

Supportive Care Needs After Gynecologic Cancer: Where Does Sexual Health Fit in?

Megan McCallum, BA, Lynne Jolicoeur, RN, MScN, CON(c), Monique Lefebvre, PhD, CPsych, Lyzon K. Babchishin, BA, Stéphanie Robert-Chauret, Tien Le, MD, and Sophie Lebel, PhD

Gynecologic cancer (GC) and its treatment are associated with changes in physical, psychological, and social dimensions including depression and anxiety, infertility, poor body image, and bladder or bowel dysfunction (Gilbert, Ussher, & Perz, 2011; Pearman, 2003; Wilmoth & Spinelli, 2000). Post-treatment symptoms are linked to many sexual health difficulties, which have been reported as the most frequent, enduring, and distressful post-treatment morbidities in this population (Abbott-Anderson & Kwekkeboom, 2012); however, discussions about sexuality between patients with GC and their healthcare providers are sparse (Gott, Hinchliff, & Galena, 2004; Lindau, Gavrilova, & Anderson, 2007; Stead, 2004).

Awareness of survivorship needs is increasing, along with efforts to implement systematic screening for distress in cancer survivors (Bultz et al., 2011). To maximize the quality of patient care, healthcare teams must provide treatment and/or appropriate referrals to assist patients who are experiencing significant distress. Unfortunately, little empirically supported guidance is available on effective interventions for sexual problems post-treatment. Only a handful of published intervention studies have shown favorable effects on symptom management behaviors that may improve sexual function (e.g., increasing compliance with vaginal dilation recommendations) (Robinson, Faris, & Scott, 1999). The few existing psychological interventions for treating sexual dysfunction in cancer survivors have seen only moderate effectiveness, and progress in this research field is challenging because of low response rates and high attrition rates (Brotto, Yule, & Breckon, 2010). A systematic review of sexual concerns in this population illustrated the current focus on physical dimensions of sexuality and emphasized a need for comprehensive assessments of sexual concerns, which would further development and testing of interventions for GC survivors (Abbott-Anderson & Kwekkeboom, 2012).

Purpose/Objectives: To inform the development of post-treatment screening and intervention services in a gynecologic oncology program by describing patient needs and desire for help.

Design: Descriptive, cross-sectional study.

Setting: Follow-up clinic of a gynecologic oncology program in a regional cancer center.

Sample: 113 women treated for gynecologic cancer.

Methods: Data were collected using standardized instruments and analyzed through descriptive and correlation statistics.

Main Research Variables: Supportive care needs, sexual health needs, vaginal changes, desire for help, and socio-demographic and medical factors.

Findings: Forty percent of the sample was worried about the status of their sex life and many wished to meet one-on-one with a health professional or to receive written information. Younger age, premenopausal status at diagnosis, and lower sexual satisfaction and more vaginal changes after treatment were associated with greater sexual health needs and desire for help.

Conclusions: Several sexual health needs were among the highest reported supportive care needs. Certain subgroups may report higher needs and desire for help; this domain merits additional research. Needs were extremely diverse, reflecting the use of an individual approach to screening for and meeting survivor needs.

Implications for Nursing: Personal perceptions of the implications and meaning of sexual health and vaginal changes create the subjective experience of a need. Discussions of the women's perceptions of their needs and their views of healthy sexuality will help develop effective treatment plans.

Key Words: gynecologic malignancies; menopausal symptoms; quality of life; sexuality and fertility; survivorship

ONF, 41(3), 297–306. doi:10.1188/14.ONF.297-306

In light of these challenges, additional research on patient needs and preferences for services directed to meeting their needs is urgently needed. To date, most needs assessments evaluated only one or two need domains at a time in patients with GC post-treatment. For

example, some explored a need for increased patient-physician communication about sexuality, whereas others paid greater attention to physical needs while neglecting psychological and social concerns (Bourgeois-Law & Lotocki, 1999; Corney, Everett, Howells, & Crowther, 1992; Gamel, Hengeveld, & Davis, 2000; Jefferies, 2002; Miller, Pittmann, & Strong, 2003; Stewart et al., 2000). Only a small number of needs assessment studies have explored comprehensive supportive care needs in patients with GC post-treatment (Beesley et al., 2008; Hodgkinson et al., 2007; Steele & Fitch, 2008). The inclusion of a wider spectrum of types of needs led to a consistent broader observation that patients' unmet needs post-treatment are most often nonphysical in nature, highlighting a need to further investigate psychological, sexual, and social dimensions.

Three gaps in the literature on supportive care and sexual health needs are observed. First, whereas a significant proportion of patients with GC report sexuality as the most compromised and distressing post-treatment issue, only one of the supportive care needs assessments measure sexuality needs as a unique domain to date (Beesley et al., 2008). Second, Steele and Fitch (2008) found that some women who report moderate to high difficulty with unmet needs do not desire help, and little is known about this subgroup of women (McCallum, Lefebvre, Jolicoeur, Maheu, & Lebel, 2012). Finally, no published studies have explored the specific types of services desired by patients (e.g., support group, pamphlet). That information may contribute to the development of interventions with higher quality services and improved participation rates.

To date, no needs assessments have comprehensively explored unmet needs, desire for help with unmet needs, or format service preferences in a mixed GC population (i.e., with all GC sites). In addition, only one study has included sexuality needs as a unique domain. The current study describes a needs assessment conducted at a regional cancer center with the objective of directly informing program development, as well as addressing gaps in the literature on needs of patients with GC. The evaluation questions included: (a) What are the unmet supportive care and sexual health needs of women treated for GC at the designated cancer center? (b) What proportion of the participants experiencing unmet needs desire help? (c) What service format is preferred by the participants reporting unmet needs? and (d) Are higher unmet needs associated with sociodemographic/medical characteristics? The current manuscript will focus on results pertaining to sexual health needs, with a general description of other supportive care needs situating sexual health needs within the larger schema of supportive care needs.

Methods

Participants

The current sample consisted of women who were diagnosed or treated for a GC and receiving follow-up care at The Ottawa Hospital Cancer Centre, a designated regional cancer center in Ontario, Canada; were aged 18 years or older; and were fluent in spoken and written English or French. The gynecologic clinic in the cancer center offers services through the regional gynecologic oncology program, which is comprised of a multidisciplinary team of healthcare professionals. In general, women who are in remission are seen in follow-up and screening for recurrence every three or four months to 12 months for as long as five years. In the center, most women with endometrial cancer who receive surgery are followed in the community by their primary care providers, and those who were treated with radiation are transitioned back to their primary care provider after two years. Therefore, these subgroups were less likely to be recruited.

Measures

The self-report questionnaire package included a 14-item **sociodemographic and medical characteristics questionnaire**, the **Supportive Care Needs Survey–gynecologic version (SCNS-gyne)** (Steele & Fitch 2008), the **Sexual Function–Vaginal Changes Questionnaire (SVQ)** (Jensen, Klee, Thranov, & Groenvold, 2004a), a **format preferences questionnaire** (developed by the team) to evaluate the preferred format of help within domains, and an open comments section. In the format preferences section, participants may circle one or more types of services they desire in meeting their various supportive care needs; services listed include “No help wanted,” “Help in written form,” “One-on-one with a health professional,” and “Group format.”

The SCNS-gyne was adapted from the SCNS, which was developed and validated to assess the global needs of patients with cancer (Bonevski et al., 2000). The original SCNS demonstrated substantial internal reliability (Cronbach alpha) ranging from 0.87–0.97 on all scales, and the five factors identified (through the principal components method) had eigenvalues greater than 1, accounting for 64% of the total variance. Preliminary interviews and a pilot study confirmed face and content validity (Bonevski et al., 2000). The SCNS-gyne was minimally altered from the SCNS and considered to have retained its psychometric properties (Steele & Fitch, 2008). Each of the 67 items is divided into two parts. In part A, respondents are asked to rate their level of difficulty experienced with an issue (e.g., pain) based on a five-point Likert-type scale ranging from 1 (I did not experience this issue) to 5 (I am experiencing a high level of difficulty with this issue). In part B,

respondents are asked to rate their level of desire for help with each issue (when applicable) on a three-point scale (no, uncertain, or yes). The item scores for parts A and B are clustered into scores for seven supportive care need domains (psychological, social, emotional, spiritual, information, practical, and physical needs). A sexuality domain (which exists in the original SCNS) (Bonevski et al., 2000) was calculated using the mean of the four sexuality-related items on the SCNS-gyne. With respect to internal consistency, Cronbach alphas for the SCNS-gyne subscales in this study were 0.6 (practical needs), 0.69 (social needs), 0.82 (psychological and physical needs), 0.84 (emotional needs), 0.87 (informational and spiritual needs), and 0.88 (sexuality needs).

To date, the SVQ is the only validated tool intended to measure cancer- and treatment-specific sexual function and vaginal difficulties in patients with GC (Jensen et al., 2004a). The SVQ consists of 24 items that are endorsed on a numeric rating scale (e.g., “not at all” to “very much”). Its conceptualization is based on four main dimensions of sexual dysfunction: sexual interest, sexual arousal, orgasm, and pain (Basson et al., 2000). Item responses were summed to create one of four validated subscales: intimacy, global sexual satisfaction, vaginal changes, and sexual functioning. A fifth existing subscale, sexual interest, was not used because it includes only one item. In Jensen et al.’s (2004a) validation study, an assessment of patient-observer agreement on symptoms was high (median overall agreement = 0.84, range = 0.46–1; median kappa = 0.8, range = 0.52–1). Multitrait analyses demonstrated moderate to high item-to-scale correlations (Pearson correlations ranging from 0.56–0.72), thereby supporting convergent and divergent validity, and internal reliability was illustrated with Cronbach alphas ranging from 0.76–0.83. In the current study, moderate to high reliability was demonstrated with the following Cronbach alphas: 0.69 (intimacy scale), 0.61 (global sexual satisfaction scale), 0.9 (sexual function scale), and 0.93 (vaginal changes scale).

Procedure

Study approval was obtained from the research ethics boards of all investigators. Two recruitment strategies were employed. The first involved mailing an information sheet to patients who were scheduled for a follow-up appointment at the cancer center. Eligible patients who were interested completed the questionnaire at their upcoming hospital visit or at home (questionnaire and return envelope sent by mail). The second recruitment strategy, employed because of a low recruitment rate (about 12%) using the first strategy, consisted of direct recruitment with nursing staff assistance at the cancer center. Patients waiting for their follow-up appointments were offered the opportunity to complete the questionnaire on site or to take the package home to complete and

return in a prepaid return envelope. All participants were informed that participation was voluntary, anonymous, and confidential, that no remuneration was offered, and that their choice to accept or decline participation would have no effect on their subsequent medical care.

Data Analysis

Data analyses were conducted using SPSS®, version 20. Frequency analyses measured levels of supportive care needs, sexual health and vaginal changes, and service format preferences. An exploratory analysis of

Table 1. Sample Characteristics (N = 113)

Characteristic	\bar{X}	SD
Age (years)	61	13
Years since treatment	2.7	5.8
Characteristic	n	%
Primary cancer site		
Uterus or endometrium	26	23
Cervix	13	12
Ovary	60	53
Vulva or vagina	9	8
Missing data	5	4
Treatment regimen^a		
Surgery	87	77
Chemotherapy	87	77
Radiation therapy	43	38
First language		
English	82	73
French	22	19
Other	9	8
Primary ethnic background		
Caucasian	109	96
Asian	2	2
African-Canadian	2	2
Civil status		
Married	76	67
Cohabiting	6	5
Single	9	8
Divorced or separated	10	9
Widowed	12	11
Education		
Primary school or high school	45	40
College	32	28
University	35	31
Missing data	1	1
Annual income (\$)		
Less than 20,000	6	5
20,000–39,999	18	16
40,000–59,999	22	20
60,000–79,999	18	16
80,000–99,999	12	11
Greater than 100,000	21	19
Missing data	16	14
Menopausal status at diagnosis		
Premenopausal	33	29
Postmenopausal	70	62
Missing data	10	9

^a Categories are not mutually exclusive.

Note. Because of rounding, percentages may not total 100.

correlations between sociodemographic and medical variables (e.g., age, civil status), sexual health needs (SCNS), desire for help with sexual health needs (SCNS), and the SVQ subscales (intimacy, global sexual satisfaction, vaginal changes, sexual interest, and sexual functioning) was conducted.

Results

Table 1 presents sociodemographic and disease characteristics of the sample. Data were collected from 113 women. Age ranged from 27–89 years ($\bar{X} = 61$, $SD = 13$), with the majority of the sample (76%) aged 50–79 years. Most women were Caucasian and ovarian cancer was the most common cancer type, with a variety of treatment modalities.

Unmet Supportive Care and Sexual Health Needs

Table 2 displays the items most frequently endorsed as unmet needs across all domains. Most are psychosocial and highlight existential struggles (e.g., fear of cancer recurrence), concerns about caregivers or loved ones, and difficulty with sexual health changes. Twenty-four percent of the sample reported moderate to high levels of difficulty with changes in their ability to have intercourse; 22% reported changes in sexual feelings. The SVQ measures difficulties with sexual function

and vaginal changes commonly associated with GC and treatment. On a scale ranging from 1 (very dissatisfied) to 7 (very satisfied), most participants reported a moderate level of satisfaction with their appearance ($\bar{X} = 4$, $SD = 1.6$) and sex life ($\bar{X} = 4.2$, $SD = 2.1$).

Thirty-five percent of the women had been sexually active in the past month. As depicted in Table 3, sexual problems were prominent, with 67% reporting at least one sexual difficulty and 40% feeling worried about their sex life. Low or no sexual interest was reported by 76% of the sample. Among the sexually active women, vaginal dryness was the most frequent difficulty, with 75% experiencing the symptom and 67% reporting associated distress. Dyspareunia (i.e., pain during intercourse) was reported by 55%, with 50% reporting distress. Forty-two percent of the sexually active women reported that their vagina “felt too small,” and 64% reported achieving orgasm either never or occasionally in sexual interactions during the past month.

Patient perceptions of changes in sexual function since their cancer diagnosis also are summarized. The most commonly reported changes were a decrease in sexual interest (41%), increase in vaginal dryness (25%), and increase in dyspareunia (18%). Most women felt their partner’s sexual interest was unchanged (59%), a minority believed it had decreased (12%), and very few perceived an increase (1%). In addition, 38% reported that their partner experienced problems with sexual arousal.

Table 2. Most Prevalent Unmet Needs and Proportions of Desire for Help (N = 113)^a

Item	Low Need		Moderate-High Need		Want Help		Uncertain		No Help Wanted	
	n	%	n	%	n	%	n	%	n	%
Fear of the cancer returning	35	31	50	44	26	23	17	15	64	57
Fear of the cancer spreading	37	33	37	33	26	23	10	9	70	62
Lack of energy or tiredness	24	21	29	26	20	18	7	6	84	74
Concerns about the worries of those close to you	34	30	28	25	20	18	14	12	72	64
Changes in ability to have sex	14	12	27	24	12	11	11	10	80	71
Feelings about death and dying	25	25	26	23	19	17	12	11	77	68
Uncertainty about the future	36	32	26	23	19	17	10	9	76	67
Not able to do the things I used to do	22	19	26	23	14	12	8	7	84	74
Fear of physical disability	19	17	25	22	19	17	7	6	84	74
Changes in sexual feelings	16	14	25	22	11	10	12	11	84	74
Changes in sexual relations ^b	11	10	22	19	14	12	9	8	80	71
To be given information about sexual relations ^b	8	7	9	8	12	11	3	3	86	76

^a Results are from the Supportive Care Needs Survey–gynecologic version (SCNS-gyne).

^b The items were not among the top 10 endorsed items; however, their results are displayed to better inform the reader on participant responses to the four sexual health-related needs of the SCNS-gyne.

Table 3. Sexual Health–Vaginal Changes Questionnaire Results (N = 113)

Current Sexual Health	Responded		Not at All		A Little		Quite a Bit or Very Much		Distressed	
	n	%	n	%	n	%	n	%	n	%
Interested in sex	104	92	50	44	36	32	18	16	–	–
Vaginal dryness ^a	13	32	10	25	15	39	14	36	26	67
Dyspareunia ^a	13	32	17	44	13	33	9	22	20	50
Vagina feels too small ^a	13	32	23	58	9	22	7	19	–	–
Current Sexual Health	Responded		Never		Occasionally		Often or Always			
	n	%	n	%	n	%	n	%		
Ability to reach orgasm ^a			12	32	9	22	17	42	14	36
Perceived Changes Since Treatment ^b	Responded		Decreased		Unchanged		Increased			
	n	%	n	%	n	%	n	%		
Interest in sexual contact			101	89	46	41	54	48	–	–
Vaginal dryness			50	43	1	1	20	18	28	25
Dyspareunia			40	35	5	4	15	13	20	18
Change in vaginal size			50	43	57	50	31	27	–	–
Partner's interest in sexual contact			83	73	14	12	67	59	1	1

^a The percentages represent the responses of sexually active women (n=39).

^b More women responded to the questions on changes in sexual function than the proportion that was sexually active; consequently, percentages are based on total sample size.

Desire for Help

Across domains, many patients did not want help with their identified needs. Of those who experienced difficulty with their ability to have sex, 46% wanted help and 42% were uncertain. Similarly, 45% of women experiencing difficulty with changes in sexual feelings wanted help and 50% were uncertain. The most frequently reported needs for which patients reported a desire for help were in the psychological (e.g., fear of cancer recurrence) and physical domains (e.g., lack of energy and feelings of fatigue).

Service Format Preferences

Participants were asked to circle one or more service formats they would prefer for the various domains (see Table 4). Across domains, 22%–48% of participants reported at least one form of desired help. Preferences for sexual health services were similar to those for most psychosocial and physical services; that is, women preferred a one-on-one format. A preference for written material (very closely followed by one-on-one contact) was seen only in the spiritual and practical need domains. Regarding preferences for sexual health needs,

64% reported no desire for help, 24% desired help via discussion with a healthcare professional, and 17% indicated that written information could help meet their sexual health needs. Only 2% of the sample reported that services provided in a group format could be helpful.

Correlates of Sexual Health Needs and Desire for Help

Table 5 depicts results from the correlation analyses, which were conducted to clarify relationships among sexual health variables, needs and distress, and desire for help in sexually active women. Sexual health needs and desire for help were highly, but not perfectly, correlated ($r = 0.65$, $p \leq 0.001$). Greater sexual health needs were positively associated with several SVQ subscales, including higher scores on the vaginal changes subscale (indicating more vaginal changes and associated distress; $r = 0.61$, $p \leq 0.001$) and decreased scores on the sexual function subscale (indicating poorer sexual function; $r = 0.59$, $p \leq 0.001$). Greater sexual health needs also were associated with sociodemographic and disease variables, including younger age ($r = -0.42$,

$p \leq 0.001$), chemotherapy treatment ($r = 0.23, p \leq 0.01$), and premenopausal status ($r = -0.27, p < 0.01$).

As with sexual health needs, greater desire for help with unmet sexual health needs was associated with higher scores on the vaginal changes subscale ($r = 0.48, p \leq 0.01$), younger age ($r = -0.36, p \leq 0.001$), and premenopausal status ($r = -0.23, p \leq 0.05$), as well as lower scores on the global sexual satisfaction subscale ($r = -0.33, p \leq 0.001$).

Low or no sexual interest, the most prevalent sexual problem, was not directly associated with sexual health needs or desire for help. However, it was significantly associated with lower scores on the sexual function subscale ($r = 0.56, p \leq 0.001$) and intimacy subscale ($r = 0.38, p \leq 0.001$), as well as higher scores on the vaginal changes subscale ($r = -0.43, p \leq 0.01$). Older age ($r = -0.25, p \leq 0.01$), fewer years since treatment ($r = 0.23, p \leq 0.05$), and postmenopausal status ($r = -0.21, p \leq 0.05$) also were associated with lower sexual interest.

The only treatment variable consistently associated with sexual function and vaginal changes was chemotherapy, which was associated with greater scores on the vaginal changes subscale ($r = 0.434, p \leq 0.01$) and lower scores on the global sexual satisfaction subscale ($r = -0.22, p \leq 0.05$) and sexual function subscale ($r = -0.34, p \leq 0.05$).

Discussion

Supportive Care and Sexual Health Needs

The current needs assessment explored unmet supportive care and sexual health needs, desire for help with needs, and format service preferences. The results of the current article confirmed previous findings that psychosocial struggles are the most common unmet needs post-treatment (Beesley et al., 2008; Hodgkinson et al., 2007; Steele & Fitch, 2008). In addition to fears of recurrence and death, the top needs demonstrate struggles adapting to the long-term physical effects of treatment (e.g., not being able to do the things one used to do, fear

of disability, sexual changes). Unmet sexual health needs were an important concern, with two sexual health needs rated in the top 10 unmet needs. On the SVQ, 76% of the sample reported low or no sexual interest, and 55%–75% of sexually active participants experienced problems with, and distress related to, sexual function.

Sexual Distress: Symptom Versus Need

As recommended by Bancroft, Loftus, and Long (2003), the measurement of sexual health needs in the current article (i.e., the SCNS) specifically addressed patient perceptions of difficulty with an issue, rather than the simple presence of a given symptom. Consistent differences were noted between symptoms and distress. Whereas 67% of the sample reported at least one sexual health problem on the SVQ, a smaller proportion (40%) reported that they felt worried about their sex life, and a similar proportion (36%) reported difficulty with sexual health changes on the SCNS-gyne. In addition, the SVQ items revealed that not all women who experienced dyspareunia and dryness were bothered by their difficulties. For instance, 70% of sexually active women experienced dyspareunia, but only 50% were bothered by it. A wide range of other factors (many still unexplored) may explain this difference, including symptom management strategies (e.g., use of lubrication), relationship factors (e.g., partner's sexual health, communication), and individual variables (e.g., coping style, mood and anxiety, existential concerns such as fear of recurrence).

Many assessment and intervention studies in the oncologic population have focused on single measures of sexual function (e.g., frequency of intercourse) without assessing distress. Qualitative work also has highlighted that women's views of sexual health vary markedly with respect to the importance of emotional intimacy, body image, sexual intercourse, and other aspects of sexuality (McCallum et al., 2012); findings from that study suggested that unmet sexual health needs were the result of a gap between women's current sexual health (including sexual self-concept, sexual function, and relationship

Table 4. Format Services Preferences by Domain (N = 113)

Format	Sexual		Spiritual		Practical		Physical		Emotional		Psychological		Social		\bar{X}^a
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	
Group	1	1	8	7	7	6	1	1	14	12	8	7	9	8	6
Written	19	17	15	13	12	11	17	15	25	22	19	17	11	10	15
One-on-one	27	24	9	8	10	9	20	18	31	27	24	21	24	21	18
No help	72	64	86	76	89	79	83	73	60	53	59	52	80	71	67

^a Mean of desire for the service format across all need domains

Note. Within each domain, participants could select one or more services they would be willing to receive. Therefore, the values for service preferences are not mutually exclusive and total percentages may not add up to 100.

factors) and their perception of ideal sexual health (based on personal characteristics and beliefs as well as cultural factors). Qualitative work by Sekse, Gjengedal, and Røheim (2013) observed an association between a sense of alienation from the body, sexual dysfunction, and existential struggles. Together, these findings emphasize a need to evaluate and address the unique and subjective experience of sexuality changes in survivorship.

Desire for Help and Help-Seeking

The current study is the first published effort to evaluate desire for help with supportive care and specific sexual health needs in a mixed GC population. A high level of ambivalence was present toward receiving help with many needs, including unmet sexual health needs, as well as difficulties with not being able to “do the things I used to do.” A relatively small number of women were open to receiving help with needs identified on the SCNS in comparison to the proportion of women who reported feeling worried about their sex life on the SVQ (40%). Some research on barriers to communicating about sexual concerns in oncology may lend insight on this discrepancy. When sexuality concerns are not addressed by the healthcare provider(s), patients may be led to believe that discussing these needs in the medical context is inappropriate (Butler, Banfield, Sveinson, & Allen, 1998; Hordern & Street, 2007); an impression that is not entirely unfounded since many healthcare providers mistakenly feel sexual health concerns are not a legitimate topic for discussion with some patients (Gott et al., 2004). Indeed, patients who are given this impression are unlikely to report desire for help, despite experiencing unmet needs. Together, these findings highlight the responsibility of the healthcare team in initiating discussions about sexuality with patients as a regular part of cancer care (Wilmoth & Spinelli, 2000).

Regarding format preferences, many participants in the current study were inclined to prefer one-on-one consultations, particularly for psychological, emotional, and sexual needs. Group-based interventions were the least popular option rated by participants across all categories. These findings may be partially explained by barriers to participation including discomfort, shyness, and practical barriers to attending regular meetings and services at the hospital (McCallum et al., 2012).

Correlates of Sexual Health Needs and Desire for Help

Correlation analyses were conducted between sexuality variables and sociodemographic variables to better describe the women at risk for sexual health difficulties following treatment. The results suggest that, generally, higher sexual health needs and desire for help with unmet sexual health needs are associated with younger age, premenopausal status at diagnosis, and greater

Knowledge Translation

Survivor distress related to sexual health needs should be discussed and evaluated on an individual basis.

Younger, premenopausal patients and those with more post-treatment vaginal changes may be more likely to experience distress and desire help.

Barriers to accepting services should be evaluated individually to address patients' ambiguity about receiving help.

vaginal changes after treatment (i.e., dyspareunia and vaginal dryness). Lower scores on the sexual function subscale of the SVQ, which includes ability to achieve orgasm and frequency of ability to complete sexual intercourse, significantly predicted greater sexual health needs but not desire for help. A possible explanation is that women may assume that this is not a medical-based problem worth discussing with the healthcare team. Alternatively, perhaps in the context of their health issues, these aspects of sexual function were not considered important enough to warrant seeking help.

Interestingly, a significant association was noted between the global sexual satisfaction subscale (e.g., worries about sex life, satisfaction with sex life) and desire for help with sexual health needs, but not with the unmet sexual health needs scores. This suggests that readiness to seek help in meeting a need is significantly related to the perception of the symptom as distressful or worrisome, and perhaps more strongly related than the actual level of sexual response.

The observed relationship between age and sexual health problems is not unique to women with cancer. With the exception of low sexual interest (which is more prevalent in older women most likely because of hormonal as well as relational factors), younger women may be more likely to experience a variety of sexual issues, possibly related to inexperience and a higher frequency of new and developing relationships (i.e., novelty, fear of STDs, insecurity in relationships) (Laumann, Paik, & Rosen, 1999). Understandably, younger women who already are coping with these challenges and must receive treatment for GC may have fewer resources to cope with treatment-induced menopause and post-treatment vaginal changes. Given the importance of these factors to women, the supportive role of a partner is likely to be an important aspect of achieving emotional and sexual health after cancer, and younger women may require more support in coping with sexual changes.

The authors' data show effects of chemotherapy on sexuality, but not radiation. Whether or not radiation causes significant vaginal changes is unknown; perhaps the over-representation of patients with ovarian cancer (who typically receive surgery and chemotherapy)

Table 5. Correlation Matrix of Sexual Health, Sociodemographic, and Medical Variables (N = 113)

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Sexual needs ^a	—											
2. Help with sexual needs ^a	0.65***	—										
3. Chemotherapy	0.23*	0.09	—									
4. Civil status	0.2*	0.09	-0.06	—								
5. Menopause	-0.27***	-0.23*	0.06	-0.01	—							
6. Years since treatment	-0.04	-0.05	-0.19	0.06	-0.2*	—						
7. Intimacy	-0.01	-0.13	0.16	0.26**	0	0.12	—					
8. Satisfaction ^b	-0.51***	-0.33***	-0.22*	0.12	0.13	0.1	0.07	—				
9. Vaginal changes ^{b,c}	0.61***	0.48***	0.43**	-0.07	-0.11	-0.2	-0.28	-0.51***	—			
10. Sexual function ^{b,c}	-0.59***	-0.3	-0.34*	0.15	-0.25	0.05	0.23	0.46***	-0.46***	—		
11. Sexual interest ^b	-0.05	-0.08	-0.13	0.18	-0.21*	0.23*	0.38***	0.12	-0.43**	0.58***	—	
12. Age	-0.42***	-0.36***	-0.03	-0.1	0.64***	0.05	-0.19	0.19	-0.26	-0.29	-0.25*	—

* $p \leq 0.05$; ** $p < 0.01$; *** $p < 0.001$

^a Sexual health needs domain score and desire for help with at least one sexual health item (from the Supportive Care Needs Survey–gynecologic version)

^b Subscales and items from the Sexual Health–Vaginal Changes Questionnaire

^c N = 39 for the vaginal changes and sexual function subscales.

masked this association. In addition, the radiotherapy service from which patients were recruited had increased its efforts to educate patients about vaginal dilator use and sexuality post-treatment, and perhaps these patients' needs were more likely to have been addressed prior to completion of the needs assessment.

Limitations

Unfortunately, information on the women who declined participation was not collected. However, the authors' findings regarding sexual difficulties are similar to past studies (Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004; Jensen et al., 2004b), which suggests that the results are generalizable to the targeted population. Given the participant demographics, the authors' results are likely limited to a middle class, middle-aged Caucasian population. In addition, the findings and implications are conceptualized with the structure of the Canadian medical system in mind. Patient experiences are likely to vary significantly across different health systems, and some study implications may not apply to other cancer centers. Further research on supportive care needs in different subgroups (e.g., younger women, other ethnicities) is required to better assess generalizability of the results.

The chosen instrument for sexual health variables, SVQ, does not provide a complete portrait of sexual dysfunction. However, it was selected for its concise and specific evaluation of sexual problems, distress, and perceived changes in sexuality after the cancer diagnosis. The higher proportion of women with ovarian cancer may mean that higher rates of difficulties and distress were measured (related to more advanced stages at diagnosis). The fourth part of the questionnaire (the format preferences questionnaire) was developed by the research team and has not undergone psychometric validation. Ideally, in future research, a first initiative would be to confirm the validity of the measure.

Sexual function is the product of functionality in the physical, psychological, and relational states (Laumann et al., 1999). A number of factors beyond cancer and its treatment are likely to contribute to the sexual health status of these women. Bancroft et al. (2003) demonstrated that emotional well-being and negative feelings during sexual interactions better predicted sexual distress than physiologic sexual response. Also, prediagnosis factors such as women's positive or negative views of their sexual selves (i.e., sexual self-schema) (Carpenter, Andersen, Fowler, & Maxwell, 2009) may have important implications for their post-treatment sexual health. A study of sexual health in vulvar cancer survivors found that optimism significantly predicted sexual function (Hazewinkel et al., 2012). Previous literature also has identified enduring post-treatment physical symptoms such as chronic fatigue (Vistad, Fossa, Kristensen, & Dahl, 2007) and lymphedema (Bergmark, Avall-Lundqvist, Dickman, Henningsohn, & Steineck, 2002), as well as other distressful practical concerns (e.g., family roles, finances) (McCallum et al., 2012) which may affect sexual health variables and desire for help. The results

emphasize the importance of evaluating patient needs within a comprehensive network. Finally, the partner's sexual response may be an important contributing factor to consider in interpreting the results. Thirty-eight percent of the women indicated that their partner had experienced difficulty with sexual arousal, and 22% indicated that their partner had no desire for sexual contact. Future research with higher statistical power could explore the relative contribution of these groups of predictors.

Implications for Nursing

Given the nature of their contact with women with GC throughout treatment and follow-up care, nursing staff have an invaluable role in assessing and addressing patient needs. Wilmoth and Spinelli (2000) call attention to the moral and legal responsibility of nurses to adhere to standards of practice related to sexuality in the provision of high quality and holistic health care. Therefore, although all members of the healthcare team should be attuned to patients' sexual health issues in their practice, the results of this study were written with implications for nursing in the forefront.

To maximize quality of care, nurses should receive training on (a) effective and efficient procedures for initiating conversations about sexuality and normalizing difficulties (Fitch, 2003; Wilmoth, 2007); (b) the most frequent post-treatment needs, desire for help, and potential barriers (McCallum et al., 2012; Steele & Fitch, 2008); and (c) potentially at-risk populations (Andersen, Woods, & Copeland, 1997; Beesley et al., 2008; Donovan et al., 2007; Hodgkinson et al., 2007). To facilitate referrals to specialists in sexual health care, a general knowledge base of etiology and treatment modalities also would be helpful (Krychman & Millheiser, 2013). Although all members of the healthcare team should have a basic knowledge of these dimensions, providing advanced training to specific individuals who would be responsible for evaluating and addressing patient concerns would help to ensure the quality and continuity of care.

The authors' recommendations are tailored to the specific cancer center; however, findings on sexual health needs, within the framework of supportive care needs, are certainly applicable to a wider context and have implications for the advancement of research on the screening and treatment of post-treatment difficulties in the GC survivor.

Conclusion

The current needs assessment suggested that the program mandate of providing holistic services was only partially met. A need for increased services directed at meeting psychosocial and sexual needs was apparent, and the current recommendations focus specifically

on the sexual health needs reported. Although many of the patient services in the program are group-based (e.g., workshops, support groups), participants clearly described a preference for discussions with a healthcare professional. The authors' findings support a growing body of research that highlights the complexity of sexual health needs and desire for help in these patients; an individualized approach would allow more flexible and effective assessment of sexual health, desire for help, and potential barriers that otherwise may not be assessed. This assessment of sexual health needs as a unique supportive care domain was fruitful and reiterated the importance of comprehensive evaluations. Screening and intervention planning should focus on a wide spectrum of post-treatment difficulties. When sexual health needs are identified, the follow-up intervention should include an assessment of the patient's perception of their current sexual health problems and their expectations of achieving sexual health. This would allow for a discussion of symptom management and strategies to improve sexual function and satisfaction; alternatively, in some cases, a discussion expanding a patient's views of intimacy beyond the scope of intercourse may be helpful. The currently administered screening tool (Edmonton Symptom Assessment Scale) (Chang, Hwang, & Feuerman, 2000) at the authors' institution is a brief measure of common physical symptoms, as well as subjective depression, anxiety, and well-being. Although this form includes space for "another problem," the sensitive and personal nature of sexuality make it unlikely that patients will share interpersonal and sexual concerns through this venue.

When asked if they desired help with overall sexual health needs, most women responded "no" or "uncertain." On the other hand, 24% indicated they would like to discuss sexual health concerns individually with a member of their healthcare team. Because needs were higher closer to treatment, a more comprehensive screening tool designed specifically for patients terminating treatment could be administered at the transition between end of treatment and follow-up care.

Megan McCallum, BA, is a doctoral candidate in the School of Psychology at the University of Ottawa in Ontario, Canada; Lynne Jolicœur, RN, MScN, CON(c), is an advanced practice nurse in the Division of Gynecologic Oncology and Monique Lefebvre, PhD, CPsych, is a clinical and health psychologist, both at The Ottawa Hospital; Lyzon K. Babchishin, BA, is a doctoral candidate and Stéphanie Robert-Chauret is an undergraduate student, both in the School of Psychology at the University of Ottawa; Tien Le, MD, is a gynecologic oncologist and the head of the Division of Gynecologic Oncology at The Ottawa Hospital; and Sophie Lebel, PhD, is an associate professor in the School of Psychology at the University of Ottawa. No financial relationships to disclose. McCallum can be reached at megan_mcc1@hotmail.com, with copy to editor at ONFEditor@ons.org. (Submitted May 2013. Accepted for publication November 18, 2013.)

References

- Abbott-Anderson, K., & Kwekkeboom, K.L. (2012). A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecologic Oncology*, 124, 477–489. doi: 10.1016/j.ygyno.2011.11.030
- Andersen, B.L., Woods, X.A., & Copeland, L.J. (1997). Sexual self-schema and sexual morbidity among gynecologic cancer survivors. *Journal of Consulting and Clinical Psychology*, 65, 221–229. doi:10.1037/0022-006X.65.2.221
- Bancroft, J., Loftus, J., & Long, J.S. (2003). Distress about sex: A national survey of women in heterosexual relationships. *Archives of Sexual Behavior*, 32, 193–208.
- Basson, R., Berman, J., Burnett, A., DeRogatis, L., Ferguson, D., Fourcroy, J., . . . Whipple, B. (2000). Report of the international consensus development conference on female sexual dysfunction: Definitions and classifications. *Journal of Urology*, 16, 888–893.
- Beesley, V., Eakin, E., Steginga, S., Aitken, J., Dunn, J., & Battistutta, D. (2008). Unmet needs of gynaecological cancer survivors: Implications for developing community support services. *Journal of Psychosocial Oncology*, 17, 392–400.
- Bergmark, K., Avall-Lundqvist, E., Dickman, P.W., Henningssohn, L., & Steineck, G. (2002). Patient-rating of distressful symptoms after treatment for early cervical cancer. *Acta Obstetrica et Gynecologica Scandinavica*, 81, 443–450.
- Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P., & Boyes, A. (2000). Evaluation of an instrument to assess the needs of patients with cancer. Supportive care review group. *Cancer*, 88, 217–225.
- Bourgeois-Law, G., & Lotocki, R. (1999). Sexuality and gynaecological cancer: A needs assessment. *Canadian Journal of Human Sexuality*, 8, 231–240.
- Brotto, L.A., Yule, M., & Breckon, E. (2010). Psychological interventions for the sexual sequelae of cancer: A review of the literature. *Journal of Cancer Survivorship*, 4, 346–360.
- Bultz, B.D., Groff, S.L., Fitch, M., Blais, M.C., Howes, J., Levy, K., & Mayer, C. (2011). Implementing screening for distress, the sixth vital sign: A Canadian strategy for changing practice. *Psycho-Oncology*, 20, 463–469. doi:10.1002/pon.1932
- Butler, L., Banfield, V., Sveinson, T., & Allen, K. (1998). Conceptualizing sexual health in cancer care. *Western Journal of Nursing Research*, 20, 683–705.
- Carmack Taylor, C.L., Basen-Engquist, K., Shinn, E.H., & Bodurka, D.C. (2004). Predictors of sexual functioning in ovarian cancer patients. *Journal of Clinical Oncology*, 22, 881–889.
- Carpenter, K.M., Andersen, B.L., Fowler, J.M., & Maxwell, G.L. (2009). Sexual self schema as a moderator of sexual and psychological outcomes for gynecologic cancer survivors. *Archives of Sexual Behavior*, 38, 828–841.
- Chang, V.T., Hwang, S.S., & Feuerman, M. (2000). Validation of the Edmonton Symptom Assessment Scale. *Cancer*, 88, 2164–2171.
- Corney, R., Everett, H., Howells, A., & Crowther, M. (1992). The care of patients undergoing surgery for gynaecological cancer: The need for information, emotional support and counselling. *Journal of Advanced Nursing*, 17, 667–671.
- Donovan, K.A., Taliaferro, L.A., Alvarez, E.M., Jacobsen, P.B., Roetzheim, R.G., & Wenham, R.M. (2007). Sexual health in women treated for cervical cancer: Characteristics and correlates. *Gynecologic Oncology*, 104, 428–434. doi:10.1016/j.ygyno.2006.08.009
- Fitch, M.I. (2003). Psychosocial management of patients with recurrent ovarian cancer: Treating the whole patient to improve quality of life. *Seminars in Oncology Nursing*, 19, 40–53.
- Gamel, C., Hengeveld, M., & Davis, B. (2000). Informational needs about the effects of gynaecological cancer on sexuality: A review of the literature. *Journal of Clinical Nursing*, 9, 678–688.
- Gilbert, E., Ussher, J.M., & Perz, J.M. (2011). Sexuality after gynaecological cancer: A review of the material, intrapsychic, and discursive aspects of treatment on women's sexual well-being. *Maturitas*, 70, 42–57.
- Gott, M., Hinchliff, S., & Galena, E. (2004). Opening a can of worms: GP and practice nurse barriers to talking about sexual health in primary care. *Family Practice*, 21, 528–536.
- Hazewinkel, M.H., Laan, E.T., Sprangers, M.A., Fons, G., Burger, M.P., & Roovers, J.P. (2012). Long-term sexual function in survivors of vulvar cancer: A cross-sectional study. *Gynecologic Oncology*, 126, 87–92. doi:10.1016/j.ygyno.2012.04.015
- Hodgkinson, K., Butow, P., Funchs, A., Hunt, G.E., Stenlake, A., Hobbs, K.A., . . . Wain, G. (2007). Long-term survival from gynaecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. *Gynaecologic Oncology*, 104, 381–389.
- Hordern, A.J., & Street, A.F. (2007). Communicating about patient sexuality and intimacy after cancer: Mismatched expectations and unmet needs. *Medical Journal of Australia*, 186, 224–227.
- Jefferies, H. (2002). Ovarian cancer patients: Are their informational and emotional needs being met? *Journal of Clinical Nursing*, 11, 41–47.
- Jensen, P.T., Klee, M.C., Thranov, I., & Groenvold, M. (2004a). Validation of a questionnaire for self-assessment of sexual function and vaginal changes after gynaecological cancer. *Psycho-Oncology*, 13, 577–592. doi:10.1002/pon.757
- Jensen, P.T., Groenvold, M., Klee, M.C., Thranov, I., Petersen, M.A., & Machin, D. (2004b). Early-stage cervical carcinoma, radical hysterectomy, and sexual function: A longitudinal study. *Cancer*, 100, 97–106. doi:10.1002/cncr.11877
- Krychman, M., & Millheiser, L.S. (2013). Sexual health issues in women with cancer. *Journal of Sexual Medicine*, 10, 5–15.
- Laumann, E.O., Paik, A., & Rosen, R.C. (1999). Sexual dysfunction in the United States: Prevalence and predictors. *JAMA*, 281, 537–544.
- Lindau, S.T., Gavrilova, N., & Anderson, D. (2007). Sexual morbidity in very long term survivors of vaginal and cervical cancer: A comparison to national norms. *Gynecologic Oncology*, 106, 413–418.
- McCallum, M., Lefevbre, M., Jolicoeur, L., Maheu, C., & Lebel, S. (2012). Sexual health and gynecological cancer: Conceptualizing patient needs and overcoming barriers to seeking and accessing services. *Journal of Psychosomatic Obstetrics and Gynecology*, 33, 135–142.
- Miller, B.E., Pittman, B., & Strong, C. (2003). Gynaecologic cancer patients' psychosocial needs and their views on the physician's role in meeting those needs. *International Journal of Gynaecological Cancer*, 13, 111–119.
- Pearman, T. (2003). Quality of life and psychosocial adjustment in gynecologic cancer survivors. *Health and Quality of Life Outcomes*, 1, 33. doi:10.1186/1477-7525-1-33
- Robinson, J.W., Faris, P.D., & Scott, C.B. (1999). Psychoeducational group increases vaginal dilation for younger women and reduces sexual fears for women of all ages with gynaecological carcinoma treated with radiotherapy. *International Journal of Radiation Oncology, Biology, and Physics*, 44, 497–506.
- Sekse, R.J.T., Gjengedal, E., & Raheim, M. (2013). Living in a changed female body after gynecological cancer. *Health Care for Women International*, 34, 14–33.
- Stead, M.L. (2004). Sexual function after treatment for gynecological malignancy. *Current Opinion in Oncology*, 16, 492–495.
- Steele, R., & Fitch, M.I. (2008). Supportive care needs of women with gynaecologic cancer. *Cancer Nursing*, 31, 284–291.
- Stewart, D.E., Wong, F., Cheung, A.M., Dancy, J., Meana, M., Cameron, J.I., & Rosen, B. (2000). Information needs and decisional preferences among women with ovarian cancer. *Gynaecologic Oncology*, 77, 357–361.
- Vistad, I., Fossa, S.D., Kristensen, G.B., & Dahl, A.A. (2007). Chronic fatigue and its correlates in long-term survivors of cervical cancer treated with radiotherapy. *BJOG*, 114, 1150–1158.
- Wilmoth, M.C. (2007). Sexuality: A critical component of quality of life in chronic disease. *Nursing Clinics of North America*, 42, 507–514.
- Wilmoth, M.C., & Spinelli, A. (2000). Sexual implications of gynecologic cancer treatments. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 29, 413–421.