

# Patient reported disease-specific concerns relating to sexuality in multiple myeloma

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## Research Article

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# Abstract

## Purpose

There is increasing recognition that cancer and its treatment can have lasting effects on sexuality. However, most studies focus on breast and reproductive cancers while hematological cancers remain understudied. Only one prior study has acknowledged the existence of sexuality concerns among multiple myeloma (MM) survivors but did not expand upon them. This study explored how diagnosis and treatment of MM may affect sexual expression and also examined patient-provider communication about sexuality.

## Methods

Men and women with MM ( $N=65$ ) were recruited internationally for an online survey. The survey included open-ended questions about MM-specific barriers to engaging in sexual activity, methods used to adapt to sexual changes, and communication with healthcare providers. Answers to open-ended questions were summarized using a qualitative descriptive approach.

## Results

Participants identified several barriers to sexual activity that may be unique to MM, such as concerns about bone health, infections, and vaginal bleeding and bruising. They also described adapting to sexual challenges by trying sexual medicines/aids, changing their sexual expression, and managing treatment risks. Half of the participants reported speaking to providers about sexuality, with a minority receiving sexual health-related recommendations.

## Conclusions

Participants often faced sexual challenges after diagnosis, many of which may be unique to MM. While some were able to adapt to these changes, sexuality concerns were under-discussed and under-treated by healthcare providers. Proposed suggestions for improving patient-provider communication about sexuality and clinical care are offered based on the gaps identified by participants.

## Background

Multiple myeloma (MM) survivors experience long-term side-effects from cancer treatment<sup>1</sup>. While the impact of cancer on sexual wellbeing has been increasingly recognized in reproductive and breast cancers, sexuality in hematological cancer remains understudied<sup>2</sup>. Further, no prior studies have been published specifically examining the experiences of sexuality within MM survivors<sup>2</sup>. Only one qualitative

study acknowledges the existence of sexuality concerns among MM survivors but does not expand upon them<sup>3</sup>. Hematological cancer treatment is known to impact sexual function, and people with MM are also likely to experience sexual concerns<sup>2,4</sup>.

Information about sexuality in MM survivors has been inferred from research on other types of hematological cancer (e.g., lymphoma) or recipients of hematopoietic stem cell transplantation (HSCT)<sup>5,6</sup>. HSCT survivors typically experience severe changes in sexual functioning<sup>7</sup> (e.g., pain and difficulty with desire, arousal, and orgasm), which negatively impact sexual satisfaction, relationship adjustment, and body image; and exacerbate sexual distress<sup>8</sup>. However, as HSCT is used to manage a variety of hematological malignancies, reports on sexuality post-HSCT do not describe MM survivors specifically, despite the possibility of unique outcomes<sup>6,7</sup>.

MM is more common among older individuals, men, and Black people<sup>9</sup>; which may correlate to systematic differences in sexual concerns or healthcare. Furthermore, disease-specific factors may also present additional sexual challenges, such as treatment trajectory<sup>10,11</sup>. Osteolytic bone disease (which causes bone pain and fractures) is observed in most MM survivors and may impact sexual expression<sup>2,12</sup>. Anemia, having a higher risk of bruising, bleeding, and infections<sup>2,12</sup> is also common within MM and potentially liable to influence sexual expression. In sum, it could be expected that MM survivors may have unique sexual concerns, but this has not been studied specifically.

In the context of continuing cancer care, patient-provider communication is recognized as an integral component of managing side effects and symptoms and reducing suffering<sup>13</sup>. Across cancer care, patient-provider communication regarding sexuality is lacking, and MM is likely similarly impacted<sup>15-17</sup>. In a qualitative study on sexuality following HSCT, all participants (n = 11) reported scarce discussion but believed it was appropriate and desirable for their providers to discuss sexuality in in-clinic visits<sup>6</sup>. Discussions surrounding sexuality can help patients adapt to sexual changes, improving their sexual and psychosocial outcomes<sup>14</sup>. Ultimately, the unknown sexuality needs of people with MM population make patient and provider sexual health communication even more challenging.

This study aims to assess the specific impact of MM on sexuality and to understand patient preferences for sexuality-related discussions with healthcare providers. As this has not been investigated before, this study will allow a more accurate understanding of MM survivors' concerns rather than inferring them from the experiences of survivors of other hematological cancers.

## Methods

### Participants

A cross-sectional online survey was administered to individuals with MM and other types of blood cancer at varying points in their disease trajectory. Inclusion criteria for the study were: having a diagnosis of hematological cancer, being over 18 years of age, and understanding written English. Due to recruitment

occurring internationally, eligibility criteria (e.g., diagnosis) could not be confirmed, therefore data quality is dependent on participant self-report<sup>15</sup>. Steps were taken by the study team to prevent and monitor for potential data quality issues that can accompany online data collection (e.g., scanning for email address similarity and abnormal responses to reverse coded items, and avoiding crowdsourcing marketplaces due to data quality issues with rare populations<sup>15</sup>). The present paper represents a secondary analysis of MM survivors' responses to three open-ended questions about sexuality, while the overarching study included sexuality, relationship, and psychological outcome measures that are reported on elsewhere.

## **Recruitment**

Using convenience sampling, recruitment was conducted online and internationally between May and September 2020. Relevant patient advocacy organizations (e.g., Myeloma Australia, Multiple Myeloma Cancer Support Group) advertised the study via social media posts, newsletters, and email-list serves. Participants were incentivized with a chance to win a \$25 Visa gift card for participating (odds: 1 in 20). Ethics approval for the study was obtained from the the Research Ethics Board of Alberta – Cancer Committee (Study ID: REB: 19-0346). Personal identifying information was stored separately from participant responses. Written informed consent was obtained from all study participants.

### **Open-Ended Survey Questions**

#### **a. Disease-Specific Barriers to Sexual Activity**

The first question queried potential barriers to engaging in sexual activity caused by MM or its treatment. The question was presented as follows:

Many cancer patients experience physical changes or side effects after diagnosis or treatment (e.g., they bleed or bruise more easily, feel fatigued, have heightened susceptibility to infections and illness, and may experience bone pain or fractures). These physical changes or side effects may impact the way patients sexually express themselves (e.g., they may be afraid that engaging in sexual activity could lead to bruising, etc.,). Since diagnosis or treatment, have any physical changes or side effects affected the way you sexually express yourself?

#### **b. Sexual Adaptation**

The second question inquired about adaptation to sexual changes:

Hematological (blood or bone) disease treatment is associated with various sexual changes. It takes time to adapt to these changes and individuals adapt to these changes in a variety of ways. We would like to know about your experience. Have you adapted or changed your sexual activities or expressions of intimacy, either alone or with a partner? If so, what changes have you made?

#### **c. Patient-Provider Sexuality Communication**

The third question began by asking participants “Have you ever mentioned sexual concerns with your health care provider?” Those who answered “yes” were directed to answer “If yes, what recommendations did the health care provider make?” and those who answered “no” were directed to answer “If no, why not? Were there any barriers that kept you from mentioning sexual concerns with your health care provider?”

## Data Analysis

Descriptive statistics were computed to describe sample characteristics. A qualitative descriptive analysis<sup>18</sup> was used to summarize common themes from responses to open-ended questions. Transcripts were coded by MH and a second coder. Coding discrepancies were discussed between coders and the senior author LW as needed. Themes are presented below and illustrated by representative quotes. Sub-themes are italicized. Quotes were edited for readability<sup>19</sup>. The data that support the findings of this study are available from the corresponding author upon reasonable request.

## Results

### Sample Characteristics

Study participants (n = 65) diagnosed with MM were on average 59.3 years old and most often men (61.5%). The sample was largely white (92.3%), heterosexual (89.1%), and in a committed relationship (89.2%). The most common treatment was chemotherapy (95.4%), followed by steroids (89.1%), and HSCT (69.2%). The majority of men were sexually active both with a partner (65%) and alone (65%), whereas a majority of women were sexually active with a partner (60%) but a minority of women were sexually active alone (36%). (See Table 1 for demographic information).

**Disease-Specific Barriers to Sexual Activity.** Within disease-specific barriers to sexual activity, three themes included symptoms of MM, sexual function concerns, and body image concerns. See Table 2 for representative quotes.

Under the theme of symptoms of MM, specific symptoms represent sub-themes. Consequences of *bone disease* such as bone pain, bone fracture, and spinal cord compression affected sexual expression and resulted in reduced mobility, painful sexual experiences, and anxiety relating to sex. Fears and experiences of *bleeding or bruising* during or after intercourse were expressed by some women. Fears and experiences of *infection* were also described. Fatigue was identified to contribute to loss of sexual desire, reduced frequency of intercourse, and lack of stamina during sexual activity. Those diagnosed with *peripheral neuropathy* reported less satisfying sexual experiences due to impairments in sensation and stability. Neuropathy symptoms reportedly worsened during sexual activity. Finally, *reduced mobility*, such as reductions in flexibility and stability and muscle pain were attributed to bone disease and peripheral neuropathy.

Participants described sexual functioning concerns including low desire, difficulties with orgasm, erectile difficulties, vaginal dryness, and painful sex. They also described body image disturbances related to changes in body weight, hair loss, incontinence which negatively affected sexual self-esteem. Perhaps more unique to MM, experiences of spinal cord compression were also reported to negatively impact body image.

**Sexual Adaptation.** Approximately one-third of participants reported adapting their sexual expression since diagnosis (n = 24). The majority of participants either specifically reported not making adaptations to sexual expression, or did not give any indication that they had (see Table 3 for quotes).

Among those who made adaptations, sexual changes took many forms. Many participants reported *behavioural changes* by altering how they engaged in sexual activities since diagnosis. Some reported trying *sexual medications* to restore sexual activity, specifically those aimed at improving sexual functioning, such as erectile function medication or treatments for vaginal dryness. *Sexual aids* (e.g., lubricants, massage tables) were described as improving comfort during sexual activity. Participants *changed their sexual expression*, including integrating new sexual positions into their repertoires, placing a larger emphasis on non-penetrative forms of intercourse, and engaging in more solitary sexual activities. Chemotherapy recipients reported *managing treatment risks* by using condoms and avoiding deep kissing, while others abstained from sexual activity altogether during periods of treatment.

Some of those struggling with sexual changes *did not adapt*. These participants mentioned that they avoided sexual activity or suppressed their sexual thoughts and expressions. Some reported that such changes resulted in feeling distant from their partner. Occasionally, participants reported that their *partner was unwilling to adapt*, providing reasons including relationship difficulties, partner's sexual problems, and partner's unwillingness to be sexually flexible. Some participants conveyed that they had *no sexual problems or changes* since diagnosis, and notably all participants who reported this were men. Others described experiencing sexual changes but prioritized focusing on survival over navigating sexual difficulties.

**Patient-Provider Sexuality Communication.** Approximately one-third of women and two-thirds of men reported discussing sexuality with their healthcare providers. (see Table 4 for quotes). A minority of participants (34.5%) reported receiving recommendations for existing or possible changes in sexual functioning from their provider, with a smaller portion of women (30.4% vs. 37.1%) disclosing having received a recommendation.

Among those who did discuss sexuality with a provider, some received *recommendations*. Several specifically received medication to address their sexual changes (e.g., sildenafil, estrogen, testosterone), while others mentioned that their providers recommended altering their cancer treatment regimen to address their sexual difficulty. For one man, a change in chemotherapy addressed his concerns about weaker erections, fatigue, and lack of sexual desire. A smaller subset of participants indicated that their providers provided them with sexual counselling, by way of advice (e.g., to try lubricant), sexual education (e.g., outlined treatment-related precautions), or through the provision of resources (e.g., informational

booklets) pertaining to sexuality after cancer treatment. Few participants reported that their provider made a *referral* (e.g., sexual health counselling, pelvic floor physiotherapy). Finally, despite reporting that patient-provider conversations about sexuality occurred, some patients felt that these *discussions did not meet their needs*. For instance, one participant disclosed that her sexual concerns were dismissed by her provider, despite mentioning their impact on her ability to develop sexual relationships.

Among those who did not discuss sexuality with a provider, some simply stated that *sexual concerns were not important*. *Barriers to patient-provider communication* were acknowledged by participants, including: taboos and discomfort surrounding sexuality discussions, perception that sexual concerns are not important enough to mention, time constraints of appointments, and patient's perception that sexuality was not an area within their provider's expertise. Finally, some suggested that such conversations were *not applicable* to them since they did not have sexual concerns.

## Discussion

The current study confirms that many individuals with MM experienced disruptive sexual changes following diagnosis or treatment and engaged in active attempts to adapt their sexual practices to varying degrees. This study uniquely describes how specific MM-related consequences impact sexual expression. Consistent with the extant literature, few patients communicated with their providers about sexual concerns. Importantly, the conversations that did occur were largely generic and genital-focused and did not appear to address the unique needs reported by MM survivors.

This study is the first to report several disease- or treatment-related sexual concerns unique to MM survivors that served as barriers to engaging in sexual activity. These include experiences/fears of bone pain, bone fracture, contraction of illness or infection, and vaginal bleeding or bruising due to sexual activity. One study to date reported that fears of infection or illness are a common concern after HSCT treatment<sup>6</sup> and may thus be common to both MM survivors and HSCT recipients, whereas concerns relating to bone disease may be more unique to MM<sup>6</sup>. High incidence of bone disease and low levels of platelets and white blood cells are known issues in MM survivors<sup>12</sup> and were reflected in participants' concerns. For example, they reported both experiencing bone pain as a barrier during sexual activity and fears of internal bruising as a factor causing avoidance of or anxiety about engaging in sexual activities. However, the prevalence and medical legitimacy of these concerns are unknown and represent an area of further research.

Additional barriers described by MM survivors such as low sexual desire, erectile difficulties, vaginal dryness, and dyspareunia have been well documented in other cancer populations<sup>20</sup>. Fatigue, impaired mobility, and body image disturbances reported here are also common among cancer survivors<sup>2,21</sup>. Loss of sensation due to peripheral neuropathy was reported but its effects on sexuality are not well documented<sup>2,22</sup>. Treatments for such concerns are recommended if patients exhibit significant sexual distress or want symptom management<sup>23</sup>.

Many participants described making adaptations to their sexual expression to cope with cancer-related sexual challenges. For example, they used sexual medications, non-medical sexual aids, modifying sex (e.g., less strenuous positions, non-penetrative activities), and switching to solitary sexual activities. Similarly, emphasizing non-penetrative forms of sexual activity has been identified as a useful strategy for cancer survivors and older adults<sup>24,25</sup>.

Not all participants reported making adapting sexual expression. Consistent with previous studies, some participants avoided sexual activity, suppressed sexual thoughts, and felt distant from their partners because of sexual challenges<sup>26</sup>. Participants in other studies have also reportedly prioritized survival and were less concerned with sexuality<sup>27</sup>.

Consistent with prior studies, patient-provider sexuality discussions were limited<sup>20</sup>. This is unsurprising as the absence of research documenting sexual concerns post-MM has hindered providers' capacity to have informed conversations about sexuality<sup>2,21</sup>. Only a small subset of the sexual concerns reported by participants were addressed by their providers and recommendations primarily aimed to restore penetrative intercourse and ignored psychosocial aspects of sexuality. Body image disturbances and fatigue were also significant but conversations about how these concerns impacted sexuality were absent. Additionally, none of the disease-specific barriers participants described experiencing were mentioned as discussion topics during patient-provider conversations. This suggests that when sexuality conversations occur, they may not be tailored to the range of concerns MM survivors describe.

There appeared to be gender differences in patient-provider communication about sexuality characterized by men reporting this more often. Barriers to sexual health communication may differentially impact individuals based on gender. For example, men's treatment focused on erectile function and excluded psychosocial considerations known to enhance sexual activity after cancer<sup>29</sup>. This trend may reflect erectile dysfunction (ED) being the primary sexual concern in men<sup>8</sup> and the nature of available treatments<sup>30</sup>, specifically ED medication which is typically viewed as successful, acceptable, and time efficient. In contrast, women tend to endorse a wider variety of sexual symptoms<sup>5</sup> which providers often feel less confident in treating<sup>30</sup>. Furthermore, treatments may need to be multi-modal and may be considered less effective, less acceptable, and more time-consuming<sup>30,31</sup>.

Patient perceived barriers to communication may also play a role. Participants in this study reported feeling their concerns were not taken seriously, feeling uncomfortable discussing a stigmatized topic, believing sexuality is outside their provider's area of expertise, not viewing sexuality as a priority, and time constraints. These barriers are consistent with those identified in other studies of cancer survivors and do not appear unique to MM<sup>27,32</sup>.

**Recommendations for Improving Patient-Provider Communication About Sexuality.** To meet the diverse and disease-specific sexual concerns endorsed by MM survivors, it is pertinent to look beyond genital functioning. Providers should prepare to give recommendations relating to bone health, infection/illness, bleeding/bruising, fatigue, and peripheral neuropathy. Attending to concerns about body image

disturbance and relationship adjustment and being able to provide appropriate referrals (e.g., to psychosocial services) is an important form of support. Communication barriers can be mitigated using routine screening tools (e.g., 5-item Sexual Distress Scale – Short Form<sup>34</sup>) and open-ended questions about sexuality<sup>22,32</sup>.

Given the disease-specific barriers that those with MM described, the following recommendations may be helpful to consider:

i) *Bone Disease-Related Concerns.* Patients with bone disease complications who wish to engage in penetrative intercourse could experiment with different sexual positions to avoid discomfort. Consultation with an occupational therapist can also address assistance with positioning<sup>10,11,37</sup>. The American Cancer Society provides illustrations of low-impact positions for sex after cancer<sup>10,11</sup> but this resource may be less applicable to non-heterosexual couples<sup>10,11</sup>. Body supports (e.g., pillows, massage tables) can alleviate pressure on bones and joints<sup>10,11</sup>. Finally, taking pain medication one hour before sexual activity, focusing on fantasies, and exploring non-penetrative forms of sexual activity (e.g., mutual masturbation, erotic massage) may also be useful strategies<sup>10,11</sup>.

ii) *Infection Related Concerns.* Concerns about the risk of infection during chemotherapy is common. Infection risk is deemed higher when the patient's neutrophil counts are  $<0.5$  with the risk of mucosal bleeding higher when the platelet counts are  $<10$ . Clinicians often advise caution when partaking in high intensity or impact physical activity when these laboratory parameters are met. As such, individual risk during sexual intercourse should be assessed, considering individual and disease-related factors. Patients whose fear of infection outweighs the risks should be counselled, as they may be unnecessarily avoiding sexual activity.

iii) *Bleeding/Bruising Related Concerns.* Apprehension around bleeding during chemotherapy is common, and should be discussed and rationalized, and any experiences should be investigated and managed. These concerns were limited to women. Counselling regarding modifying sexual positioning and incorporating more non-penetrative/external vulvar stimulation may be appropriate.

Finally, an interdisciplinary approach for sexual concerns is recommended. This approach allows patients to understand their unique risk factors from a medical perspective, assess their values and risk tolerance from a psychosocial perspective, and assist with positioning and strengthening from a rehabilitation perspective. Providers should thus have a referral network and a variety of resources to accommodate diverse sexual concerns<sup>2</sup>. An excellent table outlining types of providers and appropriateness for referral can be found in Richards et al., (2011)<sup>2</sup>.

**Clinical Implications.** Researchers should continue to characterize sexuality in the MM population so that survivorship care is tailored to their unique needs. Providers should assess possible risks for MM patients engaging in sexual activity, have discussions about sexuality with their patients, and help patients adapt

their sexual expression after diagnosis. A comprehensive referral network can further improve the healthcare experiences of people with MM.

**Limitations and Future Directions.** The first limitation to this study is a lack of diversity in terms of ethnicity and gender identity in the sample which may limit the generalizability of findings. Second, participation was based on self-selection, and it is unclear whether experiences would differ among those who decided not to participate. Third, online recruitment may have excluded those with technological barriers to participation. Fourth, the emergence of the COVID-19 pandemic may have affected participant responses. Finally, data quality is dependent on participant honesty<sup>15</sup>.

Future studies should better characterize sexuality in MM survivors to help providers tailor treatments and resources to their unique needs. First, qualitative studies with in-depth interviews may provide a richer understanding of how MM impacts sexuality. Second, studies should explore the prevalence of the mentioned MM-related barriers for engaging in sexual activity and how distressed patients are about these concerns relative to other sexual concerns. Third, the medical legitimacy of MM-specific concerns should be assessed to inform clinical recommendations for risk assessment and recommendations. This may be particularly helpful for individuals who avoid sexual activity due to fears of consequences (e.g., internal bleeding) without knowing the odds of this occurring. Fourth, examining dyadic perspectives would allow better insight into interpersonal dynamics. Finally, the sexual impact of peripheral neuropathy described in this study is a poorly understood but potentially broadly relevant topic that is worthy of further investigation.

## Conclusion

This open-ended descriptive study was the first to describe MM survivors' specific disease- and treatment-related barriers to sexual activity, methods of sexual adaptation since diagnosis, and the occurrence and content of patient-provider communication about sexuality. While some reported barriers to sexual activity were common to the cancer experience (e.g., fatigue), others appear to be unique to MM (e.g., bone health concerns). Many participants adapted well to sexual changes after diagnosis, however, some continued to struggle with disease-related concerns. Finally, there was a lack of communication with providers about sexuality and MM-specific concerns remained under-addressed. Providers should routinely ask patients about various domains of sexuality, begin screening at diagnosis and throughout the treatment trajectory, and provide relevant resources and referrals, including those specific to the experience of MM.

## Declarations

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**Conflicts of Interest.** None to disclose.

**Availability of data and material.** Study data and materials are available from the corresponding author upon reasonable request.

**Code availability.** Not applicable.

**Authors' contributions.** All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Megan Henkelman. The first draft of the manuscript was written by Megan Henkelman, editorial work was done by Lauren Walker and Kirsti Toivonen, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript

**Ethics approval.** All study procedures were approved by the Research Ethics Board of Alberta – Cancer Committee (Study ID: REB: 19-0346).

**Consent to participate.** Informed consent was obtained from all individual participants included in the study

**Consent for publication.** The authors affirm that human research participants provided informed consent for publication of individual's data

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## Tables

Table 1. *Demographic information for multiple myeloma patients (N = 65)*

	Total Mean (SD)	Women Mean (SD)	Men Mean (SD)
Age	59.25 (10.76)	55.52 (8.84)	61.58 (11.29)
	Total N (%)	Women N (%)	Men N (%)
Biological Sex			
Woman	25 (38.5)	-	-
Man	40 (61.5)	-	-
White/Caucasian <sup>†</sup>	60 (92.3)	23 (92)	37 (92.5)
Has a Medical Condition <sup>‡</sup>			
Yes	14 (21.5)	8 (32)	6 (15)
Treatment Type			
Chemotherapy	62 (95.4)	22 (88)	40 (100)
Radiation	21 (32.3)	2 (8)	19 (47.5)
Total Body Irradiation	3 (4.6)	-	3 (7.5)
Steroids	57 (89.1)	21 (84)	3 (7.7)
HSCT	45 (69.2)	15 (60)	30 (75)
Type of HSCT			
Allo	1 (2.2)	-	1 (3.3)
Auto	44 (97.8)	15 (100)	29 (96.7)
Time Since Diagnosis			
≤1 year	9 (14.1)	6 (24)	3 (7.7)
2 – 10 years	49 (66)	17 (68)	32 (82.1)
10+ years	6 (9.4)	2 (8)	4 (10.3)
Other Cancer Diagnosis <sup>§</sup>			
Yes	11 (16.9)	2 (8)	9 (22.5)
Sexual Orientation			
Heterosexual/Straight	57 (89.1)	23 (92.0)	34 (87.2)
Homosexual/Gay	4 (6.3)	1 (4)	3 (7.7)
Bisexual	3 (4.7)	1 (4)	2 (5.1)

In a Relationship	58 (89.2)	21 (84)	37 (92.5)
Married/Common-law	55 (94.8)	19 (90.5)	36 (97.3)
Dating/Casual	3 (5.2)	2 (9.5)	1 (2.7)
Living with Partner	55 (94.8)	19 (90.5)	36 (97.3)
Partner Gender			
Man	23 (40.4)	20 (95.2)	3 (8.3)
Woman	34 (59.6)	1 (4)	33 (91.7)
Partner Health Condition That May Impact Sexuality	9 (15.5)	4 (19)	5 (13.5)
Sexually Activity Status			
Active Alone	35 (53.8)	9 (36)	26 (65)
Not Active Alone	30 (46.2)	16 (64)	14 (35)
Active with Partner	41 (63.1)	15 (60)	26 (65)
Not Active with Partner	24 (36.9)	10 (40)	14 (35)

*Note.* <sup>†</sup>Other ethnicities reported were Black/African (3.1%), Middle Eastern/Arab/Indian (1.5%), Asian/Oriental/Pacific Islander (1.5%), and other (Greek; 1.5%). <sup>‡</sup>Other medical conditions in order of reported frequency were kidney disease (10.8%), diabetes (7.7%), asthma/emphysema/breathing (6.2%), and stomach ulcers/irritable bowel (4.6%). <sup>§</sup>Other cancer types in order of reported frequency were prostate (4.5%), skin (4.5%), thyroid (3%), breast (1.5%), and sarcoma (1.5%).

Table 2. *Disease-Specific Barriers for Engaging in Sexual Activity*

Main/Sub Themes	Example Quote
<b>Symptoms of MM</b>	
- Osteolytic Bone Disease	<i>"a few rib fractures . . . and [a] risk of a back fracture . . . [resulted] in a more anxious sexual experience" (Woman, 38) ; "Bone pain and difficulty turning and twisting"(Man, 69)</i>
- Risk of Bleeding or Bruising	<i>"I am afraid of internal bruising from intercourse"(Woman, 68) ; "[I am] nervous regarding vaginal penetration because of [the] potential for . . . bleeding"(Woman,71) ; "slight [vaginal] bleeding" (Woman, 65)</i>
- Risk of Infection	<i>"I only masturbate as I am scared of getting [an] infection" (Woman, 43) ; "afraid of new infections" (Man, 52)</i>
- Fatigue	<i>"[I am] fatigued,[and] only want short sex" (Woman, 56) ; "fatigue meant less sexual activity" (Man, 71)</i>
- Peripheral Neuropathy	<i>"neuropathy. . [impacts] my ability . . . [to] move freely . . . [and] feel sensual touch" (Woman, 64) ; "Neuropathy in my feet . . . flares up during sex (Man, 73)</i>
- Reduced Mobility	<i>"back pain and muscle spasms . . . occur during sex" (Man, 52) ; "Back pain . . . limited [my] movement"(Woman, 59)</i>
<b>Sexual Function Concerns</b>	<i>"difficulty getting aroused and erect" (Man, 69) ; "[a] loss [of] sexual interest due to [a] lack of lubrication and pain"(Woman, 58)</i>
<b>Body Image Disturbances</b>	<i>"weight gain [from] treatment [lead to] low self-esteem" (Man, 52) ; "[I'm] less confident in my body due to weight fluctuation" (Woman, 52)</i>

Table 3 *Sexual Adaptation*

Main/Sub Themes	Example Quotes
<b>Adapted</b>	
Sexual Medicine	<i>"I use Cialis"(Man, 48); "[I] am on hormone meds due to [sexual] difficulties"(Woman, 48)</i>
Sexual Aids	<i>"I need to use lubrication" (Woman, 45); "We have a massage table that makes it easier to have intercourse" (Man, 73)</i>
Change in Sexual Expression	<i>"[I tried] touching rather than penetrative sex" (Man, 74) ; : "[Tried] more cuddling" (Woman, 72) ; "[I experienced] compression fractures [which] cause positions to be different" (Woman, 41); "Missionary caused . . . too much back pain . . . [now I stand] behind my wife as she bends over the side of the bed"(Man, 67) ; ; "Due to . . . difficulty with erections . . . I opted to masturbate" (Man, 70)</i>
Managing Risks of Treatment	<i>"[I] . . . use condoms, [and] can't deep kiss . . . because my body fluids are toxic now" (Woman, 63) ; "no sex on the chemo infusion days and one day after" (Man, 56)</i>
<b>Did Not Adapt</b>	
Did Not Adapt	<i>"I don't have much desire anymore so I don't think about it"(Man, 51) ; "I have either ignored my feelings to [sexually] express [myself], or avoided any sexual experience" (Woman, 65)</i>
Partner Unwilling to Adapt	<i>"[My] partner isn't interested in sex now"(Man, 77) ; "[We are] less affectionate, [and my] husband [is] more distant"(Woman, 57)</i>
No Perceived Sexual Problems	<i>"I am still active with no decline"(Man, 65) ; "living [my] life is more valuable [than] having sexual pleasure" (Man, 58)</i>

Table 4 *Patient-Provider Communication About Sexuality*

**Discussed Sexuality with Provider**Made a  
Recommendation:

Medication

*"Medication only" (Man, 57) ; "[a] local hormone due to dryness . . . after stem cell transplant" (Woman, 38)*

Treatment

*"changed chemo" (Man, 70) ; "started HRT [hormone replacement therapy]" (Woman, 55)*

Counselling

*"provided [with a] booklet" (Man, 67); "[To try] lubricant" (Woman, 68) ; "Go gently while in treatment" (Woman, 52) ; "[My provider] outlined precautions related to chemotherapy" (Man, 57)*

Made a Referral

*"provided . . . [with a] referral to sexual health counselling" (Man, 67) ; "[Told] to see a pelvic floor physiotherapist" (Woman, 58)*Did Not Meet Patient's  
Needs*"I don't feel as though I was taken seriously" (Woman, 65); "We went [to the provider] with no results" (Man, 55)***Did Not Discuss Sexuality With Provider**Sexual  
Concerns Not*"Not bothered" (Man, 52) ; "Not a top priority" (Woman, 63)*

Important

Barrier to  
Communication*"due to social anxiety [I] couldn't mention sexuality" (Man, 58) ; "[the topic is] private I guess" (Woman, 70) ; "[The] time constraints [for] appointments" (Woman, 52) ; "[I] do not feel [as though sexuality] is their area of expertise" (Man, 65)*Not  
Applicable*"no concerns" (Woman, 41) ; "No real sexual problems" (Man, 56)*