importance of providers giving newly diagnosed patients complete information about their options. A few suggested this should include information about alternative therapies: “The main thing is that people should know all the modalities that are available, even if they’re not yet all available in the United States” (AR-15). At the same time, several said providers need to be an authoritative source of reliable information, “to put all the facts out there so that people know from the get go, what they’re getting into and can make an intelligent decision” (A-62) and “to discount all the nonsense that people put on social media” (AR-16). Many advised that this information should be detailed, “that doctors should give more thorough advice to the patients about the effects of each and every treatment” (S-47), letting patients know “what is and isn’t known, and what can and can’t be done” (A-53). Interviewees acknowledged, however, that detailed written information can be overwhelming, and urged health care teams to review the information verbally:

> When I was first diagnosed, Dr. [Name] gave me a book on prostate cancer. Well, it’s a booklet, and it was probably 3/16-inch thick talking about options… These caregivers ought to take time, use a nurse practitioner, use someone on their staff to go through what these options mean and what the side effects and everything will do, and especially the probabilities of success because most of the literature underestimates the complexity of the side effects… Most people don’t take time to even read what the doctor gives them. (R-21)

They further advocated being clear about the timeframe or level of urgency for decision-making:

> What happens if I decide to wait 30 days? What happens if I decide to wait six months? Can I do that? Can I wait 30 days? Can I wait six months? Can we look at this. Is it non-aggressive? Is it aggressive? How aggressive is it? (A-22)

Other information-related advice for providers included the importance of being honest (“the doctors need to be honest with their patients—don’t pull the rug over their eyes” (A-26)) and providing guidance (“discuss the options with the patient [and] at the same time, not leave it entirely up to the patient, but make a recommendation” (R-03)). Interviewees urged providers to support second opinions:

> [Providers should] advise their patients to consult with different specialists before any decision was made, that would be better rather than appearing to know everything. (AR-25)

They also made suggestions regarding provider-patient interactions more generally. A major theme was time:

> I know they’re busy people, but a lot of times when I go for a doctor visit, they’ve got so many people scheduled, they don’t take enough personal time with their patient to talk freely and ask the right questions and voice concerns. (R-27)

They particularly highlighted the importance of compassion…

> You know, you’re talking to a person, not a patient. You’re talking to somebody who has a problem. They come to you, they got a problem, and they’re looking for some help. (R-27)

… and taking time to focus on and connect with patients:

> It’s very easy to be dismissive of things that have become routine… The way the doctors and staff, the nurses, interact with the patient by connecting with them, making them feel comfortable, making them feel confident that they are being paid attention to, that they’re listening to their concerns or their complaints, makes the patient feel more confident that they are getting treated properly and as well as can be expected. (S-01)

Other men

For other men, interviewees offered advice spanning from screening for prostate cancer through coping with a prostate cancer and its treatment.

For all men, they counseled the importance of attending to their overall health, including regular check-ups (“Don’t be afraid of going to a doctor. Go to the doctor. Get your physicals.” (S-32)) and routine PSA screening (“Number one, make sure you absolutely, positive, unequivocally have your PSA checked on an annual basis.” (S-06)). Several acknowledged controversies around PSA testing, but largely endorsed it nonetheless:

> For guys that just don’t want to check it, I’d caution against that… I’ve read articles where we examine [PSA] too much, and [prostate cancer] is not going to kill you, and don’t worry about it, and it alarms people unnecessarily. I don’t buy that. I think knowledge helps you deal with the process. (A-50)

Many attributed their successful outcomes to early detection:

> I suspect there’s a lot of people out there that don’t get physicals like me. They should. When I hit 40, I started pushing to get a physical once a year and that’s probably why they were able to determine it and catch it

> the way they did. If I just chickened out and not gone, I probably would have had more serious problems and they may not have been able to resolve it. (S-46)

Once confronted with a prostate cancer diagnosis, interviewees recommended a thorough approach to decision-making. Many advised patients to take time and ask questions:

> Ask plenty questions and don't be afraid to wait to get all your questions answered. Otherwise, be patient, don't rush into it, make sure you feel comfortable with the decision you make. (S-10)

Nearly all suggested that patients understand all their options: "I would advise them to really do their homework, really examine all of their options, in as great as detail as possible, and make the best decision for them" (R-66). For several, this included an explicit element of autonomy:

> Here's a key to the whole thing, is talking to the doctor, having as much knowledge yourself on your own behalf. If you don't have no knowledge yourself, then you don't know what the hell, the doc say, "Hey, let's do surgery tomorrow." You don't know no difference. You got to have a knowledge yourself, make some kind of decision based on what is best for you. Knowledge is a key. (A-22)

Seeking out information from multiple sources was a prominent theme:

> There's a lot of information available. Your doctor certainly is one obvious major source. Maybe you talk to your GP as well as talking to a urologist, an oncologist, depending on whatever your prognosis is. And do avail yourself with the literature that's out there. (S-17)

Although this included talking with other patients, several cautioned against giving too much weight to what worked for others, given that outcomes vary:

> I would say that they could talk to other people to find out what the options are but I wouldn't rely on somebody else's experiences... Do a little bit of research or a lot of research and then make the decision that's best for your circumstances not just because they your friend and that work out best for them. (A-42)

Interviewees also offered advice to other men concerning health care providers. A few recommended skepticism; as one stated:

> I'm much more cynical about medicine. I am much more questioning about everything that doctors suggest and want to do. I follow my own body much more carefully… It's made me very cautious about whom I go to for medical advice… I used to think of medicine as sacrosanct. If the doctor said, "Go, right," you go right. Now, they're going to have to give me really detailed information before I will do anything that they suggest. (AR-15)

A few noted that health care providers may have conflicts of interest and biases:

> There's so much evidence over the years of doctors recommending things that enrich themselves or that support their long-held biases even though current best practice no longer supports those long-held biases, that I fear that there might be victims out there who are having their prostates removed for no good reason. (A-14)

Beyond these themes, however, interviewees' comments about providers were generally more positive. Many underscored the importance of patients feeling confident and comfortable with their physicians:

> First off I would ask them the question, "How much confidence do you have in your urologist?" Based on their response, I would probably suggest, "If you don't have confidence in that person, maybe you ought to look elsewhere." (S-35)

They urged patients to seek out recognized expertise and the best possible care:

> If you've got an opportunity to get the best, get the best. Forget about this nonsense, "Well, it's too far to travel and I can't do this." No... I'm a firm believer in go to the place that's most practiced. The first suggestion I would make is go to where you can get the best treatment. (AR-16)
> Oh, I'm horrified to hear of men being treated for things like mine ... at random hospitals all over the place… I would advise any man going through this to find the highest quality specialized cancer institute they can find … to get the best care you can possibly get. (R-36)

Finally, when discussing advice about prostate cancer in general, interviewees had a clear dual message for other patients—don't panic but also don't ignore it:

> I guess the most important thing is don't be afraid of it… Prostate cancer is a very treatable illness. Of all the cancers, prostate is one of the ones that you can be reasonably assured that you're going to have a successful outcome and you can be cured. (S-01)
> One of the bad things is that there's a general perception out there that prostate cancer grows slow. People say, "Well it grows slow and you don't have to worry." … But you know what? That might not be the type of prostate cancer that you have... Prostate cancer can be

> different and can be aggressive and stuff. So you really got to address it with your doctor and stay in contact on it and not try and put it out of your mind and get into denial. (R-05)

Discussion

We conducted in-depth qualitative interviews to explore the early and long-term experiences of prostate cancer survivors and the advice these men have for others. We accrued patients from a well-characterized cohort of men with prostate cancer who have been followed for 10 years after undergoing contemporary treatments for localized prostate cancer. The CEASAR study recently reported 5-year quality-of-life outcomes based on standardized instruments that measure the severity of urinary, bowel, and sexual dysfunction after treatment [5].

The current qualitative study sheds light upon those findings, including patients' experiences and satisfaction in the (1) immediate aftermath of treatment; (2) longer-term experiences with side effects, as well as the impact of cancer and cancer treatment on relationships, life approach, self-perception, and finances; and (3) their advice for health care providers and other men.

First, we noted that most interviewees had a positive or neutral experience within the early post-treatment period, reporting that treatment was easier than or as expected. However, some men had negative perceptions about the management option selected, where anxiety was commonly reported, particularly those who underwent active surveillance. Active surveillance aims to defer the harms of treatment and ultimately preserve the quality of life with respect to urinary, bowel, and sexual function. However, it appears that cancer-related anxiety is an unintended short-term consequence of that choice. While this anxiety is reported to decrease over time [16], it is estimated that around 10% of patients on surveillance will undergo definitive treatment without an apparent clinical trigger, presumably due to anxiety [17]. Common causes of anxiety that emerged from our study included the notion of living with cancer and doubts about whether men should have chosen surgery or radiation therapy. To reduce anxiety associated with surveillance and potentially improve adherence to surveillance, Wade et al. highlighted the importance of having a strong relationship between men on active surveillance and their treating physicians in ameliorating anxiety [18]. Another strategy tested in a randomized trial highlighted the importance of exercise in reducing anxiety associated with surveillance [19]. Therefore, recognizing anxiety and working to reduce it has the potential to improve prostate cancer patients' survivorship experience.

Studies assessing treatment-related regret, including one that utilizes the current cohort, report that 10–15% of men regret their initial treatment of choice, while the remainder are satisfied with their choice [20, 21]. Similarly, our study found that most men expressed satisfaction with prostate cancer treatment irrespective of treatment choice. Those who had radiation therapy and active surveillance reported "being whole" as a source of satisfaction. In contrast, men who had surgery were satisfied that the cancer was removed from their bodies.

Second, within the context of long-term experience, men reported on how their relationships with their partners and others were affected by prostate cancer. Some men noted that their relationships were strengthened, including those with sexual dysfunction, as they focused on enhancing other aspects of their relationships with their partners. In contrast, some relationships suffered from the strain of coping with cancer and the anxiety associated with it. Generally, treatment positively affected prostate cancer survivors' overall approach to life, where men became more appreciative, compassionate, and focused more on their overall health.

Moreover, we noted that many men accepted the urinary and sexual side effects of treatment because they understood the trade-off with mortality, i.e., dealing with side effects was better than death. Acceptance was also aided by life stage; men recognized that even if they had not had cancer, they might have urinary and sexual issues related to aging. In addition, men accepted the mortality risk and cancer itself—where the latter has been shown to play an essential role in reducing general and cancer-specific distress [22]. Another qualitative analysis of a study that randomized men to radiation therapy found that men develop coping strategies to deemphasize and normalize the side effects of treatment by blurring age-related declines with treatment-related side effects [23].

On the other hand, prostate cancer treatment is known to negatively affect masculinity in the long term [24]. In a systematic review that assessed coping mechanisms in prostate cancer patients, some of the meta-themes noted included reframing masculinity and accepting a more flexible definition of it [25]. Our interviewees expressed similar sentiments, where the effects of prostate cancer impacted their self-perception of masculinity and their role as life partners.

Another important aspect of long-term survivorship is the financial burden associated with cancer treatment. Financial toxicity (or burden) is reported to decrease over time, affecting 15% of men with localized prostate cancer within 6 months of treatment and 3% within 5 years [26]. Some qualitative studies have found that the financial burden of cancer is linked to adverse psychological outcomes [27]. We found that most men managed well financially because many were retired at the time of treatment, and, for many, costs were covered by insurance. Among working men, minimal impact on work was reported because they either had adequate leave time or seemed to have had a quick recovery. However, in English couples younger than 65 years affected by prostate cancer, Collaco et al. noted that many experienced financial burdens, particularly those self-employed [28]. The authors elaborated that patients at that age may have more financial obligations, such as education expenses for their children. While some differences may be partly due to different healthcare systems, self-employed men or those working on commission appear to be most subject to financial loss, as noted in our study.

Third, some of the novel insights in this study were related to the advice men would provide to physicians and others diagnosed with prostate cancer. The importance of prostate cancer patients collecting detailed information upfront and seeking multiple sources of information to make an informed decision, including understanding the side effects associated with treatment, was encouraged. In a similar study of prostate cancer survivors in South Wales, Mazariego et al. also found that men reported a lack of informational support for treatment side effects, further highlighting the importance of careful counseling and effective communication about expectations by healthcare providers [29].

Furthermore, throughout the interviews, an essential factor associated with acceptance was being prepared and informed before undergoing treatment. Both early and long-term effects were easier to deal with when men felt like they had been told about side effects up front and that conversation had been part of their decision-making.

Our findings may help guide the efforts of clinicians and third-sector organizations in supporting men with prostate cancer. For instance, care providers may coordinate with non-profit organizations that provide financial aid or social support to working men who are subject to miss work and lose income because of treatment. Moreover, clinicians and other organizations, such as philanthropic or professional medical organizations, may proactively educate men on available therapies. For example, providing informative and easy-to-understand educational handouts about prostate cancer treatments and their associated side effects or organizing online or in-person support groups where survivors can speak about their experience and provide insight to newly diagnosed men. Lastly, efforts should focus on promoting guideline-concordant treatments, such as encouraging active surveillance for indolent prostate cancer and offering tools to alleviate the associated anxiety demonstrated in this study and others.

Our qualitative study had several strengths, including the diverse geographic locations from which participants were recruited and the targeted recruitment of long-term survivors who had chosen different treatment approaches to prostate cancer. As in most qualitative research, our goal was to elucidate a range of perspectives and experiences articulated by participants. Rather than statistical power, non-probabilistic sampling is guided by the concept of saturation, which we achieved overall and within each treatment subgroup (see Appendix B).

Some of the limitations of this study are related to long-term survivorship, such as recall bias of experiences that have spanned a decade or more. Additionally, because of the qualitative nature of our study and because some participants experienced several types of treatment (e.g., active surveillance followed by surgery), we did not attempt to characterize similarities and differences by the initial treatment group. Despite a concerted effort to enroll a highly diverse population, most of our interviewees were non-Hispanic White. However, our study remains one of the most diverse compared to other studies. Future research should examine in more detail the lived experience of specific sequences of treatments and outcomes among more diverse populations. For example, exploring the early experience of men who initially were managed with active surveillance and who later received surgery. Moreover, disparities by race and ethnicity, and rurality exist in prostate cancer care [30]. Thus, qualitative analyses are needed to assess the different experiences to allow for equitable interventions and improve prostate cancer survivorship.

Conclusion

The study highlights the lived experience of men with localized prostate cancer 10 years after diagnosis. Immediately after treatment, men were mostly satisfied with radiation and active surveillance due to "remaining whole." Meanwhile, men treated with surgery felt relieved by the removal of cancer. In contrast, some negative perceptions were related to short-term anxiety, particularly among men who underwent active surveillance. In the long term, men accepted the trade-offs of urinary and sexual side effects with survival. Most fared well financially and advised other men and physicians to obtain detailed treatment information and establish a strong relationship with treating physicians. Overall, the study demonstrates that following the initial challenges associated with the diagnosis and treatment of prostate cancer, most men generally do well and establish strengthened relationships, acceptance, and an improved sense of appreciation and compassion.

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Author contribution Dr. Beskow led the design of the study and instrument development; supervised recruitment, data collection, and qualitative coding; performed data analysis and interpretation; and drafted major sections of the manuscript. Drs. Al Hussein Al Awamlh and Wallis drafted major sections of the manuscript. Ms. Diehl, under Dr. Beskow's supervision, recruited participants and conducted interviews; and assisted with qualitative coding. Dr. Barocas led the conception and design of the study; assisted with instrument development, data analysis, and data interpretation; and drafted major sections of the manuscript. All authors commented on previous versions of the manuscript and read and approved the final version.

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Declarations

Competing interests The authors declare no competing interests.

Ethics approval This study was reviewed and approved by the Vanderbilt University Institutional Review Board.

Consent to participate All participants reviewed a study information sheet and provided verbal agreement to take part in an interview and for audio recording.

Conflict of interest The authors declare no competing interests.

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