

INTEGRATING SEXUAL HEALTH INTO PROSTATE CANCER CARE

Perspectives from Patients, Care Partners, and Healthcare Professionals

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Executive Summary

Sexual health and intimacy are important components of quality of life for men with prostate cancer and their care partners, yet they remain inconsistently addressed across the care continuum. This project brings together the perspectives of patients, care partners, medical oncologists, urologists, and advanced practice providers (APPs) to examine how these concerns are experienced and addressed in prostate cancer care.

Across all stakeholder groups, a consistent picture emerged. Sexual health concerns extend well beyond erectile dysfunction to include changes in libido, orgasm, self-confidence, emotional intimacy, relationship dynamics, fatigue, and urinary symptoms associated with sexual activity. Clinicians acknowledged that many of these concerns remain underreported and often only emerge when providers ask proactively or broaden discussions beyond erectile function.

The research also identified an important gap between recognition and care delivery. Physicians and APPs consistently described limited visit time, competing treatment-related priorities, discomfort initiating sensitive discussions, fragmented care, and inconsistent referral pathways. APP interviews further highlighted how routine follow-up visits are often structured around treatment monitoring and acute toxicities, leaving sexual health outside the standard workflow unless the patient or partner raises it.

Care partners represent another important but frequently underrecognized part of the prostate cancer experience. Care partner respondents reported substantial effects on intimacy and emotional well-being, while clinicians described partners as both affected by treatment-related changes and, in some cases, instrumental in initiating conversations that patients may hesitate to raise themselves.

Taken together, the findings suggest that improving sexual health care will require more than encouraging clinicians to have additional conversations. Earlier education, routine screening, realistic expectation setting, defined referral pathways, stronger oncology-urology collaboration, greater access to specialized sexual health and mental health resources, and integration of these concerns into survivorship and longitudinal follow-up are needed to make sexual health a consistent component of prostate cancer care.

Key Findings

Sexual health is broader than erectile dysfunction.

Patients, care partners, and clinicians described effects on libido, intimacy, self-image, emotional well-being, relationships, and other treatment-related sexual changes.

Conversations remain inconsistent and are often patient initiated.

Sexual health may be discussed, but the depth, timing, and follow-up vary considerably across care settings.

The primary barriers are operational as well as clinical.

Limited time, competing treatment priorities, provider comfort, fragmented care, and lack of clear referral resources repeatedly emerged across physician and APP interviews.

Care partners are affected but not consistently incorporated into care.

The care partner experience demonstrates that prostate cancer-related sexual health changes are often experienced at the couple level, even when care remains focused primarily on the patient.

Survivorship offers a critical opportunity to close the gap.

Routine screening, proactive education, multidisciplinary referral pathways, and defined roles for APPs and other supportive care professionals may help move sexual health from an episodic discussion to an expected component of longitudinal prostate cancer care.

Clinical Context: Sexual Health and Survivorship in Prostate Cancer

Advances in prostate cancer detection and treatment have shifted the focus of care beyond disease control alone. As more men live for years following diagnosis and treatment, the long-term consequences of therapy, including effects on sexual function, intimacy, and relationships, have become increasingly important components of quality of life. Sexual dysfunction is among the most common and persistent treatment-related concerns, with longitudinal studies demonstrating substantial effects on sexual outcomes that may persist for years after treatment.[1-4]

Erectile function represents only one dimension of sexual health after prostate cancer. Patients may experience changes in sexual function, including libido, orgasm, ejaculation, and urinary symptoms related to sexual activity. These changes may also affect confidence, emotional intimacy, and relationship dynamics. Patient-reported outcome studies, including ProtecT and CEASAR, have demonstrated that sexual function can remain altered over the long term, with the degree and trajectory of impairment varying by treatment approach.[2,4] These findings underscore the importance of preparing patients for potential changes before treatment and continuing to assess sexual health during follow-up.[5,6]

These effects do not occur in isolation. Research involving patients and their spouses or partners has documented effects on psychosocial well-being, sexual satisfaction, and quality of life.[1,7,8] Communication and intimacy also play an important role; studies of couples affected by prostate cancer suggest that withholding cancer-related concerns can influence psychological and relationship outcomes for both members of the couple.[9] Sexual health after prostate cancer is therefore not solely an individual functional outcome but an issue that may affect the couple and the relationship as a whole.

Clinical guidance recognizes many of these needs, but translating recommendations into routine care is more complex. The National Comprehensive Cancer Network® (NCCN®) Guidelines® Insights: Survivorship, Version 2.2024 specifically addresses sexual health and fertility within survivorship care.[10] Guidance from the American Society of Clinical Oncology (ASCO) recommends proactive discussion and ongoing assessment of sexual health concerns, with counseling or referral when appropriate.[11] The American Cancer Society (ACS) Prostate Cancer Survivorship Care Guidelines similarly address sexual dysfunction, psychosocial health, and coordination of follow-up care.[12] Guidance from the American Urological Association (AUA) and American Society for Radiation Oncology (ASTRO) further emphasizes shared decision-making and consideration of anticipated functional outcomes when counseling patients about prostate cancer treatment.[13,14]

The importance of these discussions extends to treatment decision-making itself. Treatment-related regret has been associated with poorer functional outcomes, including sexual function, as well as outcomes that differ from patients' expectations.[5] A systematic review and meta-analysis further identified associations between decision regret and post-treatment functional outcomes.[6] Together, these findings reinforce the importance of informed decision-making, realistic expectation setting, and support that continues beyond the initial treatment decision.

The challenge is translating these principles consistently into practice across a multidisciplinary care environment. Prostate cancer care may involve urologists, medical oncologists, radiation oncologists, advanced practice providers (APPs), nurses, and supportive care professionals at different points along the care continuum. Responsibility for initiating sexual health discussions, assessing concerns, providing support, and coordinating referrals may therefore be distributed across clinicians and care settings. Understanding how patients and care partners experience this care, and how healthcare professionals perceive their roles, barriers to care, and opportunities for improvement, is important for identifying practical approaches to integrating sexual health more consistently into prostate cancer care.

To address this need, this project combines quantitative surveys of patients and care partners with qualitative interviews among medical oncologists, urologists, and APPs. By integrating these perspectives, this white paper examines how sexual health is experienced, discussed, and managed across prostate cancer care, identifies areas of alignment and unmet need, and explores practical opportunities to strengthen education, communication, referral, and survivorship support.

Study Design and Methods

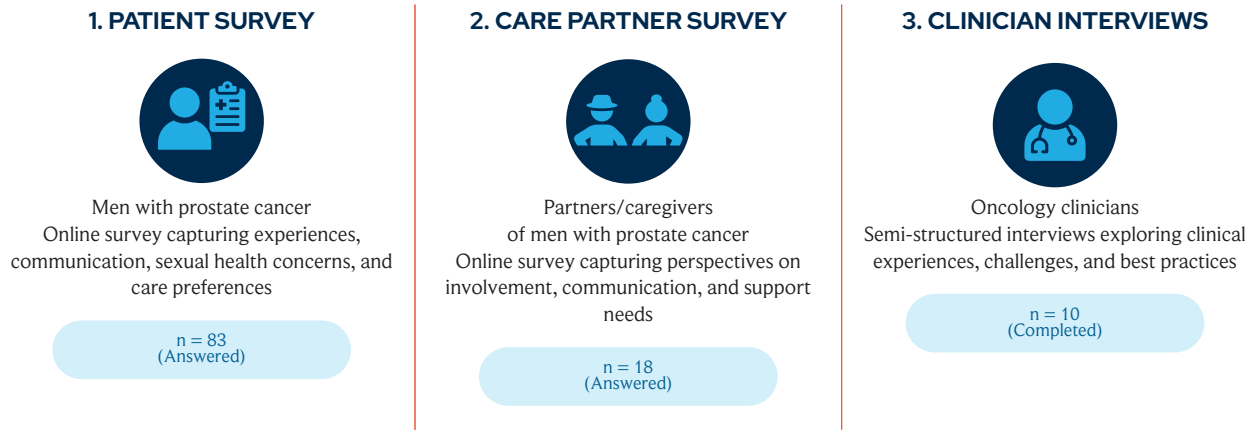
Project Overview

This project used a mixed-methods approach to examine sexual health and intimacy in prostate cancer care from the perspectives of patients, care partners, and healthcare professionals. Quantitative surveys were conducted with patients with prostate cancer and care partners to characterize their experiences, including the impact of prostate cancer and its treatment on sexual health, intimacy, emotional well-being, communication, and access to support. Qualitative interviews with medical oncologists, urologists, and APPs were conducted to explore how these concerns are addressed in clinical practice, including the timing and scope of discussions, barriers to care, referral practices, and opportunities for improvement.

The quantitative and qualitative components were designed to provide complementary perspectives. Survey findings characterized the experiences and needs reported by patients and care partners. These findings were then incorporated into the HCP interviews, allowing physicians and APPs to reflect on the patient and care partner experiences, assess how closely they aligned with what they observe in practice, and provide clinical context regarding current practices, barriers to care, and opportunities for improvement. Findings from both components were subsequently synthesized to identify areas of alignment and disconnect and to inform practical opportunities for more consistently integrating sexual health into prostate cancer care.

Figure 1. Study Design

Mixed-methods approach to understand sexual health and intimacy in prostate cancer care



Patient and Care Partner Surveys

Quantitative surveys were conducted among patients with prostate cancer and care partners to characterize their experiences with sexual health and intimacy across the prostate cancer care continuum. NCODA partnered with ZERO® Prostate Cancer to support survey outreach and recruitment of patient and care partner respondents.

Patients and care partners completed separate survey pathways designed to capture their respective experiences. Patients were asked about their experiences with sexual health and intimacy following prostate cancer diagnosis and treatment, including communication with healthcare providers, expectations and understanding of treatment-related sexual side effects, changes in sexual function and intimacy, emotional and relationship impacts, information and support resources, and unmet needs for sexual health care. Care partners were asked about their involvement in clinical discussions, understanding of potential sexual side effects, the impact of changes in sexual health on intimacy and emotional connection, communication within the relationship, emotional distress, and availability of supportive resources.

Survey responses were analyzed descriptively using response counts and percentages. Because respondents could skip individual questions, the number of responses varied across survey items; percentages were therefore calculated using the number of respondents who answered each question rather than the total survey sample. Findings from the patient and care partner surveys were reviewed to identify patterns in reported experiences, communication, information and support needs, and opportunities for improvement.

Healthcare Professional Interviews

Qualitative interviews were conducted with 10 healthcare professionals involved in prostate cancer care: three urologists, three medical oncologists, and four APPs representing both urology and medical oncology. The APP participants included two medical oncology nurse practitioners, one medical oncology physician assistant, and one urology physician assistant. Interviews explored how sexual health and intimacy are addressed in clinical practice and obtained clinical perspectives on findings from the patient and care partner surveys.

Using a structured interview guide, participants were asked about the timing and scope of sexual health discussions, responsibility for initiating and revisiting these conversations, barriers to addressing sexual health, current management and referral practices, and the role of care partners. Participants were also presented with key survey findings and asked to reflect on how closely the reported experiences aligned with what they observe in practice, including areas where patient or care partner experiences may be more significant than typically recognized.

Interview responses were reviewed to identify recurring themes across specialties and roles, as well as differences in perspectives and practice patterns. These themes were then considered alongside the patient and care partner survey findings to identify areas of alignment and disconnect and to inform opportunities for more consistently integrating sexual health into prostate cancer care.

Data Analysis and Synthesis

Survey and interview findings were examined together to identify recurring themes across patient, care partner, and clinician perspectives. Particular attention was given to areas where clinician perspectives reinforced, contextualized, or differed from experiences reported in the surveys. The integrated analysis focused on patterns related to communication, treatment expectations, the breadth and impact of sexual health concerns, care partner involvement, barriers to care, management and referral practices, and access to supportive resources.

The resulting themes provided the framework for the findings presented in this white paper, allowing quantitative patient and care partner experiences to be considered alongside clinical perspectives on current practice and opportunities for improvement.

Integrated Findings

Sexual Health Extends Beyond Erectile Dysfunction

Although erectile dysfunction was the most commonly reported sexual health concern, the patient survey demonstrated that the effects of prostate cancer treatment were considerably broader. Among the 72 patients who answered this question, 86.1% (62/72) reported erectile dysfunction, but substantial proportions also reported dry orgasm (70.8%; 51/72), reduced sexual desire (63.9%; 46/72), and difficulty achieving orgasm (59.7%; 43/72). Other concerns included avoidance of intimacy (37.5%; 27/72), feeling less masculine (29.2%; 21/72), urinary issues affecting intimacy (27.8%; 20/72), body image changes (23.6%; 17/72), emotional withdrawal (12.5%; 9/72), and relationship strain (9.7%; 7/72).

Clinician interviews reinforced the importance of looking beyond erectile function, while also suggesting that these broader effects may not routinely surface in clinical conversations. One urologist described erectile dysfunction as a common entry point for referral but noted that concerns involving libido, orgasm, self-confidence, and well-being frequently emerge when clinicians ask more detailed questions. He characterized many of these issues as underreported and underrecognized, including urinary leakage specifically associated with sexual activity.

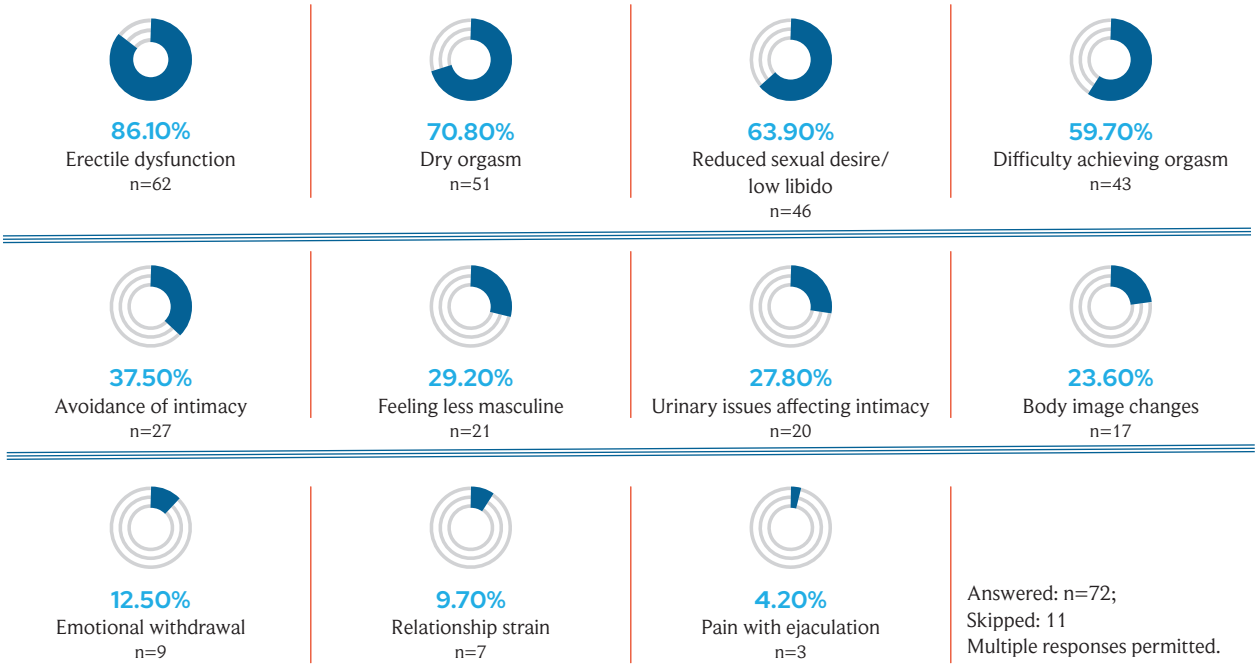
Medical oncology perspectives similarly highlighted a potential difference between what is readily discussed in practice and the broader experience captured in the survey. One medical oncologist noted that the emotional and intimacy components of sexual health were particularly striking because clinical conversations tend to focus on erectile dysfunction

and other physical aspects of sexual function. He also identified patients' reports of changes in masculinity and self-perception as an area that may be less visible to clinicians and acknowledged that self-image, emotional distress, and relationship strain are rarely addressed in routine discussions.

Erectile dysfunction therefore represents only one dimension of the sexual health burden associated with prostate cancer treatment. Changes in desire, orgasm, urinary function, self-image, emotional well-being, and intimacy may be clinically meaningful even when they are not spontaneously reported. The findings also point to the limitations of using erectile function alone as a proxy for sexual health and support a broader approach to assessment that allows these less visible concerns to emerge.

> We definitely know that male sexual health is fairly broad, and most of the focus has been on erectile function, but there are a lot of different aspects of sexual health that are under-recognized and can affect quality of life.
>
> Darshan Patel, MD, Urologist, University of California, San Diego Health

Table 1. Sexual Health and Intimacy Effects Extend Beyond Erectile Dysfunction



Patient-reported sexual health and intimacy concerns following prostate cancer treatment, demonstrating the breadth of effects beyond erectile function. Respondents could select more than one concern.

Sexual Health Conversations Are Inconsistent and Often Patient Initiated

Patient survey findings indicate that sexual health discussions were not consistently initiated by the healthcare team. Among 75 patients who answered the question, 44.0% (33/75) reported that they most often initiated conversations about sexual health themselves, compared with 20.0% (15/75) who said their healthcare provider initiated the discussion and 18.7% (14/75) who described the conversation as mutually initiated. For 17.3% (13/75), these conversations did not occur at all.

When conversations did not occur or felt limited, competing clinical priorities emerged as the most frequently reported barrier. Among 68 respondents, 54.4% (37/68) indicated that the appointment focused on other medical priorities, while 22.1% (15/68) cited insufficient time during the visit. Other respondents reported that they did not think sexual health was important at the time (16.2%; 11/68), were not given an opportunity to discuss it (13.2%; 9/68), or felt embarrassed raising the topic (10.3%; 7/68). Some sought information elsewhere: 20.6% (14/68) discussed their concerns with another

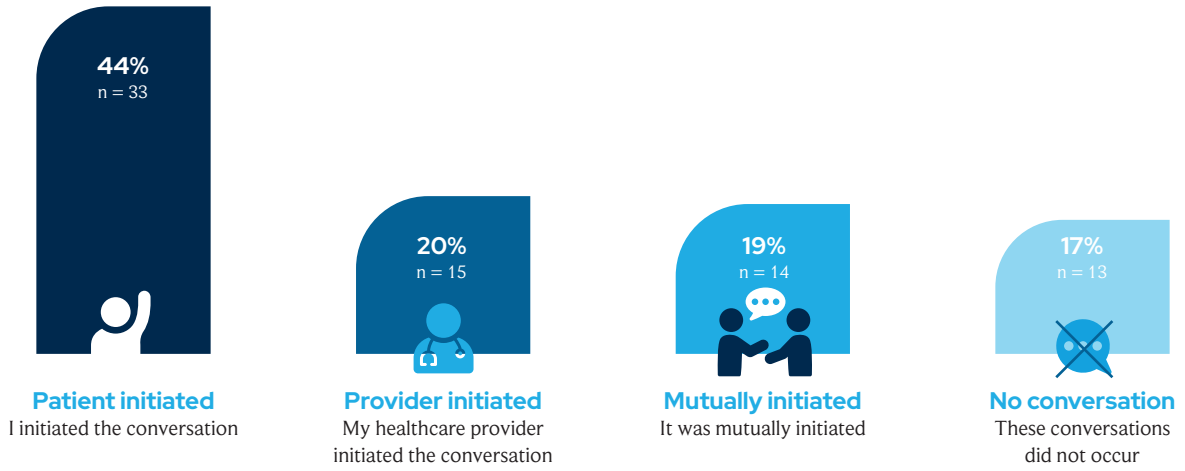
healthcare provider and 19.1% (13/68) obtained information from non-clinical sources such as online resources or support groups.

The clinician interviews provided context for these findings. Medical oncologists described sexual health as a topic that may not arise at the initial visit, when attention is centered on the cancer itself, and noted that some patients raise these concerns only after rapport has developed or when a care partner is present. APPs similarly described routine oncology visits as focused primarily on treatment, disease status, and acute toxicities, with sexual health more likely to be addressed when a patient or care partner raises a specific concern.

Clinicians also acknowledged the limitations of relying on patients to initiate these conversations. One urologist emphasized the value of brief, proactive screening questions that signal to patients that sexual health is an appropriate topic for discussion and identified time, clinician comfort, and uncertainty about how to respond once a concern is identified as barriers to routine initiation.

Figure 2. Who Starts the Conversation?

Patients most often initiate conversations about sexual health.



Answered: n = 75; Skipped: n = 8

Survey question: Who most often initiated conversations about sexual health?

These findings point to a care model in which sexual health discussions remain episodic rather than routinely integrated into prostate cancer care. Although patients may raise concerns themselves, reliance on patient initiation risks leaving needs unidentified, particularly when cancer-related priorities dominate the visit or patients are hesitant to introduce sensitive concerns. More proactive discussion may help establish sexual health as an expected component of care rather than a topic dependent on the patient raising it.

> Get good at asking one or two gentle screening questions. (For example), 'Most patients with prostate cancer struggle with sexual health. Is that something that's been frustrating for you?' ... So at least the patient knows they can talk about it.
>
> Kadee E. Thompson, MD, Urologist, Sutter Health

Care Partners Are Affected but Not Consistently Integrated Into Care

Care partner survey findings demonstrate that the effects of prostate cancer-related sexual changes extend beyond the patient. Care partners reported effects on intimacy, emotional connection, and their own well-being, reinforcing that sexual health after prostate cancer is often experienced at the couple level rather than by the patient alone.

Their involvement in care, however, was inconsistent. Among 19 respondents, 47.4% (9/19) agreed or strongly agreed that they were invited and welcomed to participate in discussions about their partner's sexual health, while 26.3% (5/19)

disagreed or strongly disagreed. Only 38.9% (7/18) agreed or strongly agreed that their perspective was valued during sexual health discussions. Support directed specifically toward care partners was also limited: only 29.4% (5/17) agreed or strongly agreed that counseling, support groups, or educational resources for spouses or partners had been discussed.

> I think it's quite common to see that the spouse is the unmentioned sufferer.
>
> Kadee E. Thompson, MD, Urologist, Sutter Health

Clinician interviews reinforced this disconnect. Several clinicians acknowledged that care partners may be substantially affected by changes in sexual health and intimacy, yet clinical encounters remain primarily structured around the patient. Clinicians also described care partners as important participants in these conversations and, in some cases, the person who raises concerns that the patient has been reluctant to discuss.

The care partner findings highlight a fundamental tension in prostate cancer care: sexual health consequences may affect the relationship, while care delivery remains centered primarily on the individual patient. Greater recognition of the care partner experience may be important to addressing the full impact of treatment on intimacy and relationships.

Survivorship Provides an Opportunity for More Consistent Care

Clinicians identified survivorship and longitudinal follow-up as important opportunities to address sexual health concerns that may receive limited attention during active treatment. When disease management, treatment tolerance, and acute toxicities take priority, broader quality-of-life concerns may be deferred or addressed only when patients raise them.

The interviews also highlighted an important gap after treatment. Sexual health concerns may persist or evolve even as oncology follow-up becomes less frequent, leaving some patients without a clear pathway for addressing long-term effects. Clinicians emphasized the value of survivorship care that extends beyond disease status to include sexual function, intimacy, emotional well-being, and other lasting consequences of treatment.

APP perspectives further underscored the need to consider sexual health throughout longitudinal care rather than only after treatment completion. For patients receiving prolonged therapy, including those with advanced disease, traditional survivorship programs may not represent a distinct phase of care. Routine follow-up therefore provides another opportunity to incorporate sexual health assessment and connect patients and care partners with appropriate support.

Survivorship therefore represents both a defined phase of care and a broader opportunity to address needs that may otherwise remain unresolved. Incorporating sexual health into longitudinal follow-up may help create greater continuity between treatment, recovery, and longer-term quality of life.

> A lot of prostate cancer patients are cured, either with surgery or radiation, and then they're left to the 'Wild West'... But no one addresses these long-term continence [and] sexual side effect problems. This is where survivorship will play a big, big role.
>
> Bijoy Telivala, MD, Medical Oncologist, Cancer Specialists of North Florida

Table 2. Alignment of Patient, Care Partner, and Clinician Perspectives

Theme	Patient/Care Partner Experience	Clinician Perspective	Clinical Opportunity
Breadth of sexual health	Effects extend beyond ED	Broader concerns may be underrecognized	Broaden assessment
Communication	Often patient initiated	Competing priorities and discomfort limit initiation	Proactive screening
Care partners	Intimacy and emotional effects extend to partners	Partners may initiate concerns, but visits remain patient-centered	Include care partners when appropriate
Care delivery	Information/support needs persist	Time, expertise, resources, and referrals vary	Define roles and pathways
Long-term needs	Concerns may persist	Survivorship/follow-up offers an opportunity	Reassess longitudinally

Survey and interview findings demonstrate areas of alignment across stakeholder groups and highlight corresponding opportunities to strengthen sexual health care across the prostate cancer continuum.

Clinical Interpretation

The insights reveal a persistent gap between recognition of sexual health as an important component of quality of life and its consistent integration into prostate cancer care. Clinicians generally recognized the experiences reported by patients and care partners, yet competing clinical priorities, limited time, variable comfort, and access to appropriate resources can make sexual health difficult to address routinely. Importantly, the findings suggest that this gap reflects challenges in care delivery rather than a lack of awareness alone.

The breadth of concerns reported by patients also reinforces the limitations of approaching sexual health primarily through erectile function. Changes in desire, orgasm, self-image, emotional well-being, and intimacy may persist alongside or independently of erectile dysfunction, while care partner findings demonstrate that these effects can extend to the relationship itself. These observations are consistent with the broader literature recognizing sexual function and relationship well-being as important components of quality of life following prostate cancer treatment.

Addressing these needs therefore requires more than increasing the frequency of sexual health conversations. A more systematic approach is needed to support proactive assessment, realistic expectation setting, appropriate management and referral, and reassessment over time. This is particularly important because sexual health needs may evolve throughout treatment and survivorship, including among patients receiving long-term therapy who may not transition into a traditional survivorship program.

The central challenge is therefore not establishing that sexual health matters but determining how to address it consistently within the realities of prostate cancer care. The results provide a foundation for practical strategies that clarify when these concerns should be assessed, who is best positioned to address them, and what resources are needed when additional support is required.

Recommendations for Clinical Practice

The findings identify practical opportunities to more consistently address sexual health and intimacy within prostate cancer care. Importantly, improving care does not require every clinician to become a sexual health specialist. Rather, clinical teams need feasible approaches to identify concerns, provide appropriate education, initiate management when within their scope, and connect patients and care partners with additional expertise when needed.

Normalize sexual health assessment.

Incorporate brief, proactive screening questions at defined points in care to reduce reliance on patients or care partners to initiate these discussions. Screening does not require an extensive assessment during every visit; even one or two standardized questions can signal that sexual health is an appropriate clinical topic and identify patients who may benefit from further discussion. Assessment should extend beyond erectile function to include concerns related to desire, orgasm, intimacy, emotional well-being, self-image, and relevant urinary symptoms.

Set expectations early and revisit them over time.

Pretreatment counseling should provide realistic information about potential sexual health effects, including concerns beyond erectile dysfunction and the possibility that some effects may persist or evolve over time. Because patient priorities and experiences can change throughout the course of care, these discussions should be revisited during treatment, follow-up, and survivorship rather than treated as a one-time component of treatment decision-making.

Establish clear roles and pathways for follow-up.

Clinical teams should define how physicians, APPs, nurses, and supportive care professionals contribute to screening, education, initial management, and referral. Identifying a concern is only useful if there is a clear next step. Practices should develop accessible pathways to appropriate expertise, which may include urology, sexual medicine, mental health services, pelvic health, or other supportive care resources based on the needs identified.

Recognize and incorporate the care partner experience.

Sexual health changes following prostate cancer treatment frequently affect intimacy and relationships, yet care remains primarily centered on the patient. When appropriate and with the patient's agreement, care partners should be given opportunities to participate in education and discussions about anticipated and ongoing sexual health changes. Educational and supportive resources should also acknowledge the emotional and relationship effects that care partners may experience themselves.

Use survivorship and longitudinal follow-up to address unresolved needs.

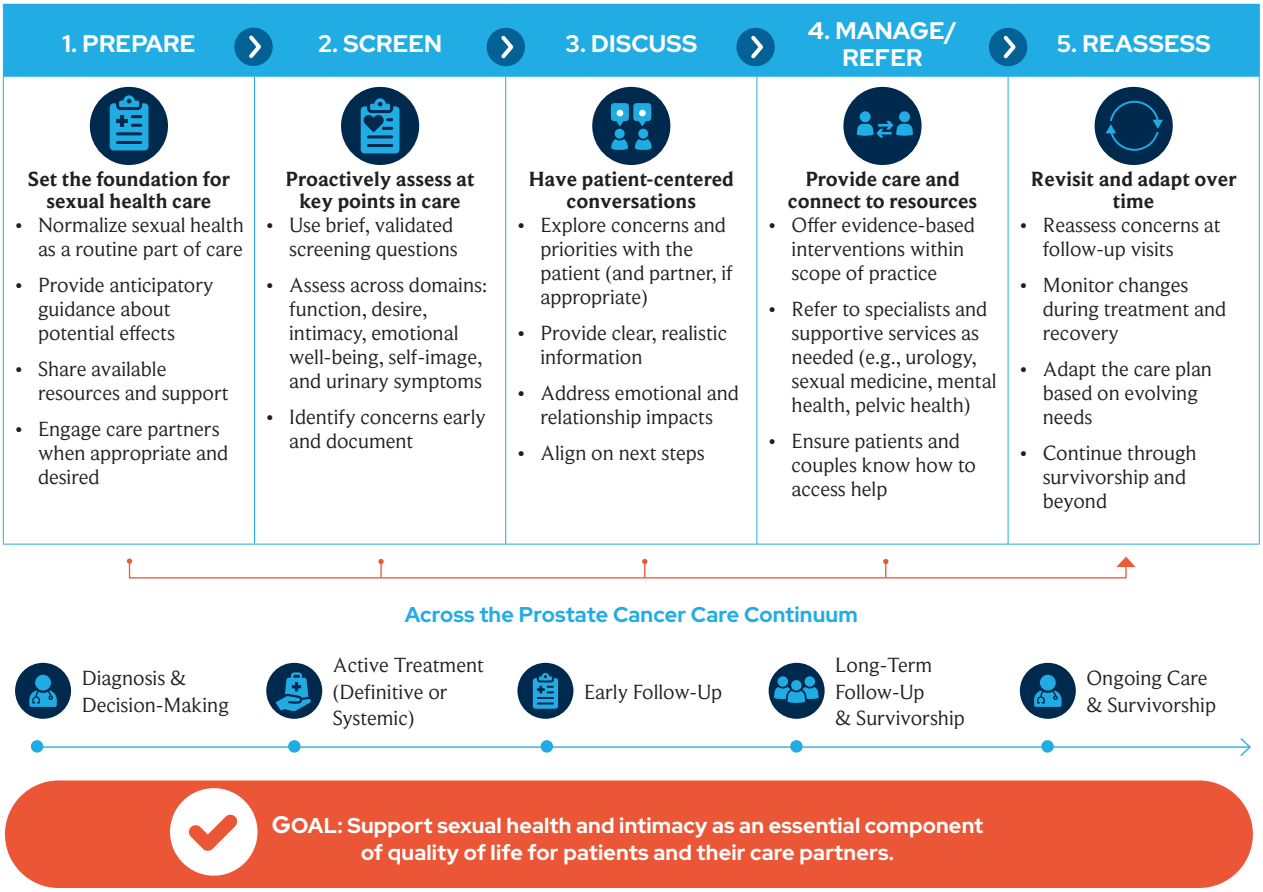
Survivorship provides an important opportunity to reassess concerns that may have received less attention during diagnosis and active treatment. However, this approach should not be limited to patients who complete therapy and enter a formal survivorship program. Patients receiving prolonged or maintenance treatment may have persistent sexual health concerns while remaining in active oncology care. Incorporating assessment into routine follow-up for clinically stable patients may help ensure that these needs are not deferred indefinitely.

Strengthen clinician education and access to resources.

Clinician education should build comfort with initiating sexual health discussions, broaden recognition of concerns beyond erectile dysfunction, and increase familiarity with available management and referral options. Standardized screening tools, patient education materials, and readily accessible resource directories may help make these conversations more feasible within routine practice. The goal is not for every clinician to manage every concern, but for patients to encounter a care team that can recognize the need, begin the conversation, and connect them with appropriate support.

Figure 5. Clinical Pathway for Integrating Sexual Health and Intimacy in Prostate Cancer Care

A continuous cycle across the prostate cancer care continuum



Conclusion

Sexual health and intimacy are meaningful components of quality of life throughout the prostate cancer experience, yet the findings of this project reveal that they are not consistently integrated into care. Patients and care partners experience effects that extend beyond erectile dysfunction, while clinicians recognize both the importance of these concerns and the practical barriers to addressing them.

Improvement will depend less on any single conversation than on creating consistent processes that support assessment, education, follow-up, and access to appropriate care. Integrating these elements across treatment and survivorship offers an opportunity to more fully address the long-term needs of patients with prostate cancer and their care partners.

Acknowledgments

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