Brief Report

Assessing the Impact of Serious Illness on Patient Intimacy and Sexuality in Palliative Care

Anne Kelemen, LICSW, John Cagle, PhD, MSW, Julia Chung, LICSW, and Hunter Groninger, MD, FAAHPM
Section of Palliative Care (A.K., H.G.), MedStar Washington Hospital Center; Georgetown University Medical Center (A.K., J.Chung, H.G.), Washington, District of Columbia; and University of Maryland School of Social Work (J.Cagle), Baltimore, Maryland, USA

Abstract

Context. Palliative care (PC) clinical practice guidelines recommend providers assess the impact of illness on intimacy and sexuality. Previous studies around sexuality and intimacy in patients with advanced illness have largely focused on patients with a cancer diagnosis in the outpatient setting. Little is known about such impact of illness on inpatients receiving PC consultation.

Objectives. To assess the impact of patient illness on intimacy and sexuality through use of a screening tool and brief clinical questionnaire in hospitalized patients receiving PC consultation.

Methods. Between January 2016 and May 2017, palliative social workers at three hospitals asked patients to report the level of impact that their illness(es) had on intimacy and to describe the impact. Data were analyzed using descriptive statistics and chi-square analysis. Qualitative data were analyzed using constant comparison methodology.

Results. Among the 97 PC patients screened for intimacy concerns, the majority were female (57.7%), African American (71.1%) and on average 57.9 years of age. Most (91.7%) reported that they had not been previously asked about how their illness had impacted their intimacy. Nearly half (48.4%) reported that illness had moderately or significantly impacted their intimacy; these patients tended to be younger and in a current relationship ($P < 0.05$).

Conclusion. Patients with advanced illness commonly report negative issues regarding intimacy and sexual health. Incorporating routine screening into PC consultation may be warranted. J Pain Symptom Manage 2019;58:282–288.

Key Words
Palliative care, end-of-life care, sexuality, intimacy

Introduction/Background

Palliative care (PC) aims to improve quality of life for patients with a serious illness. A comprehensive palliative assessment includes exploring a patient's physical, psychosocial, emotional, and spiritual needs.[1,2] One aspect of this assessment includes addressing sexuality and intimacy needs. However, research shows this is an area often excluded from a palliative assessment.[1–3] In one study, 90% of nurse respondents indicated they do not routinely assess for sexual health.[4] Intimacy can include physical and emotional closeness, sexual interactions, and communication of thoughts/feelings.[1–5] The World Health Organization defines sexuality as "a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction."[6] Barriers to these conversations include the clinician's fear of being intrusive, misconceptions about the importance of sexuality and intimacy within this patient population, and lack of training on how to have these discussions.[1–4,7] Evidence suggests that patients want to talk about intimacy and sexuality, have important concerns that are not being addressed, and prefer their health care team broach the topic.[5,7–10]

Address correspondence to: Anne Kelemen, LICSW, Section of Palliative Care, Department of Medicine, MedStar, Washington Hospital Center, 110 Irving Street NW, Room 2A68, Washington, DC 20010, USA. E-mail: anne.m.kelemen@medstar.net

Accepted for publication: April 16, 2019.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2019.04.015

The current National Coalition for Hospice and Palliative Care Clinical Practice Guidelines indicate that a social assessment include "[t]he effect of illness or injury on intimacy and sexual expression".[11] Previous studies around sexuality and intimacy have largely focused on outpatient settings with a cancer diagnosis; little is known about the impact on inpatients with advanced illness(es).[12–15] Our previous single-center study focused on hospitalized patients receiving PC consultation and concluded that a majority of patients had not previously been asked about intimacy or sexuality yet illness significantly or moderately impacted intimacy.[5] This multisite study was designed to build on this previous work to better understand the importance of sexuality and intimacy within an inpatient PC population.[5]

Methods

We conducted a multisite study to assess the impact of patient illness on intimacy and sexuality through use of a screening tool and brief clinical questionnaire. The study took place across three hospitals located in the Baltimore-Washington region: a Level 1 trauma center, an urban academic hospital, and an urban community hospital. Data collection occurred between January 2016 and May 2017. Consistent with the case-mix of PC services across the study sites, a majority (32.7%) of cases had a primary diagnosis of cancer, followed by end-stage cardiac disease (17.2%) and end-stage pulmonary disease (11.8%). All methods and procedures were reviewed and approved by the institutional review board at the lead author's affiliated institution. The study sample consisted of adult patients aged 18+ years who were capacitated (determined by clinical judgment of the primary hospital teams), receiving inpatient hospital-based care, and had been referred for PC consultation. Patient characteristics, such as gender, race/ethnicity, and principal diagnosis, were obtained from the medical record. Data on relationship status, intimacy impact on personal well-being and on relationship status, and whether intimacy had been discussed by other clinical providers were reported by participating subjects.

Self-reported rating of how much the patient's intimacy had been affected by the illness (0 = none, 1 = little, 2 = moderately, and 3 = significantly) and specific issues/concerns were collected using the screening tool during PC initial or follow-up consultation. The tool used the term "intimacy" and if patients were allowed to define the meaning of intimacy in the context of their illness. A subsequent open-ended question was used to determine how intimacy had been affected. Responses, including direct, verbatim quotes from the patient, were documented by the PC social worker in detailed clinical notes. Notes also included clinician impressions.

Two authors (A. K. and H. G.) reviewed electronic medical records of each patient to determine if they survived three months after discharge. If information was not found in the electronic medical record, the lead author searched public record and called facilities where patients were discharged.

Descriptive statistics appropriate to the measure (means and standard deviations for continuous data; frequencies and percentages for categorical data) were used to summarize sample characteristics. Independent *t*-tests and chi-squared analyses were used to identify differences in self-rated impact (responses of "no" or "little" vs. "moderate" or "significant") of one's illness on intimacy based on sample characteristics. Similar difference testing was used to compare patients at the end of life (EOL; i.e., determined retrospectively as those patients who died within three months after screening) vs. those who were not at the EOL (i.e., those still living beyond three months after screening). A subsequent post hoc analysis of variance was conducted to help explain observed differences in patient mortality across medical centers.

Qualitative data from the intimacy screening tool and clinical notes were coded for thematic content using the tenets of the constant comparison method.[15] An initial coder (J. Cagle) reviewed the data, identified preliminary themes, and developed a coding dictionary. Two additional coders (A. K. and H. G.) used the preliminary themes and data dictionary to refine and confirm coding decisions. Select patient quotes and excerpts from clinical notes are provided to give case-based exemplars of the identified themes. Qualitative findings are stratified based on patient intimacy impact rating to allow for a thematic comparison of patients reporting that the illness had little/no impact on intimacy in patients who reported a moderate/significant impact.

Results

As Table 1 displays, among the 97 PC patients screened for intimacy concerns, the majority were female (57.7%), African American (71.1%), and on average 57.9 years of age (SD = 16.2). The prevailing primary diagnosis was cancer (41%) and 39.2% died within three months of being given the intimacy screening tool. A large majority of patients (91.7%) reported that they had not been previously asked about how their illness had impacted their intimacy before the PC consultation. Just less than half (48.4%) of the sample reported that illness had moderately or significantly impacted their intimacy.

Table 1
Patient Characteristics for a Multisite Study of Intimacy Concerns in Palliative Care ($N = 97$)

Characteristic	Descriptive Statistics, N (%)
Age, yrs	
18–39	13 (13.0)
40–49	14 (14.0)
50–59	22 (22.0)
60–69	29 (29.0)
70–79	11 (11.0)
80+	10 (10.0)
Missing	1 (1.0)
Gender	
Male	41 (42.3)
Female	56 (57.7)
Race/ethnicity	
African American	69 (71.1)
Caucasian	22 (22.7)
Other race/ethnicity	6 (6.2)
Relationship status	
Married/partnered	30 (30.9)
Widowed	8 (8.2)
Boyfriend/girlfriend/engaged	8 (8.2)
Single	37 (38.1)
Divorced/separated	13 (13.4
Missing	1 (1.0)
Principal diagnosis	
Cancer	42 (43.3)
Congestive heart failure	18 (18.6)
Other condition	21 (21.6)
Sepsis/infection	6 (5.2)
Chronic obstructive pulmonary disease/respiratory failure	8 (8.2)
Missing	3 (3.1)
Died within three months of admission?	
Yes	38 (39.2)
No	50 (51.5)
Missing	9 (9.3)
Site	
A	14 (14.4)
B	55 (56.7)
C	28 (28.9)
Intimacy impact rating	
None	30 (30.9)
Little	19 (19.6)
Moderately	20 (20.6)
Significantly	27 (27.8)
Elected not to respond	1 (1.0)
Intimacy previously discussed?	
Yes	5 (5.2)
No	89 (91.7)
Missing	3 (3.1)
Intimacy conversation helpful?	
Yes	79 (81.4)
No	8 (8.2)
Ambivalent/unsure	4 (4.1)
No response/not asked	3 (3.1)
Missing	3 (3.1)

Table 2
Self-Reported Impact of Illness on Intimacy by Patient Characteristics ($N = 97$)

	Impact of Illness on Intimacy		
Characteristic	% None/ Little	% Moderate/ Significant	*P*-value
Age, yrs			**0.019**
18–39	38.5	61.5	
40–49	35.7	64.3	
50–59	36.4	63.6	
60–69	51.7	48.3	
70–79	80.0	20.0	
80+	90.0	10.0	
Gender			0.227
Male	43.9	56.1	
Female	56.4	43.6	
Race/ethnicity[a]			0.219
African American	53.6	46.4	
Caucasian	52.4	47.6	
Other race/ethnicity	16.7	82.3	
Relationship status[a]			**0.028**
Married/partnered	**30.0**	**70.0**	
Widowed	**87.5**	**12.5**	
Boyfriend/girlfriend/ engaged	**50.0**	**50.0**	
Single	**59.5**	**40.5**	
Divorced/separated	**58.3**	**41.7**	
Principal diagnosis[a]			0.521
Cancer	50.0	50.0	
Congestive heart failure	38.9	61.1	
Other condition	57.1	42.9	
Sepsis/infection	50.0	50.0	
Chronic obstructive pulmonary disease/ respiratory failure	75.0	25.0	
Died within three months of admission?			0.757
Yes	48.6	51.4	
No	52.0	48.0	
Site			0.115
A	76.9	23.1	
B	49.1	50.9	
C	42.4	57.1	
Intimacy previously discussed?[b]			**0.024**
Yes	**0.0**	**100**	
No	**54.5**	**45.5**	
Intimacy conversation helpful?			0.188
Yes	46.8	53.2	
No	57.1	42.9	
Ambivalent/unsure	100	0.0	
No response/not asked	66.7	33.3	

Missing cases were excluded from all bivariate analyses. Statistically significant results ($P < 0.05$) are highlighted in bold. Percentages may not total 100% because of rounding.
[a]*P*-values reported despite low cell counts for chi-squared tests.
[b]Fisher's exact chi-squared test.

Younger patients were more likely to rate the impact of the illness on their intimacy as moderate/significant (see Table 2). More specifically, those reporting a moderate/significant impact were on average 10 years younger than patients reporting none/little impact (52-year-olds vs. 62-year-olds, respectively; $P = 0.002$). Respondents who were currently in a relationship with a significant other were also more likely to indicate that their illness was having a moderate/significant impact on their intimacy ($P = 0.028$). For example, only 13% of those who were widowed reported a moderate/significant impact compared with 70% of married/partnered patients. Illness impact was associated with whether the patient had had a previous conversation with a health care provider ($P = 0.024$). Although few patients ($n = 5$; 5.2%) reported having had a previous conversation about

Table 3
Differences Between Patients Who Died Within Three Months After Screening vs. Those Still Alive

Characteristic	Died Within Three Months After Screening? $N = 50$, % No	$N = 38$, % Yes	*P*-value
Age, yrs			0.929
18–39	41.7	58.3	
40–49	61.5	38.5	
50–59	60.0	40.0	
60–69	58.3	41.7	
70–79	54.5	45.5	
80+	55.6	44.4	
Gender			0.499
Male	61.1	38.9	
Female	53.8	46.2	
Race/ethnicity[a]			0.334
African American	61.3	38.7	
Caucasian	42.9	57.1	
Other race/ethnicity	60.0	40.0	
Relationship status[a]			0.576
Married/partnered	50.0	50.0	
Widowed	40.0	60.0	
Boyfriend/girlfriend/engaged	62.5	37.5	
Single	65.7	34.3	
Divorced/separated	46.2	53.8	
Principal diagnosis[a]			0.119
Cancer	48.6	51.4	
Congestive heart failure	76.5	23.5	
Other condition	47.6	52.4	
Sepsis/infection	40.0	60.0	
Chronic obstructive pulmonary disease/respiratory failure	85.7	14.3	
Site			**0.045**
A	**37.0**	**63.0**	
B	**65.3**	**34.7**	
C	**66.7**	**33.3**	
Intimacy previously discussed?[b]			0.456
Yes	56.1	43.9	
No	75.0	25.0	
Intimacy impact rating			0.757
None/little	59.1	40.9	
Moderate/significant	55.8	44.2	
Intimacy previously discussed?[b]			0.456
Yes	56.1	43.9	
No	75.0	25.0	
Intimacy conversation helpful?[a]			0.200
Yes	61.1	38.9	
No	25.0	75.0	
Ambivalent/unsure	66.7	33.3	
No response/not asked	33.3	66.7	

Missing cases were excluded from all bivariate analyses. Statistically significant results ($P < 0.05$) are highlighted in bold. Percentages may not total 100% because of rounding.
[a]*P*-values reported despite low cell counts for chi-squared tests.
[b]Fisher's exact chi-squared test.

intimacy with a health care provider, all (100%) of these patients reported that the illness had a moderate/significant impact on their intimacy.

The comparison of patients at the EOL vs. those who were not at the EOL resulted in only one statistically significant association—the site of care (see Table 3). A larger proportion of patients who were screened at Hospital Site "A" died within three months of the intimacy screening (63%), compared with Sites "B" (35%) and "C" (33%, $P = 0.045$). A post hoc analysis found that the patient population at Site "A" was substantially older than those from Sites "B" and "C." In the study sample, the average patient age at Site "A" was 70 years (SD = 11), compared with a mean age of 58 years (SD = 17) at Site "B" and 53 years (SD = 15) for Site "C" ($P = 0.005$ for the omnibus analysis of variance test; $P < 0.05$ for both Bonferroni's post hoc evaluations comparing Site "A" to Sites "B" and "C"). The impact rating did not statistically differ based on proximity to death ($P = 0.757$). In both groups, over three-quarters reported that the intimacy discussion was helpful, 77.8% for EOL patients and 89.8% for patients who were alive beyond three months after screening (note: percentages reported here are based on column totals, which are not shown in Table 3). A slight majority of EOL patients (52.6%, also a column total) reported that their intimacy had been moderately/significantly impacted by their illness.

As Table 4 shows, among patients who provided an intimacy impact rating of little/none, we identified one overarching commonality and six main themes, which emerged from the qualitative data. In general, findings from clinical notes suggest that patients reporting little/no impact of the illness on intimacy also tended to have little or no pre-existing interest in sexual intimacy. For example, "I'm not doing 'that' right now, so that's not a worry" (<65-year-old female, EOL status unknown). Nested within this overarching commonality of diminished interest in intimacy, patients also shared six thematically grouped reasons for their limited, or nonexistent, interest: 1) a focus on recovery; 2) being older; 3) being sexually inactive; 4) past sexual trauma; 5) a lack of energy/low libido; and 6) body image concerns. Many attributed their lack of interest in pursuing intimacy to the fact that they were concentrating on improving their health and wanting to get better. Multiple patients also reported that they were not currently sexually active. This was largely due to not having a partner, for example, because of widowhood, separation, or divorce. Multiple older respondents ($N = 4$) indicated that they were "too old" to be interested in sexual intimacy. Table 4 describes the remaining themes, including subthemes with specific examples from patient quotes and excerpts from clinical notes.

Individuals who reported that their illness had moderately/significantly impacted their intimacy generally reported having an interest/desire for intimate contact (a prominent overarching commonality) but also shared that disease-related issues created multiple barriers. Five main themes were identified as barriers to intimacy. Specifically, these barriers were 1)

Table 4
Qualitative Themes, Subthemes, and Descriptions of the Impact of Illness on Patient Intimacy

Themes and Subthemes	Exemplary Quotations
Subsample 1	
Respondents Reporting the Illness Had Little/No Impact on Intimacy	
Limited interest/desire due to the following:	
Focus on recovery	"I'm not thinking about that now. I need to get better" [<65 yrs, F, EOL]
Being older	"Sex is no longer a part of my life. I'm too old for that" [65+ yrs, M, unknown EOL status]
Being sexually inactive	
By choice	Patient is working on herself and not interested in a relationship [<65 yrs, F, not EOL]
No partner	Patient has not dated in many years [<65 yrs, F, EOL]
Widowed	"My husband died 10 yrs ago so I'm no longer intimate" [<65 yrs, F, not EOL]
Past sexual trauma	Past trauma; no intimacy since high school [65+ yrs, F, not EOL]
Lacking energy/libido	"I do not have the energy for all that anymore" [65+ yrs, M, EOL]
Body image concerns	
Catheter	"I have a catheter" [<65 yrs, F, not EOL]
Lesions	Patient expresses concerns regarding body image due to skin lesions. [<65 yrs, F, EOL]
Subsample 2	
Respondents Reporting the Illness Had a Moderate/ Significant Impact on Intimacy	
The desired level of intimacy was limited by the following:	
Symptoms	
Pain	"I have trouble moving my body because of the pain" [age unknown, F, not EOL]
Dyspnea	"[Intercourse] is over soon because of my breathing" [<65 yrs, M, not EOL]
Stress/strain	"[After the diagnosis] everything was exacerbated by stress" [<65 yrs, F, not EOL]
Treatments/equipment	
Devices	"Who would want to be with me like this?"; pointing to implant [<65 yrs, M, not EOL]
Ostomies	"The [colostomy] bag 'kills the mood'" [<65 yrs, M, EOL]
Side effects	Difficulties related to patient's confusion due to treatment toxicity [<65 yrs, F, EOL]
Hospital bed	Patient has to sleep in a hospital bed in a different room [<65 yrs, F, EOL]
A relationship breakup	"[The illness/surgery] led to my relationship ending in some ways" [65+ yrs, F, not EOL]
Impaired ability	
Being bed bound	Patient has been bed bound for three months [65+ yrs, F, EOL status unknown]
Erectile dysfunction	Patient is self-conscious regarding erectile dysfunction [65+ yrs, M, EOL]

EOL = end of life (i.e., died within three months of receiving the intimacy screening); M = male; F = female.
Direct patient quotes are indicated with quotation marks. Other excerpts are from clinical notes. Some patient information has been obscured to protect patient identity.

symptoms (e.g., pain, dyspnea); 2) treatments or medical equipment (e.g., ostomies, single occupancy hospital beds); 3) stress/strain; 4) relationship dissolution (i.e., a breakup) connected to the illness; and 5) impaired ability (e.g., erectile dysfunction).

Several patients described a yearning for physical intimacy and/or affectionate human contact. After reporting that his illness had significantly impacted his intimacy, one patient expressed, "I long for sexual intimacy" [>65-year-old male at the EOL]. Another patient who reported a moderate impact of the illness on her intimacy shared that "People do not touch me. No one touches me anymore" [<65-year-old female, not at the EOL]. Although intimacy was often interpreted by patients as a form of physical sexual expression, multiple patients remarked that, for them, intimacy also included nonsexual displays of affection, such as hugging and snuggling. One patient commented, "I think of intimacy as holding hands, cuddling, et cetera. I do not miss sex anymore, but it was good while it lasted" [>65-year-old male, not at the EOL]. Some patients had not previously recognized that their intimacy had been negatively affected by the illness.

For example, one patient shared, "This really bothers me—I didn't even notice the problem until we started talking about it, but now I see it is a problem" [<65-year-old male at the EOL].

Discussion

In our sample, the presence of a serious or life-threatening illness was shown to impact patient intimacy to at least some degree in over two-thirds (68%) of cases; and a clear majority of patients (81%) reported the screening conversation about intimacy concerns was helpful. Among EOL patients, a majority (53%) expressed that their illness had moderately/significantly impacted their intimacy; and 78% found the conversation helpful, suggesting that intimacy remains important even with a prognosis of just months to live. PC clinicians should recognize that patient illness occurs within a larger social/relational context. Intimate relationships begin, evolve, and dissolve even in the face of serious illness. Furthermore, our qualitative data show that the presence of disease disrupts patient intimacy in a wide variety of ways, including by burdensome physical symptoms, overwhelming levels of stress and strain, treatments or equipment that complicate physical intimacy, impaired functional capability, and contributing to relationship breakups. Consistent with previous findings, these data also suggest a need for assessing sexuality and intimacy concerns for PC patients. Even patients who reported little or no impact on their sexuality and intimacy largely found the conversation helpful, perhaps, allowing space to process this loss was valuable. It is important for clinicians to be aware of any distress that might be caused by initiating the conversation, as it may bring up issues that patients or partners previously ignored.

Patients who were younger and partnered were more likely to report a moderate or significant impact on intimacy, a finding that differed from our previous study.[5] This might be explained because intimacy is sometimes interpreted as only relevant within the context of couplehood or only for younger or middle-aged adults.[16] Another possible reason is that, compared with our previous pilot work, this study had greater analytic power to detect statistically significant associations.

Additional study is needed to identify and test interventions designed to address concerns related to intimacy that are appropriate for PC populations. For the themes identified in Table 4, even patients who reported intimacy having little or no impact still had important concerns, which could be further explored. For example, individuals reporting past sexual trauma might benefit from a therapist referral. Or individuals with body image concerns (ostomy bags, catheters, skin lesions, etc.) could have tailored interventions to address those concerns.

The intimacy screening used in this project did not explicitly assess a patient's desire for intimacy or sexual contact nor how that level of desire was affected by illness. Our qualitative results suggest that these elements are clinically relevant. Thus, future study should examine how the manifestation of disease influences patient libido and their preferred level of intimacy.

Although not a primary objective of this project, results also demonstrated that the intimacy screening can be easily implemented by multiple clinicians working at three different hospital sites. More evidence, however, is needed to better understand optimal implementation strategies, including training for screeners and effective interventions to address intimacy problems and concerns. We suspect that, given the general feelings of discomfort with bringing up this topic, more education is warranted for clinicians on how to bring up the subject, facilitate discussion, and explore possible, viable interventions.

Results should be considered with respect to project limitations. Data came from patients receiving care at one of three urban hospitals located within the same general geographic region. Thus, findings may have limited generalizability. We determined patients to be at EOL if they died within three months after discharge, but we could have used hospice eligible (less than six months) to categorize EOL patients. However, it was not feasible for our clinical team to track patient mortality beyond three months after screening. Reports that the intimacy conversation was helpful may be inflated because of a lack of blinding. Data were collected by the clinician who facilitated the conversation, and thus, patients may have been subject to social desirability bias. In addition, we allowed patients to define what intimacy means to them, and future studies could provide a more concrete definition of either intimacy or sexuality. Finally, data regarding the gender of patient's intimate partner were not collected as part of this study. Future research is needed to explore whether experiences of intimacy are similar for both same-sex and heterosexual couples.

Conclusion

Intimacy and sexuality are core dimensions of patient quality of life that are often overlooked in PC settings.[1,3] Our data show that patient intimacy is critically threatened when serious illness occurs and that most patients—even those at the very EOL—want to talk about issues related to sexuality and intimacy with PC providers. Hence, PC teams could consider including an assessment of relevant sexuality and

intimacy concerns as a routine part of a comprehensive psychosocial assessment and collaborate to develop care plans that address pertinent patient concerns.

Disclosures and Acknowledgments

The authors have nothing to disclosure.

References

1. Cagle J, Bolte S. Sexuality and life-threatening illness: implications for social work and palliative care. Health Social Work 2009;34:223–232.

2. Cagle J, Osteen P, Sacco P, Jacobson J. Psychosocial assessment by hospice social workers: a content review of Instruments from a National sample. J Pain Symptom Mgt 2017;53:40–48.

3. Gallo-Silver L. Sexuality, sensuality, and intimacy in palliative care. In: Altilio T, Ots-Green S, eds. Oxford textbook of palliative social work. New York, NY: Oxford University Press, 2011:261–270.

4. Matzo M, Hijjazi K. If you don't ask me…don't expect me to tell. A pilot study of the sexual health of hospice patents. J Hosp Palliat Nurs 2009;11:271–281.

5. Kelemen AM, Cagle JG, Groninger H. Screening for intimacy concerns in a palliative care population: findings from a pilot study. J Pal Med 2016;19:1102–1105.

6. World Health Organization. Sexual and reproductive health: defining sexual health. 2006. Available from https://www.who.int/reproductivehealth/topics/sexual_health/sh_definitions/en/. Accessed April 21, 2019.

7. Lemieux L, Kaiser S, Pereira J, Meadows L. Sexuality in palliative care: patient perspectives. Palliat Med 2004;18:630–637.

8. Den Ouden MEM, Pelgrum-Keurhorst MN, Uitdenhaag MJ, DE Vocht HM. Intimacy and Sexuality in women with breast cancer: professional guidance needed. Breast Cancer 2018;26:326–332.

9. Taylor B. Experiences of sexuality and intimacy in terminal illness: a phenomenological study. Palliat Med 2014;28:438–447.

10. Taylor B. The impact of assistive equipment on intimacy and sexual expression. Br J Occup Ther 2011;74:435–442.

11. National Consensus project for quality palliative care. Clinical practice guidelines for quality palliative care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care, 2018:27. Available from https://www.nationalcoalitionhpc.org/ncp.

12. Bartula I, Sherman KA. Screening for sexual dysfunction in women diagnosed with breast cancer: systematic review and recommendations. Breast Cancer Res Treat 2013;141:173–185.

13. Hordern AJ, Street AF. Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. The Med J Aust 2007;186:224–227.

14. Flynn KE, Reese JB, Jeffery DD, et al. Patient experiences with communication about sex during and after treatment for cancer. Psycho-oncology 2012;21:594–601.

15. Grove R. An analysis of the constant comparative method. Int J Qual Stud Education 1988;1:273–279.

16. Yoo H, Bartle-Haring S, Day R, Gagamma R. Couple communication, emotional and sexual intimacy and relationship satisfaction. J Sex Marital Ther 2014;40:275–293.