

# Communication About Sexuality in Advanced Illness Aligns With a Palliative Care Approach to Patient-Centered Care

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**Abstract** Treatment-related sexual complications are common in cancer patients although rarely discussed in the palliative care setting. Sexuality is an important survivorship issue and remains relevant even in the terminal setting. There are multiple barriers in dialoguing about intimacy and sexual functioning from the patient and provider perspectives. Palliative care providers, while not expected to be sexual health experts, can provide comprehensive patient-centered care by including sexual health as part of their evaluation. They can explore how sexual dysfunction can impair functioning and utilize an interdisciplinary approach to manage symptoms. Palliative care providers can help patients identify their goals of care and explore what anticipated sexual changes and treatment-related side effects are tolerable and intolerable to the patient's quality of life. Principles on addressing sexuality in the palliative setting and practical ways of incorporating sexual history into the palliative care assessment are provided.

**Keywords** Palliative care · Sexuality · Communication

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## Introduction

Two topics most health-care providers often tend to avoid discussing with their patients and families, let alone discussing the intersection of the two, include sexuality and death. Advanced illness such as cancer and the complications of treatment can create significant disruptions in sexual functioning on all levels including the biological, psychological, and social [1•]. Despite the well-documented prevalence of treatment-related sexual complications such as decreased libido, vaginal atrophy, dyspareunia, and erectile dysfunction [2, 3, 4•], patients continue to have large unmet need when it comes to sexual health and function, predominantly due to a lack of communication with their providers. Still, the literature is replete with evidence that patients have a strong desire to more openly discuss sexual issues and prefer their clinicians to broach the topic [5, 6, 7•]. Because palliative care providers are well versed in addressing patients' needs at the physical, emotional, and interpersonal levels, they may be ideally suited to bring sexual health and functioning to the forefront as part of providing patient-centered care. Such discussions can provide critical support to relieving distressing symptoms including sexual dysfunction, particularly among patients with cancer.

## Sexuality in the Palliative Care Setting

Sexuality has received limited attention in the palliative care literature [8]. The few studies available suggest that palliative care patients may experience more severe sexual dysfunction compared to patients with cancer not involved in palliative care. For example, in a cross-sectional study, compared to a general oncology patient sample, those receiving palliative care overall rated lower on sexual well-being scores [9]. The

palliative care group scored 1.6 compared to 3.7 for the oncology group on the Derogatis Sexual Satisfaction Scale (maximum score of 10 for high satisfaction), 0.6 to 1.4 on strength of emotional relations with a partner (maximum score of 10 for good relations), and 0.2 to 0.5 to frequency of sexual relations (0=not at all, 1=not for a long time, 2=less than once a month, 3=every few weeks, 4=weekly, 5=more than weekly) [9]. A second study showed that those patients receiving palliative care in an inpatient setting reported low sexual satisfaction scores [10]. Of the 65 randomly patients sampled, only 12 % reported good sexual satisfaction while 30 % had insufficient satisfaction and 45 % had no sexual satisfaction.

These data highlight that sexuality remains important, even for those who are in the terminal phase of their illness. Terminal patients continue to desire sexual function and intimacy although the type of intimate relationships may change over the course of their illness. Some patients may see their sexuality as a means to reinforce emotional connectedness. Although there might be less emphasis on physicality, intimacy (whether verbal or non-penetrative) remains important [11]. Couples living with lung cancer report positive changes in emotional intimacy with notable increased mutual appreciation relationship cohesion, and frequency of non-coital physical touching [12]. Changes such as disfigurement, immobility, alopecia, weight changes, surgical scars, impaired immune response, and uncontrolled symptoms such as pain can be disruptive and change the dynamics between couples. The interactive biopsychosocial model provides a framework for understanding how sexuality and cancer interact with one another bidirectionally [13]. This health-centered model describes and explains the relationships among the biophysical, psychocognitive, and social dimensions of health. One's individual health is seen as a construction relative to another person; it is affected not only by one individual's intrinsic health (e.g., pathophysiological changes with disease) but also by another person's health and, ultimately, the couple's health. Rather than viewing cancer strictly as a process that impairs sexual functioning (e.g., vaginal atrophy caused by chemotherapy), the interactive model expands the range of physical impairments affecting sexual function to include the partner's sexual health as a determinant of the patient's sexual functioning. Partners who are compromised sexually such as in the case of caregiver burnout or seeing their loved one with cancer as a patient rather than as their partner [14] will adversely affect the patient's sexual health. Some partners even fear causing pain or death during sexual activity and avoid physical intimacy [15]. On the other hand, partners who are physically and mentally in good health can enhance the cancer patient's sexual well-being such as being more physically attuned to their partner's need. Patients and their partners receiving palliative care in nursing homes or inpatient settings may be limited in expressing their sexuality because of a lack of privacy, staff intrusions, and few private rooms [11, 16].

The presence of a single hospital bed can even adversely affect the intimacy between a couple [17]. Finally, the theme of disconnection also surfaces as patients and their partners face their coupled relationship dying [18•].

Discussions about sexuality can also be life affirming as it can help give patients a sense of normalcy during a fragile period [19]. Despite this, there are limited guidelines on addressing sexuality in the palliative care setting. The National Consensus for Quality Palliative Care recognizes sexuality and intimacy as important components to a comprehensive interdisciplinary social assessment [20]. As palliative care continues to demonstrate the potential for terminal patients to live longer with the emphasis around improved quality of life [21], issues around sexual health become more important. Along with topics such as pain, sleep disorders, and cognitive function, the National Comprehensive Cancer Network (NCCN) identifies sexual function as an integral component of standard survivorship care [22•]. The NCCN 2015 guidelines are currently in development at the time this manuscript is being published.

## Barriers to Sexual Health Communication

Both the perspectives of the patient and provider influence whether conversations about intimacy and sexuality occur. Patients often do not initiate these discussions with their physicians because of concerns about how their provider may react despite a desire to talk about their sexual issues. In a generalized sample not specific to any disease, 71 % of adults felt that their doctors would dismiss any concerns related to sexual health [23], although at the same time, patients appear to believe their providers to be experts in assuming that sexuality is important for providers to query about it and initiate the conversation [24•]. Patient's shame, fear, and embarrassment also are barriers in treating sexual problems [25, 26], especially during initial consultations. They may prioritize the medical aspects of their diagnosis, treatment options, and prognosis over quality of life concerns including sexual function [19]. Finally, the timing of discussions appears to play a role. In one study, patients reported that they did not realize until after treatment how much their sexual functioning could be compromised, and wondered how much of their personal experience was the norm relative to similar patients [6, 27]. Other patients may hold fearful beliefs about cancer and sexuality that deter them from bringing the topic up. Some of these fears include cancer being contagious or sex exacerbating cancer [28•, 29•].

Patient characteristics, provider's knowledge and attitudes, and systems issues often affect providers' sexual health communication [30]. Providers may make assumptions about their patients' age, gender, prognosis, race/ethnicity, sexual orientation, or partner status. These factors may influence whether

or not they broach the issue of sexuality. For example, sexual issues are easily overlooked in the older population and sexual discussions are more often raised with younger than older patients [31–33] despite many older patients remaining sexually active [34]. Since sexuality does not immediately affect survival, some providers are more concerned about other aspects of their patients' care that impact prognosis rather than quality of life issues like sexual functioning [5, 31].

In a qualitative study exploring how palliative care and oncology providers' attitudes led to uncomfortable feelings and behaviors, three major themes emerged: avoidance, vulnerability, and denial [27, 35]. While some providers avoided talking about sexuality because they felt there were other more pressing issues, others assumed that different clinicians addressed the issue especially when they themselves had limited training or education on this topic. Some providers felt vulnerable, expressing concerns that talking about sexuality with their patients would result in disclosing their own sexuality in their personal life or prompting them to examine their own upbringing or negative sexual experiences [36]. Sexuality is also seen as distinct from the cancer experience which leads to a denial of the potential impact the illness has on sexuality. However, there are strong data showing the effects of cancer and illness on sexual function. Survivors at highest risk of treatment-related sexual dysfunction are patients with tumors that involve the sexual or pelvic organs and those whose treatments affect hormonal systems that mediate sexual function. Other cancers that do not directly involve sexual organs can adversely affect sexual function via the side effects of multimodality therapy [37]. Finally, systems issues such as a lack of time and resources available have been identified as additional barriers [6, 19, 38].

### Why Palliative Care Providers Are Most Apt to Talk About Sexuality

Conversations about changes with sexuality in the setting of an advanced illness are fitting in the palliative care setting where an interdisciplinary team and multimodal approach to patient-centered care are adopted. Most palliative care providers will not and should not be expected to become sexual health experts. Nevertheless, we propose that the inclusion of sexual health conversations early in the provider-patient relationship is a necessary component to providing comprehensive patient-centered care. Prior training in communication skills, which is essential in the fellowship for palliative care specialization, and a psychosocial orientation are two important factors that predict physician's interest in taking a sexual history [39]. After taking a sexual health history, palliative care providers can refer patients to a sexual health clinician to further explore patient issues and treatment options.

Palliative care providers spend a significant time with patients in ensuring that care aligns with patient values, preferences, and goals of treatment. In-depth discussions about risks, benefits, and alternative options help patients make appropriate treatment decisions for themselves [40]. For example, complications of prostate cancer treatment including erectile dysfunction have a major influence on treatment decisions [41]. Likewise, patients with colorectal cancer may forgo surgery if the outcomes include incontinence and erectile dysfunction. Open communication provides an opportunity for education while also normalizing anticipated sexual changes and treatment-related side effects.

One of the definitive goals of palliative care is intensive symptom management. Palliative care providers utilize both pharmacological and non-pharmacological strategies to treat symptoms. For example, poor pain control detracts from sexual desire. To reach effective pain management, providers discuss timing breakthrough pain medications before periods of intimacy while helping couples reframe expectations about intimacy and sexuality. They can also help patients find comfortable positions for sexual activity and recommend the use of pillows and other supportive devices. Palliative care providers' embracement of interdisciplinary teams may make them most prepared to coordinate care with other specialties in order to comprehensively evaluate and help manage sexual health concerns. The inclusion of other specialties like urology, gynecology, psychology, psychiatry, and social work can attend to patients' specific needs. These specialties can address both the non-physical aspects of the illness experience such as the partner change in relationship that may occur with advanced illness and the physical symptoms such as erectile dysfunction, vaginal atrophy, and dyspareunia.

### Guidance and Practical Tips for Exploring Sexual Functioning With Patients

Communicating about sexuality with patients who have advanced disease requires a non-judgmental approach. The topic of sexuality engenders feelings, prejudices, upbringing, and beliefs, all of which influence our assumptions and hesitations. An important first step to having an uninhibited conversation with patients about sexuality is to explore the provider's level of comfort and personal attitudes toward sexuality in cancer patients [15, 42, 43]. How comfortable does it feel to talk about sexuality and what type of physical response is evoked? How comfortable is it to use specific words such as orgasm and arousal? What personal values regarding sexual behaviors and sexuality can potentially conflict with caring for patients? After an opportunity for self-examination, the next step is training and practicing how to ask and respond empathically.

Two guiding principles to addressing sexuality in patients with advanced illness are (1) to use a curiosity approach to ask open-ended questions to permit patients to express themselves and (2) to attend constantly to details. The curiosity approach builds rapport and affectively connects with patients by asking how the illness and/or treatment has affected them, how they feel about themselves, and how the relationship with their partner has changed. Introduction of sexuality early in the palliative care relationship demonstrates to patients that sexuality can be discussed at any point in the illness trajectory. At different stages of disease, patients will have different perceptions and needs [3]. Early assessment of sexual functioning is critical after treatment since some sexual problems can persist over time. Some other sexual functions will improve. In a study of women who received bone marrow transplant, as high as 87 % of sexual problems continued 3 years post-transplant if the sexual problems were not addressed or resolved by the first year [44]. Symptom management may be more common in the early stages of treatment, whereas psychological and relationship distress may appear in the middle to later stages of disease. Therefore, sexual symptoms should be addressed both during and after cancer treatment and through the course of the patient's disease. Close attention to details about the patient's concerns or worries can decrease the impact physical and psychological symptoms have on sexual function. For example, cancer patients frequently experience pain and fatigue. Palliative care providers can offer behavioral strategies such as napping before intercourse or laying on one's side to conserve energy.

One facile way to incorporate sexual history into the palliative care assessment is to add it to the review of symptoms. Before delving into the symptoms review, an explanation of why questions about sexual function are included normalizes the process and prepares patients to feel more at ease knowing that the provider is comfortable about this topic. Another comfortable point in the history taking to ask about sexual functioning is when providers ask patients how their advanced illness has impacted their relationships with their partners. While the concepts of intimacy and sexuality differ with intimacy revolving around concepts of identity, mutual acceptance, and reciprocity, both concepts are intrinsic to a sense of self, which is threatened by advanced illness [29•, 45].

As the topic is introduced, gauge the patient's readiness and desire to discuss. The use of normalizing and validating language can diffuse patients' anxieties and help them understand how their treatment influences their sexual function. Even if patients appear uncomfortable, a quick screening tool will give providers data points to revisit at a later time. In addition, a screening tool may be helpful in the initial visit when multiple issues are addressed while providing a comprehensive assessment. Although there are many validated questionnaires for sexual health such as the Female Sexual Function Index [46], Body Image Scale [47], or Personal Assessment of Intimacy in Relationships [48], the NCCN recommends the Brief

**Table 1** PLISSIT model for addressing sexuality in the medical setting

Level		Goal	Sample language
1	Permission	Offer permission for the patient to share while normalizing and validating experiences	<p>"Many patients with similar conditions have concerns about sexual function. How has your experience of sexuality been affected?"</p> <p>"The kind of treatment you receive can make it difficult to be intimate. I'd like to ask what questions or concerns about changes with intimacy or sexuality do you have?"</p>
2	Limited Information	Provide patient education regarding common sexual side effects related to treatment and correct misconceptions	"Treatment sides often have a big impact on sexual activities including experiencing painful intercourse. How has your experience been?"
3	Specific suggestions	Give concrete advice on how to cope with the effects of the illness including utilizing non-pharmacological and pharmacological strategies	<p>"You can use an appliance cover or lingerie to cover the ostomy bag and avoid odor-producing foods."</p> <p>"Vaginal lubricants and moisturizers are effective in treating vaginal dryness before and during sex."</p>
4	Intensive Therapy	Refer to experts for additional support if palliative providers are uncomfortable or unsure how to advise	"Your concern is extremely important to me, but falls outside my expertise. I would like to refer you to an expert in sexual health who is familiar with concerns like yours."

Sexual Symptom Checklist as a primary screening tool in its 2013 survivorship guidelines. The Brief Sexual Symptom Checklist assesses how long patients have been dissatisfied with their sexual function, type of sexual dysfunction experienced, and whether patients want to speak with their provider about it [49]. Alternatively, the use of open-ended questions elucidates patients' level of understanding and concern and jump starts a dialogue. Patients share a significant amount of information when providers elicit the impact and distress of illness on sexuality when asked in an open-ended style [50••].

There are a number of patient-centered communication frameworks health professionals use to address sexuality in



the medical setting including the 5As-Ask, Advise, Assess, Assist, Arrange [30], BETTER [51], ALARM [52], and PLISSIT [53]. The most commonly cited is the PLISSIT model which stands for Permission, Limited Information, Specific Suggestions, and Intensive Therapy (Table 1). PLISSIT emphasizes that health professionals are not expected to work above their personal comfort or skill level. The model has four levels of increasing intervention and interaction related to what kind of and how much help is offered.

## Conclusion

Sexuality is a critical component of quality of life. Patients want their health-care providers to initiate a conversation about their sexual health even though they have a serious illness. Faced with a number of barriers including attitudes, knowledge, time constraints, and anxieties, providers overlook an opportunity to provide comprehensive patient-centered care when sexuality is not addressed. Palliative care providers are skilled communicators who frequently become involved in difficult situations. Such skills carry over when talking with patients about sexuality in an open-ended and empathic style. Palliative care's emphasis on psychosocial aspects of illness highlights the importance of understanding the impact and distress of a serious illness, even in the terminal setting, on sexual health. The field has challenged medicine to reevaluate ideas about quality of life and how we care for our patients. Sexuality, therefore, is a fundamental, integral aspect of palliative care.

## Compliance with Ethical Standards

**Conflict of Interest** Margaret W. Leung, Shari Goldfarb, and Don S. Dizon declare that they have no conflict of interest.

**Human and Animal Rights and Informed Consent** This article does not contain any studies with human or animal subjects performed by any of the authors.

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