Gynecological Cancer: Practical Implications for Identifying and Meeting Supportive Care and Sexual Health Needs After Treatment

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Dr. Sophie Lebel, my research supervisor, oversaw and guided all of my research activities; more specifically, she assisted me with study design, ethics review board applications, data collection, analysis and interpretation, and manuscript preparation.

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General Abstract

Women treated for a gynecological cancer report longstanding post-treatment difficulties for which they rarely seek or receive help. Few intervention studies have successfully improved global sexual health within this population. Research in this domain is challenging due to inconsistent measurements of sexuality, low response rates and high attrition rates.

The overarching study objectives were: (a) To contribute to the advancement of research on supportive care needs (including sexual health needs), desire for help, and predictors of needs; and, (b) To inform the development of services for gynecological cancer survivors.

In Study 1, a qualitative interview study explored the experiences of 15 gynecological cancer survivors. Interviews were conducted and analysed based on the Interpretive Description approach . In Study 2 (for which results were analyzed in two parts), a descriptive, cross-sectional needs assessment was conducted to measure supportive care needs, desire for help, sexual health and vaginal changes, and service format preferences in 113 patients. In Part 1 of Study 2, descriptive and regression analyses explored patient needs, desire for help and potential predictors of these variables. In Part 2, a descriptive analysis explored sexual health needs and vaginal changes, desire for help with sexual health needs, and their associations with sociodemographic and medical variables. Qualitative results from Study 1 suggested that psychological, emotional and relational aspects of sexuality were as important to the participants as physiological sexual response. In the needs assessment, the strongest predictors of greater unmet needs and increased readiness for help were younger age and shorter time since treatment. Moderate to high sexual and social needs were equally prevalent in women recently treated and those treated several years prior to the study, suggesting that sexual and social needs may remain unaddressed over time. Further, many women who reported a need did not desire help, demonstrating the subjectivity of needs and

distress, as well as the potential presence of barriers to seeking help. Both studies revealed a common finding, where sexual health needs were a product of the discordance between participants' current sexual experiences and their perceptions of ideal sexual health. Overall, the two studies indicate that a significant subgroup of patients experience unmet needs in cancer survivorship, most of which are non-physical; also, while some needs were higher following treatment, unmet social and sexual health needs show little relationship with time since treatment. Ambivalence about receiving help with unmet needs is related to beliefs about the role of the health care team in meeting non-physical needs, as well as other perceived barriers. Patient's perceived sexual health needs and barriers to receiving help should be evaluated within a comprehensive framework of needs and discussed one-on-one. Future research should explore the added predictive value of other groups of medical and psychological variables.

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General Introduction

Overview

The current document is an introduction to an article-based dissertation work. The context and setting in which the dissertation work was planned and conducted will be described, followed by an overview of gynecological cancer types and a brief description of the common treatments. A detailed medical review of gynecological cancer and its treatment is beyond the scope of the current study; only basic information that is relevant to understanding the following studies will be provided. The introduction continues with a review of the literature on impacts of treatment, supportive care needs, and interventions for gynecological cancer patients. Gaps in the current literature will be discussed, followed by a description of study objectives and the resulting articles.

Context and Population

The Regional Gynaecologic Oncology Program, formally in service at The Ottawa Hospital since 1968, incorporates both surgical and medical services in oncology. Holistic health care is provided to women with gynecological cancer from early diagnosis to treatment or, as necessary, palliative care. To this end, the program ensures the close collaboration of numerous units and centres at the Ottawa Hospital, including the Shirley Greenberg Women's Health Centre at the Riverside Campus (diagnoses and planning of care), 8 West at the General Campus (surgery, symptom management and palliative care planning), the Chemotherapy Day Care Unit (General Campus), and the Cancer Centre at the General campus (follow-ups, detection of recurrence and long-term symptom management).

All services in the Gynaecologic Oncology Program aim to deliver of high quality care to the community via cancer prevention, clinical services, research, and palliative care. Their two primary goals call attention to the promotion of: (1) academic proliferation of

health care research, and (2) the provision of comprehensive and quality care to women who are at risk for or who have a gynecological cancer. This academic program strives to incorporate a multidisciplinary and collaborative approach in education and research to contribute to a more profound understanding of human health and health care. Moreover, the program's mandate is to provide high quality holistic care to gynecological cancer patients with a commitment to understanding quality of life issues, providing a conducive and supportive environment to patients, and providing adequate continuity of care.

The Gynaecologic Oncology Program is comprised of a multidisciplinary team including five oncologists, a clinical pharmacist, a clinical psychologist, several nurses, and a social worker. A variety of informational pamphlets are provided to patients throughout their cancer journey. Additional services are offered when needed, and include nutritional services, physiotherapy, palliative care, occupational therapy, spiritual support, and a social support group. Upon request, patients are occasionally referred to collaborators in the community, including a pelvic physiotherapist and gyne-oncologist at the Women's Health Centre on the Riverside Campus.

The current study's targeted population is comprised of patients of the Gynaecologic Oncology Program. Gynecological cancer encompasses uterine/endometrial, ovarian, cervical, vaginal, and vulvar cancers. Gynecological cancer, the fourth most prevalent cancer that affects women, is diagnosed in over 8,600 Canadian women per year (Canadian Cancer Society, 2011). The most common types are uterine/endometrial, ovarian, and cervical cancer, and each cancer site is unique in its presentation of symptoms and required treatment regimens. Consequently, no single trajectory can describe the patient experience. Generally speaking, once patients have undergone screening and cancer diagnosis, they are offered a treatment regimen that includes one of the following options: chemotherapy, radiation

therapy, and/or surgery; or, quite often, a combination of these modalities. After treatment, frequency and duration of follow-up care will vary depending on cancer type and patient needs. In the year 2010-2011, the Gyne-Oncology and Radiation Oncology departments reported the following proportions of patients: endometrial cancer (43%), ovarian cancer (32%), cervical cancer (14%) and "other" (including vulvar/vaginal; 13%).

Gynecological Cancer Types

Uterine/endometrial cancer. Most cancers of the uterus begin in the endometrium, or lining of the uterus; hence the interchangeable use of the term uterine and endometrial cancer. Endometrial cancer is the most common gynecological cancer and is often diagnosed in women who are post-menopausal, with an average age at diagnosis of 61 years (Paniscotti, 1997). Surgical interventions are a common treatment modality, with common procedures including the total abdominal hysterectomy (i.e., removal of the uterus and cervix) and the bilateral salpingo-oopherectomy (i.e., removal of the ovaries and fallopian tube). When the cancer is diagnosed at a later stage, more extensive surgery may be required, including the radical hysterectomy (i.e., removal of the uterus, cervix, upper vagina, pelvic lymph nodes, and parametrium), radiation, chemotherapy, and hormonal therapy (Wilmoth & Spinelli, 2000).

Ovarian cancer. As with endometrial cancer, ovarian cancer can occur at all ages but is more commonly diagnosed following menopause. Due to the subtle nature of its symptoms, ovarian cancer is most often diagnosed in an advanced stage and is associated with more aggressive treatment and a poorer prognosis. A combination of surgical intervention and chemotherapy is the standard treatment regimen for advanced ovarian malignancies. Occasionally, for earlier stages, and when the preservation of fertility is ideal, only the affected ovary and fallopian tube will be removed; in other cases, total abdominal

hysterectomy and bilateral salpingo-oopherectomy may be required (Wilmoth & Spinelli, 2000). Most often, adjuvant chemotherapy will be administered following surgery to treat residual disease; rarely, radiation therapy will ensue.

Cervical cancer. Cancerous lesions on the cervix are estimated to be linked to human papillomavirus (HPV) in most cases of cervical cancer, and newly diagnosed patients are often younger than other gynecological cancer patients (Walboomers et al., 1999). While the cancer causes few noticeable symptoms, it can be detected via a routine pap test. Surgical procedures may include simple hysterectomy or radical hysterectomy, sometimes with oopherectomy and removal of lymph nodes (Wilmoth & Spinelli, 2000). Radiation includes external beam radiation of the pelvis and brachytherapy (internal radiation), or both. For advanced stages, chemotherapy may be necessary.

Vulvar and vaginal cancer. In vulvar cancer, a less common gynecological cancer, a growth appears in the labia or surrounding genital area. Abnormal cells can spread via the lymph system and may invade adjacent areas (e.g., vagina, urethra, rectum). Surgery is the primary intervention; in early stages, a wide local excision (i.e., removal of a small area of tissue) or a simple vulvectomy (i.e., removal of the vulvar tissue) may be chosen; in more advanced cancers, more invasive surgical procedures may be administered including radical vulvectomy (i.e., removal of the vulva, clitoris, lymph nodes and surrounding tissue) (Wilmoth & Spinelli, 2000). Radiation therapy is less commonly, but occasionally, administered after surgery.

Post-Treatment Symptoms

Physical outcomes. The taxing and sometimes enduring physical effects of radiation therapy have been amply explored. A majority of patients will experience some degree of vaginal stenosis (i.e., narrowing and/or loss of flexibility of the vagina) and/or fibrosis (i.e.,

the formation of scar tissue), accompanied by a vaginal shortening and a reduction in the amount of vaginal lubrication and changes in the size and number of blood vessels in the vagina (Bruner et al., 1993). Further, some women experience treatment-induced menopause (i.e., ovarian failure), which can exacerbate previous described complications such as vaginal dryness due to sudden hormonal changes. Some research indicates that the extent of vaginal fibrosis and stenosis can be minimized through vaginal dilation (i.e., inserting a tube into the vagina to break scar tissue and stretch vaginal tissues) and/or regular intercourse (Cartright-Alcarese, 1995); however, many patients are non-compliant to these recommendations (Flay & Matthews, 1995).

In chemotherapy patients, a prominent treatment effect is fatigue (also described as lack of energy, confusion, and poor concentration; Smets, Garssen, Schuster-Uitterhoeve, & deHaes, 1993). Sometimes enduring years after treatment, chronic fatigue has been found to significantly affect quality of life (Vistad, Foss, Kristensen, & Dahl, 2007). Chemotherapy often compromises ovarian function, resulting in premature menopause (i.e., hot flashes, hormonal imbalances) and its sequelae (i.e., infertility). Patients also report that enduring bladder and bowel dysfunction significantly affects quality of life (Burns, Costello, Woolley, & Davidson, 2007).

Surgery patients experience a variety of changes depending on the type of cancer and surgical procedure entailed. Whereas hysterectomy results in infertility, premature menopause, and their sequelae (e.g., hormonal changes), surgery for vaginal and vulvar cancer can result in nerve damage and changes in vaginal anatomy that are disfiguring and cause significant psychological distress and sexual dysfunction, to be further discussed below (Barton-Burke & Gustacon, 2007).

Psychosocial outcomes. Many psychological struggles are associated with changes in the appearance and function of reproductive and proximal organs. Changes in the body's appearance, removal of internal and/or external organs, and the loss of fertility have been associated with shock, grief, poor body image, and a feeling of lost femininity (Auchincloss, 1995). Many women, in an effort to maintain their roles as partners and wives, set these difficulties and needs aside in order to focus on supporting their loved ones (Butler, Banfield, Sveinson, & Allen, 1998); this can result in feelings of loneliness and isolation (Auchincloss, 1995).

A review of quality of life in gynecological cancer patients during and following treatment concluded that this population experiences higher rates of depression and anxiety during treatment compared to other cancer types (Pearman, 2003). In many patients, overall quality of life improves to levels equivalent to other cancer survivors 1-2 years following treatment; however, a significant minority of survivors are found to continue to experience enduring, high emotional distress (Pearman, 2003). Depression and anxiety have been reported in up to 50% of samples of women treated for a gynecological cancer (Steginga & Dunn, 1997) and are associated with a variety of worries, including negative feelings about sex and fear of pain upon intercourse (Hellsten, Lindqvist, & Sjostrom, 2007), fear of cancer recurrence (Burns et al., 2007; Saewong & Choobun, 2005; Tangjitgamol et al., 2007), and fear of cancer transmission through sexual activities (Saewong & Choobun, 2005).

While psychosocial distress is prevalent in gynecological cancer populations, the literature demonstrates significant variability with regard to the amplitude of distress experienced, where patients with certain problems report no or little distress, and others experience high distress. Several theories provide possible explanations for this diversity. Quality of life research describes a mechanism known as the response shift (Sprangers &

Schwartz, 1999), where an individual's self-evaluation of their own quality of life changes due to the evolution of internal standards, values, and definitions of quality of life throughout significant life events such as experiencing a life-threatening illness. Further, a body of literature has applied the transactional model of stress and coping (Lazarus & Folkman, 1984) to examine how patients respond to psychosocial stressors in attempting to reduce their distress. Across several cancer populations, problem-focused coping (e.g., planning, positive reinterpretation, instrumental support) has been associated with lower symptoms of anxiety and depression, and emotion-focused coping (e.g., ventilation, denial, restraint) with higher distress and poorer adjustment (Osowiecki & Compas, 1998; Ben-Zur, Gilbar, & Lev, 2001).

Sexual health outcomes. Sexual health can be described as a state of physical, emotional, mental and social well-being in relation to sexuality. Sexuality in this research was conceptualised as a central aspect of humanity which encompasses sexual activities, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction (World Health Organization, 2006).

Up to 50% of gynecological cancer patients report sexual health-related difficulties (Lindau, Gavrilova, & Anderson, 2007). Treatment for gynecological cancer affects many facets of sexuality including sexual interest, arousal, orgasm and pain. Up to 80% of gynecological cancer patients experience vaginal dryness, dyspareunia, and bleeding upon intercourse, all of which are associated with early menopause and vaginal fibrosis/stenosis (Jensen et al., 2004), which are in turn associated with declines in sexual activity and satisfaction (Bruner et al., 1993; Cochran , Hacker, Wellisch, & Berek, 1987; Flay & Matthews, 1995). Changes to, or removal of, external genitals such as the clitoris affect orgasmic function, body image and sexual satisfaction (Wilmoth & Spinelli, 2000).

Objective measures have demonstrated lower rates of vaginal blood flow following radical hysterectomy, which has important implications for sexual arousal (Maas et al., 2004), and low arousal has been reported as many patients' most distressing post-treatment symptom (Bergmark, Avall-Lundqvist, Dickman, Henningsohn, & Steineck, 2002).

Sexual satisfaction and interest may be hindered indirectly by treatment-related nausea, vomiting, alopecia, weight fluctuations, and bowel dysfunction, all of which can affect confidence and body image long after symptoms subside (Wilmoth & Spinelli, 2000; Burns et al., 2007). While many physical complications of treatment subside over time, longitudinal studies have shown that vaginal dryness and low sexual interest persist (Jensen et al., 2004).

Many of these studies demonstrated that sexual difficulties are more prevalent in this patient population compared to women in the general population (Andersen, Lachenbrunch, Anderson, & deProsse, 1986; Gershenson et al., 2007; Lindau et al., 2007; Maas et al., 2004); a further description of these studies is provided in the general conclusion. Despite the high prevalence of sexual problems, research has shown that few health care professionals address sexuality related issues with their patients. In one study, as few as 20-25% of health care providers reported discussing sexual health issues with their gynecological cancer patients, despite awareness of the prevalence of such problems in this population (Stead, Brown, Fallowfield, & Selby, 2003). Reasons for their resistance included a diffusion of responsibility, embarrassment, lack of knowledge/experience, and lack of resources to refer patients to. In another study, more than half of gynecological cancer patients surveyed were not given information about the effects of gynecological cancer on sexuality (Tangjitgamol et al., 2007).

Health care providers' perceived lack of skills in addressing these problems is not surprising, since traditionally medical interventions for women's sexual difficulties have been largely ignored, and there have been few attempts to conceptualize women's sexuality and sexual problems in ways that are meaningful to women (Bancroft, Loftus, & Long, 2003). Whereas most studies have focused on reporting physical symptoms of sexual function, more recent evidence suggests that, for women, emotional wellness and negative emotional feelings during sexual interaction are superior determinants of distress about sexuality than physical impairment of sexual response (Bancroft et al., 2003). Bancroft and his colleagues strongly encouraged a distinction between "sexual dysfunction" (i.e., due to maladaptive psychophysiological response) and a "sexual impairment" or "sexual problem" (i.e., an expected reaction to relationship factors, mental health, or other influences), and argued that much of previous literature on sexual dysfunction is flawed due to a negligence in measuring women's distress (e.g., their identification of symptoms as "a problem"). This research is in line with the parallel growth of research on supportive care needs in cancer survivorship. Whereas most physicians and nurses are more comfortable evaluating and discussing patient needs in the physiological domain, a gradual movement toward patient-centered care means cancer centres are striving to support all realms of well-being, including psychological and sexual health. The following section reviews the literature on efforts that have been made to evaluate patient's comprehensive supportive care needs.

Supportive Care Framework

In 1997, Cancer Care Ontario (CCO) integrated supportive care in its mandate (Whelan et al., 2000), maintaining that quality care must endeavor to be more patient-centered. Supportive care is the provision of services geared to meet patient's multidimensional unmet needs throughout the cancer trajectory (Fitch, 1994).

The Supportive Care Framework is a taxonomy of cancer patients physical, practical, informational, psychological, emotional, spiritual, and social needs. The framework has been used extensively in education, intervention development, and needs assessments, and its comprehensive nature allows for an assessment of the full spectrum of patient needs, which is an integral element of high-quality, patient-centered care. While many "supportive care" frameworks exist, our research team chose the framework described by Fitch (1994) because it is assessed using a tool modified for and previously used in the gynecological oncology population.

Patients require varying levels of intervention following cancer treatment. The majority will experience needs which can be met through standard, mostly informational services, while a smaller minority will experience more significant, enduring distress and will require more long-term care (Fitch, 2000). Presently, there is limited information dictating how this at-risk sub-group (i.e., with unmet sexual health needs) can be effectively identified and helped.

A literature review of needs assessments in gynecological cancer patients revealed few studies exploring comprehensive needs after gynecological cancer treatment (Bourgeois-Law & Lotocki, 1999; Corney, Everett, Howells, & Crowther, 1992; Jefferies, 2002; Miller, Pittmann, & Strong, 2003; Stewart et al., 2000). These survey studies, and one interview study (Corney et al., 1992) had sample sizes ranging between N=24-105 and generally focused on only one or two aspects of post-treatment needs. Most frequent needs explored were informational needs in the sexuality domain. Several of these studies documented patient dissatisfaction with the provision of information about sexuality after treatment. A review of the literature on informational needs indicated that many patients desire information on the impact of treatment on sexuality, and associated symptom management

(Gamel, Hengeveld, & Davis, 2000). Bourgeois-Law & Lotocki (1999) investigated the patients' preferred methods of information communication and found that most women preferred to receive information verbally from a health care provider (60%), followed by written information (pamphlet; 45%); finally, the least popular option was group format. Overall, these studies consistently called for a need for more specific information about treatment sequelae, symptoms management, and guidelines around resuming sexual intercourse. As the studies evaluating sexuality focused only on this domain, it is unknown whether other concurrent needs were a higher priority for these women.

Needs assessments exploring comprehensive post-treatment supportive care needs in gynecological cancer patients are scarce. When this study was designed, three studies measuring a variety of needs using standardized surveys were identified (Hodgkinson et al., 2007, Beesley et al., 2008; Steele & Fitch, 2008); all were cross-sectional survey studies, and the two former studies also conducted analyses of correlates and potential predictors of unmet needs.

Hodgkinson et al. (2007) examined psychosocial outcomes (e.g., depression, anxiety) and five supportive care need categories (i.e., existential survivorship, comprehensive cancer care, information, quality of life, relationships) as measured by the Cancer Survivors Unmet Needs measure, which had been recently developed and validated by the same first author and a group of colleagues (Hodgkinson et al., 2007b). In this study, about half (52%) of the survivors reported at least one unmet need, and the most highly endorsed needs were in the existential survivorship and comprehensive cancer care domains. Fear of cancer recurrence was the most frequently endorsed need (24%).

Beesley et al. (2008) conducted an assessment of supportive care needs within a larger sample of 802 gynecological cancer survivors. This survey study administered the

Supportive Care Needs Survey Short Form (SCNS-SF34; McElduff, Boyes, Zucca, & Girgis, 2004), a well-validated tool that measures four need domains: psychological, physical/daily living, sexuality, and health system/information. Items most endorsed were within the psychological and physical/daily living need domains, and some unmet sexuality and health system/information needs were also reported in more than ten percent of the sample.

Steele and Fitch (2008) explored physical, emotional, social, spiritual, psychological, informational, and practical needs of 103 gynecological cancer patients, of which 65 had terminated treatment. Most frequently endorsed needs were nonphysical, with fear of cancer recurring or spreading again being most frequent. This was the only needs assessment to evaluate both unmet needs as well as associated desire for help. The authors reported that about half (42-58%) of women reporting top needs also wanted help, and highlight that a better understanding of women's desire for help would guide clinicians to better identify and assist those who want help.

Based on these studies, the proportion of gynecological cancer patients with unmet supportive needs have been found to range from 45% (Beesley et al., 2008) to 52% (Hodgkinson et al., 2007). The inclusion of a wider spectrum of need domains in these three studies led to a consistent observation that patients' post-treatment unmet needs are most often non-physical in nature. Across all these studies, the most consistent top needs included fear of cancer recurrence, fatigue, anxiety/sadness, and interpersonal concerns. Unfortunately, none of the studies included a focus on reporting levels of sexual health needs compared to other need domains. However, other useful findings of these assessments are described in the section below.

Predictors of supportive care needs. The identification of predictors of patient needs may help health care practitioners identify vulnerable patient groups. A number of

survey studies (which used mostly univariate or correlational analyses) suggest that being partnered, receipt of radiation therapy, and increased vaginal changes predict greater sexuality and relational concerns (de Groot et al., 2007; Tangjitgamol et al., 2007; Donovan et al., 2007; Andersen, Woods, & Copeland, 1997). Further, being unpartnered predicted a significantly higher need for information about sexual health and cancer (de Groot et al., 2007). Some studies have revealed reduced quality of life and significant distress about infertility following chemotherapy-induced menopause (Lutgendorf et al., 2000; Schover, 2012).

In addition to sociodemographic and medical variables, some pre-diagnosis psychological factors may affect levels of distress after treatment. A negative sexual self-schema (i.e., view of sexual self; Andersen, Woods, & Copeland, 1997) may increase the effect of treatment on women's sexual behaviour, responsiveness, and satisfaction; similarly, a positive sexual self-schema may moderate emotional distress related to sexual changes after treatment (Carpenter, Andersen, Fowler, & Maxwell, 2009).

Unfortunately, there is a paucity of literature exploring predictors of overall and specific supportive care needs. In univariate analyses, Hodgkinson et al. (2007) reported significant correlations between higher overall needs and anxiety, depression, and younger age. In multivariate analyses, higher anxiety and later stage of cancer at diagnosis predicted reporting "at least one unmet need". Beesley et al. (2008), aiming to contribute to the development of community services for women post-treatment, explored predictors of supportive care needs with a socio-ecological perspective. Their results suggested that women with gynecological cancer were more likely to report at least one unmet need across multiple supportive care domains if they were experiencing lymphedema, were unable to work due to illness, lived in rural locations, or had undergone more recent treatment. As only

two studies have observed supportive care needs in women with various types of gynecological cancer, it is important to further evaluate the relationship between sociodemographic and medical characteristics and supportive care needs; further, no articles have measured predictors of desire for help with reported needs in this population. An understanding of these differences is important to better identify vulnerable groups that may require additional services.

Interventions for Sexual Morbidity Post-Treatment

At the time this study was conducted, only nine published intervention studies for sexual health in gynecological cancer patients were identified; findings and limitations of these studies have been recently reviewed by Brotto, Yule, & Breckon (2010). The definition and measurement of sexuality outcome measures varied significantly across these studies, making comparisons challenging. Only two studies utilized comprehensive measures of sexuality; one included physiological sexual response, self-reported sexual arousal and function (orgasm, pain, lubrication, sexual desire, and satisfaction), sexual beliefs, and sexual knowledge (Brotto et al., 2008), and Robinson, Faris, & Scott (1999) included a measure of "global sexual function" including frequency of various sexual activities, desire, arousal, orgasm, and dyspareunia. These studies represent a trend toward the utilization of more comprehensive measures of sexuality. The remaining studies conceptualized sexual health narrowly (e.g., frequency of sexual intercourse). This more traditional view of sexuality significantly limits our understanding of these patients' levels of sexual health; for instance, it is now recognized that, even when frequency of sexual activity returns to pre-cancer levels, sexual dissatisfaction and dysfunction may persist (Tangjitgamol et al., 2007).

Overall, the literature suggests that interventions may improve some aspects of sexual health, such as the frequency of sexual activity (Capone, Good, Westie, & Jacobson, 1980;

Caldwell et al., 2003), and vaginal dilator use and fears about sexuality after cancer (Robinson, Faris, & Scott, 1999), but only one noted a significant effect on sexual function (Brotto et al., 2008). In their pilot study, Brotto and her colleagues reported significant improvement in all self-report sexual health variables and highlighted the importance of a multifaceted approach in measuring and improving sexual health; unfortunately, as the authors aim to further validate and improve their intervention, these findings cannot currently direct health care providers seeking practical implications in this research. Further, intervention studies continue to report significant challenges, with low response rates and high attrition rates, suggesting barriers to participation impede the advancement of this research (Brotto et al., 2010). Altogether, the current literature provides little empirical guidance in developing services to improve sexual health in this population.

Summary of Gaps in the Literature

First, there is a longstanding lack of agreement regarding the definition of sexual health and function within this population. Simplistic conceptualisations of sexual function of many sexual health interventions limit the current literature regarding the provision of guidance toward effectively improving sexual health in patients. In addition to a need for a more consistent measure of sexual function and dysfunction, there is a need to evaluate patients' subjective expectations and beliefs about sexuality, which are equally important in the perception of sexual satisfaction (and, thereby, "met needs"). This gap speaks to a need to apply more comprehensive theoretical approaches to investigating sexuality in this population; the current study explored sexuality based on several holistic models which consider physiological, psychological, relational, and other factors contributing to sexuality in gynecological cancer patients and survivors (Woods,1987; Cleary & Hegarty, 2011; Weijmar & Schultz, 2003).

Second, whereas research on physiological sexual dysfunction in the gynecologic cancer population has been at the frontline of research for over two decades, to date only one comprehensive needs assessment has conceptualized sexual health needs as a unique domain (Beesley et al., 2008). Other assessments based on the Supportive Care Framework included the sexuality items within psychological, social and physical domains. In order to better understand sexual health needs and their relevance in the wider context of post-treatment needs, it would be beneficial to include sexuality as a unique domain.

Third, information on patient readiness to receive help with unmet needs, as well as the types of services they desire, is sparse. Some women, despite reporting high needs, report little or no desire to receive help from the health care team with unmet needs (Fitch, Gray, & Franssen, 2000). These results highlight that ambiguity persists in regards to discordance between patient needs and readiness for help. The vast majority of currently published intervention studies were provided in group format. Psychoeducational and social support groups are popular choices due to cost-effectiveness and the encouragement of peer support and normalization of the patient experience, but may not be the treatment modality choice of patients, who tend to prefer a more intimate setting to discuss sexuality (Burns et al., 2007).

Finally, differences in unmet needs amongst subgroups (i.e., age, marital status) are rarely examined. When predictors have been examined, needs (initially scored on a Likert scale) were unfortunately dichotomized into “no need” and, “at least one need”. Maintaining responses as a continuous variable would better preserve the richness of this data. Overall, an understanding of these differences is important to provide individualized care and to better identify vulnerable groups that may require additional services.

The Current Study

The current study was designed and conducted in collaboration with members of the Gyne-Oncology Program at The Ottawa Hospital, whose program mandate is to provide holistic care to gynecological cancer patients with a commitment to understanding quality of life issues. At the time the study was conducted, the multidisciplinary health care team was undertaking important changes with regard to coordinating patient care and post-treatment services.

Given identified gaps in the literature regarding patient needs and effective interventions for sexual health in this population, the stakeholders and research team opted to conduct the current needs assessment. Needs assessments are an essential component of program evaluation wherein the extent of need for a program or service is measured (McDavid & Hawthorn, 2006); moreover, the Canadian Cancer Society (2011) emphasizes in its annual report that it is imperative that the evaluation of patient quality of life and unmet needs be included in interdisciplinary health care services. A vital aspect of this approach is engaging all clients and stakeholders in all steps of the assessment, from study design to the dissemination of data. Several steps preceded the development of evaluation and research questions pertaining to the described needs assessment. These included: (a) an evaluation of supportive care needs in ovarian cancer patient needs during the treatment phase (Jolicoeur**,** Lefebvre, Le, Tourigny, & Flieler, 2008); (b) a qualitative study of endometrial cancer patient's experiences in follow-up services (Jolicoeur et al., 2010); (c) a focus group with primary care providers; and (d) multi-disciplinary meetings with an advanced practice nurse, two psychologists, and a gynecological cancer patient to discuss perceptions of program outcomes and patient needs, and to complete a literature review of post-treatment symptoms and published interventions in gynecological cancer.

Based on the literature review and findings from the aforementioned efforts, a research group was formed with the goal of conducting a comprehensive evaluation of the needs of gynecological cancer patients receiving follow-up at the Regional Cancer Centre of the Ottawa Hospital. The global objectives of the current dissertation were twofold: 1) to build on current research by designing two exploratory studies which address important gaps in the literature, and 2) to inform the development of interventions to be included in a survivorship program for gynecological oncology patients at The Ottawa Hospital via a comprehensive needs assessment.

A mixed methods design (i.e., inclusion of qualitative and quantitative data collection) was chosen in order to enhance the richness of data collected by participants. Indeed, it is increasingly acknowledged that such an approach provides improved insight into various levels of data analysis (Creswell, 2003); further, qualitative feedback is considered valuable in program evaluation as it can provide data that otherwise may not be detected via quantitative response choices with pre-determined responses (McDavid & Hawthorn, 2006). Approval was obtained from the three Institutional Research Ethics Board of all affiliated investigators; that is, of the University of Ottawa, The Ottawa Hospital, and York University. The appendices following the Conclusion section illustrate the informed consent forms and questionnaire package.

Study 1. The manuscript, "Sexual Health and Gynecological Cancer: Conceptualizing Patient Needs and Overcoming Barriers to Seeking and Accessing Services", describes a qualitative analysis of women' experiences of sexual health following gynecological cancer. The study objectives were to describe sexual health as perceived by women treated for gynecological cancers, to obtain a clearer understanding of the nature of desired services among this patient population, and to identify potential barriers to

participation in interventions focusing on sexuality. A one-on-one interview method was favoured to provide a comfortable, intimate interview setting. The results of this study were intended to a) provide a richer understanding of patient perceptions and components of sexual health, and b) compliment and provide further insight to results of a more detailed, quantitative needs assessment. This manuscript was published in the Journal of Psychosomatic Obstetrics & Gynecology (McCallum, Lefebvre, Jolicoeur, Maheu, & Lebel, 2012).

Study 2. The dissemination of results from the needs assessment took two forms. Manuscripts for both parts have been submitted for publication and are currently undergoing peer review. Part 1, entitled, "Filling in the Gaps: Sociodemographic and Medical Predictors of Supportive Care Needs and Desire for Help in Gynecological Cancer Survivors," illustrates a hypothesis-based analysis of predictors of supportive care and sexual health needs and desire for help with these needs. The results of this analysis are intended to expand research on supportive care and sexual health needs, and to explore possible at-risk subgroups that require extended support. In times of limited resources, the latter implication is especially relevant and valuable to the health care team involved.

Part 2 of this study is described in the manuscript, "Supportive Care Needs After Gynecological Cancer: Is Sexual Health a Priority? A comprehensive assessment of unmet sexual health needs and desire for help", provides a descriptive illustration of sexual health needs within the Supportive Care Framework, allowing for a broader understanding of sexual health needs and their relevance in the wider context of gynecological cancer survivorship.

The needs assessment was developed based on the following evaluation questions: (1) What are the unmet supportive care and sexual health needs of women treated for gynecological cancer at the designated cancer center?; (2) What proportion of the

participants experiencing unmet supportive care and sexual health needs report a desire for help?; (3) What format of assistance or help is preferred by the participants reporting unmet needs?; (4) Are higher unmet needs associated with and/or predicted by certain characteristics or individual differences? Given the relative lack of information on sexual health needs, the study results were illustrated, in this dissertation work, with a focus on sexuality. However, information on other need domains will also be illustrated when appropriate to allow for a wider perspective on patient needs.

Due to extensive recruitment efforts, data collection for the study 1 (the qualitative study) overlapped with study design and preparation for Study 2 (the needs assessment). Despite the lack of perfect sequentiality, these two studies complement one another favourably and, combined, provide a more complete depiction of sexual health and supportive care needs. The qualitative study explored subjective perspectives on the meaning of sexual health, needs, and obstacles in accessing help for these needs. Results proliferating from the qualitative interviews emphasized the value in distinguishing between patient needs and desire for help, which guided the authors' choice of assessment tools for Study 2. The quantitative needs assessment allowed for a comprehensive portrayal of supportive care and sexual health needs and desire for help, sexual health and vaginal changes, as well as a more detailed and representation of specific service format preferences. The larger sample size and validated needs questionnaire provided a more representative portrayal of sub-group differences and underscored the distinction between patient needs and desire for help. In the course of data interpretation for Study 2, the qualitative results from study 1 were valuable in providing a richer understanding of the relationships and associations that were detected. Overall, our mixed-methods approach broadened our insight on women's perceptions of sexuality and provided greater validity to our interpretations.

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Study 1

Sexual Health and Gynecological Cancer: Conceptualizing Patient Needs and Overcoming Barriers to Seeking and Accessing Services

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Abstract

The current study explored the subjective experiences of women treated for a gynecological cancer, with a focus on filling gaps in the current literature. Topics explored were: 1) women's own definitions of healthy sexuality; 2) services desired to meet needs; and 3) barriers to participation in sexual health-related services. In this qualitative study, 15 women participated in a one-on-one, semi-structured interview. Data collection and analysis were based on guidelines of interpretive description. Results revealed definitions of healthy sexuality including emotional intimacy, body image, sexual self-schema, and sexual response. Unmet sexual needs were reported when women's current sexual experiences did not correspond with their subjective perceptions of healthy sexuality. Most women desired informational services, delivered one-on-one or through written material. Younger women often did not utilize services due to practical barriers and emotional avoidance, while older women reported that shyness and stigma discouraged them from discussing sexuality with their health care team. In order to understand patient needs and desire for help, health care providers should assess current sexual health and patient perceptions of healthy sexuality. To increase effectiveness of distress screening and treatment interventions, potential barriers must be evaluated and addressed.

Sexual health and gynecological cancer: Conceptualizing patient needs and overcoming barriers to seeking and accessing services

The profound impact of gynecological cancers on women's sexuality is well-documented. Gynecological cancer treatment is associated with physical and psychological complications including vaginal changes (e.g., scarring of the vaginal wall), premature menopause and infertility, bladder and bowel dysfunction, depression, and anxiety (Stead, 2004; Bergmark, Avall-Lundqvist, Dickman, Henningsohn, & Steineck, 2002; Lagana, McGarvey, Classen, & Koopman, 2001; Burns, Costello, Ryan-Woolley, & Davidson, 2007; Steginga & Dunn, 1997). These invasive and enduring symptoms are associated with a wide range of sexual health difficulties (Gilbert, Ussher, & Perz, 2011) which, in turn, are associated with poorer quality of life (Carpenter, Andersen, Fowler, & Maxwell, 2009). The current literature on the development and implementation of interventions for evaluating and treating sexual health difficulties in gynecological cancer patients is sparse; at the time this study was conducted, only nine published intervention studies were identified (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Robinson, Faris, & Scott, 1999; Capone, Good, Westie, & Jacobson, 1980; Caldwell et al., 2003; Brotto et al., 2008; Maughan & Clarke, 2001; Jeffries, Robinson, Craighead, & Keats, 2006; Scott, Halford, & Ward, 2004; Robinson, Scott, & Faris, 1994; for a review, see Brotto, Yule, & Breckon, 2010). This paucity may be partially explained by a number of limitations in the literature.

First, there is a longstanding lack of agreement regarding the definition of sexual health within this population. This is demonstrated by a lack of consistency in screening criteria and outcome measures in interventions studies. While a number of holistic theories of sexuality have been proposed, many researchers and health care providers continue to

prioritize physiological facets of sexual function and neglect the psychological and social dimensions (Brotto, Yule, & Breckon, 2010; Cleary & Hegarty, 2011).

The challenge of conceptualising sexuality was addressed by Weijmar Schultz and Van de Wiel (2003), who presented an illustration of factors contributing to sexual satisfaction in gynecological cancer patients. Their work illustrates an overlap between a woman's real or current sexual experience and her envisioned "ideal" sexual experience, and is unique in its emphasis on the importance of patients' subjective expectations and beliefs about sexuality. This perspective is extremely valuable, as evidenced by studies reporting that not all women who experience post-treatment changes in sexual function report distress or a need for help (Steele & Fitch, 2008). Unfortunately, little or no work has been done to further validate and apply this conceptualization of sexual satisfaction in a gynecological cancer population. A recent review of treatment effects on sexual well-being in women with gynecological cancer highlighted a need for future research on the interactions between the diverse dimensions of women's sexuality rather than considering them only independently (Gilbert et al., 2011). In order to comprehensively identify patients who are dissatisfied with their sexual lives and require assistance with sexual health needs, further research must explore the interaction between biopsychosocial measures of sexuality (i.e., as portrayed in the Neotheoretical Framework of Sexuality) and one's subjective understanding of healthy sexuality.

A second limitation of the current literature pertains to reports of low participant response rates and high attrition rates for intervention studies (Brotto et al., 2010). Steele and Fitch (2008) demonstrated that, despite reports of unmet needs, many patients are not prepared or willing to receive help with their difficulties. With the exception of some studies exploring health care provider and patient discomfort in discussing sexuality-related issues

(Stead, Brown, Fallowfield, & Selby, 2003), few studies have explored possible barriers to seeking or utilizing sexual health-related services in this population. As the aim of this study was to inform the development of a future intervention that improves sexual health in women following gynecological cancer treatment, it was important to better understand the nature of barriers to requesting and utilizing sexual health-related services.

The current study

Given the absence of validated applied models of sexual health needs in this population, the questions emerging from the existing research, and the sensitive nature of sexuality-related discussions, we elected to conduct a qualitative study. Where a patient-centered approach to health care is prioritized, qualitative studies are especially valuable in providing patient perspectives to inform and facilitate the development of interventions (Gamel, Hengeveld, & Davis, 2001). The study objectives were to describe sexual health as defined by women treated for gynecological cancers, to obtain a clearer understanding of the nature of desired services among this patient population; and to identify potential barriers to participation in interventions focusing on sexuality.

Method

Participants

Study inclusion criteria included the following: 1) having been diagnosed and treated for a gynecological cancer, 2) being 18 years of age or older; and 3) fluency in English or French. A body of literature suggests that sexual health difficulties may differ across subgroups including cancer site, treatment type, and menopausal status. Recruitment targeted a heterogeneous sample based on these variables in order to obtain a wide range of patient experiences as well as capture differences in interpretation, rather than trying to avoid them (Ezzy, 2001). First, women with all gynecological cancer types (i.e., endometrial/uterine,

ovarian, cervical, and vaginal/vulvar) were recruited. Second, we included women who received radiation treatment (which is known to cause severe and enduring vaginal changes; Lagana et al., 2001, Burns et al., 2007) and some who had not. Third, the team attempted to include an equal number of women who were pre-menopausal and post-menopausal at diagnosis (due to known hormonal and fertility changes; Dennerstein, Dudley, Hopper, Guthrie, & Burger, 2000). These targeted patient variables, as well as the number of patients obtained within each category across variables, are demonstrated below:

Table 1.

Recruitment Sheet with Obtained Participant Characteristics, N=15

	Pre-Menopausal at Diagnosis		Post-Menopausal at Diagnosis	
Cancer site	Radiation	No Radiation	Radiation	No Radiation
Endometrium	1	2	2	0
Cervix	2	1	0	0
Ovary	1	1	0	1
Vulva/Vagina	1	0	2	1

Notes. It was hoped that a minimum of one participant in each cell would be recruited. The current table illustrates the obtained number of participants in each cell.

Procedure

Approval was obtained from the three Institutional Research Ethics Board of all five affiliated investigators (see Appendix A for the approved consent form). A qualitative interpretive descriptive study approach (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997) was chosen due to the research goal of exploring descriptions and interpretations of sexuality following treatment. This inductive approach emphasizes the exploration of health and illness experiences in their embedded context. Based on a purposive sampling approach, health care providers (i.e., nurses, psychologist) of a regional cancer centre selected and approached women who met the study's inclusion criteria and who were in treatment follow-up. The study was described to

patients with the offer of a chance to participate. Interested participants were called, further informed on study procedures, and offered the opportunity to be interviewed either at the hospital or in their homes. All study participants were accorded a pseudoname to protect anonymity.

Semi-structured interviews were conducted by the first author and consisted of four main questions/probes (see Appendix B for full interview guide); 1) Did the cancer experience and treatment impact your sexual health? If yes, how? And how did you cope with this? 2) What would you like your sexuality to look like now? 3) What types of psychological or informational services would you have liked to help meet your needs? 4) What types of barriers would prevent you from participating in needed sexual health-related services? The first section of questions on treatment impact were included as a general opening to the interview. As ample literature currently exists on this more general topic, only novel information will be presented in the current study results. Due to the semi-structured nature of the interview protocol, the four areas of interest were probed in different sequences and using only brief statements, with the focus on participants' statements and the flow of the interview. Interview duration ranged from one to two hours.

All study participants were accorded a random pseudoname to protect anonymity. Interviews were tape-recorded and transcribed, and participant statements were coded thematically (with data analysis program NVivo9) according to the guidelines of Interpretive Description (Thorne et al., 1997; Thorne et al., 2004). This qualitative approach aims to produce a synthesis of the main themes and patterns observed in the phenomenon studied. The procedure involves an inductive analytical interpretation, where themes are derived directly from the participant transcriptions without any preconceived theory. Following the initial coding by one team member, the team met on a regular basis to review and revise the

coding themes as needed. All codes that were retained were based on full-team consensus. Overall, this type of data collection and analysis leads to descriptions and an understanding of practical knowledge from shared and unique human experiences.

Results

Participants

Table 2 displays the sociodemographic and medical characteristics of the sample. Fifteen women accepted to participate (9 at home, 6 in a hospital interview room). Participant age ranged from 26 to 71 years, with a mean of 52. Ten women were married or in a serious relationship, and 5 were single or widowed. Certain subgroups (e.g., endometrial patients transferred back to their family physicians due to very low risk of recurrence) were more difficult to identify. Consequently, some recruitment table cells were not filled. Notwithstanding, there was a good range on cancer site, menopausal status, and treatment type.

Findings and themes

Fourteen of the fifteen participants reported that their cancer treatment had negatively affected their sexual health. The most frequently cited sexual-health related post-treatment symptoms reported included decreased sexual arousal and desire, dyspareunia, and vaginal scarring, shortening, and dryness. Participants described a reciprocal relationship between physical, psychological, and interpersonal experiences, which combined in their effect on current sexuality. The most commonly reported difficulties reported include anxiety (e.g., fear of partner rejection or abandonment), a changed sexual self-concept, grief (e.g., of fertility, womanhood), and both positive and negative interpersonal changes. Themes were identified within three overarching areas of interest; 1) descriptions of

Table 2

Participant Characteristics, N = 15

Variable	*M*	*SD*
Age (years)	51.7	12.9
Time since treatment (years)	2.2	2
	n	*%*
Civil status		
Married/In a relationship	10	67
Single/Widowed	5	33
Primary cancer site		
Uterus / Endometrium	5	33
Cervix	3	20
Ovary	3	20
Vulva / Vagina	4	27
Treatment regimen		
Surgery	4	26.7
Chemotherapy	1	6.7
Radiation therapy	3	20
Chemotherapy and radiation therapy	1	6.7
Surgery & chemotherapy	1	6.7
Surgery & radiation therapy	1	6.7
Surgery, radiation therapy, & chemotherapy	4	26.7
Menopausal status at diagnosis		
Pre-menopausal	9	60
Post-menopausal	6	40

healthy sexuality, 2) services desired, and 3) barriers to participation in sexual health-related services.

1) Healthy sexuality. When asked to describe what health sexuality might look like to them, most women initially responded by describing what healthy sexuality was not. Many participants specified that physical factors such as intercourse and orgasm were of lesser importance than several other factors. The most common themes identified in womens' descriptions of healthy sexuality included having a strong intimate connection, a good body image, a healthy sexual self-schema, and physiological aspects of sexual function.

Within the first theme regarding an intimate connection, several women indicated that healthy sexuality hinges on a mutual emotional bond between partners. They described

the importance of reciprocal caring and loving, which was expressed through a variety of activities such as cuddling and kissing. These women also explained that what made their own sexual relationship healthy was the special connection they shared with their partners through mutual hobbies, communication of thoughts and feelings, and maintenance of a strong sense of trust and comfort. Selina, who had been married to her husband for 45 years, shared her thoughts on the importance of the emotional connection in her sexual relationship:

> It's not what we had when we were in our twenties... But it's still a very satisfying sexual life... I think because we can talk so openly about it. I think it's the communication and the trust.

In addition to the importance of an intimate connection, many women described the common theme of having good body image as a factor in attaining healthy sexuality. These women felt that healthy sexuality includes the ability to feel attractive and confident in their sexual relations. This theme was especially prevalent in women who reported feeling distressed by enduring physical changes (e.g., post-surgery scars, weight gain, removal of external genitals). These women felt that an inability to accept certain bodily changes was a barrier to achieving healthy sexuality after cancer treatment due to lingering insecurities. The following quotation describes Selina's view of the role of body image in her ability to achieve healthy sexuality:

> Your sexuality is so much in your head. It's about how you feel about yourself, and how you feel about your body, and how you feel about being intimate with somebody else, and how comfortable you are with the other person, and how easily you can completely let yourself go to that other person.

A third theme of healthy sexuality was sexual self-schema, or one's cognitive view or thoughts about sexual aspects of oneself (Carpenter et al., 2009; Andersen, 1999). The

patients described a significant change in their self-view with respect to femininity in their sexual relationships. This theme stood apart and was coded separately from the theme of body image in that these comments described a need for their partner (or future partner) to be attracted not only to their physicality, but to their nature and presence as woman and sexual being. Some of the women's sexual self-schemas were associated with their sexual response cycle; for instance, their ability to desire sexual contact and to be physically aroused. Isabella, who experienced decreases in sexual desire and physiological sexual arousal following radiation treatment, stated the following:

> So you've gotta have libido… You have got to wanna have sex, and you have to be able to get turned on. And so that physical expression of love has to come from somewhere… you have to feel like you want to.

Finally, within the fourth theme of sexual function, three participants emphasized that they highly valued the physical aspects of sexuality. Many women indicated that they would be able to achieve their envisioned healthy sexuality if they could manage their physical post-treatment changes (e.g., vaginal changes causing pain, discomfort, or worries). The ability to engage in sexual intercourse and attain orgasm was, for them, as important as a good emotional connection. Changes in sensations experienced during sexual encounters were also distressful to Isabella, and affected her self-schema as a fully functional woman:

> The cervix and the uterus produce a kind of orgasm that's different from... it's a different kind of orgasm, you know, from the other types of organs… you almost feel that you aren't fully functioning 'cause it doesn't always work.

2) Suggestions for services. The majority of the women described a need for more in-depth and accessible informational services; for instance, information on the nature and effects of their treatment, whether/when sexual intercourse becomes safe, managing vaginal

changes, and coping with the effects of premature menopause. Several communicated a desire to better understand the nature and effects of their treatment. In discussing her needs, Kristin described confusion with respect to the physical changes she underwent during surgery:

> How is it supposed to be? Because sometimes I was like, 'Is this normal?' I feel like there's a big hole or, like… it's not the same as before.

More specifically, the three younger women indicated that they, before and after treatment, would have liked more information on the effects of treatment on fertility, and on options for preserving fertility prior to treatment (e.g., egg harvesting).

Many of the women described a need for a more structured screening and information delivery system, where all patients are screened for distress, given the opportunity to ask questions, and offered appropriate services. While some felt written information would have adequately met their needs, many patients indicated that they would have appreciated one-on-one time with a health care provider to ask questions and discuss any distress. Patients felt that for both written information and one-on-one interactions, there should be more communication of an openness and readiness to assist patients with post-treatment symptom management and sexuality-related difficulties. The following quotation helps demonstrate the high value placed on health care team willingness to have open discussions about sexuality:

> I think there should be something on the pamphlet, that 'We are available to talk to you'…I think that, for those that have more specific physical problems, it should be brought up more readily. (Sophia)

3) Barriers. The women were asked to identify factors which had discouraged them, or might discourage them, from requesting and/or utilizing sexual health-related resources

after treatment. Responses revealed four themes: expectations and stigma, shyness and discomfort, practical barriers, and emotional avoidance.

Expectations and stigma. Comments representing the theme of expectations and stigma were related to participants' beliefs about mental health services, about sexual health as a "taboo" subject, and about the "types of people" who receive and seek such services. Interestingly, many stated that most people believe the sole purpose of social support groups is the facilitation of crying and comforting one another. As a result of this perception, women who were seeking other types of support -- such as information about post-treatment symptoms or partner communication – were less likely to visit existing support groups (including a group intended for this patient population offered by the program itself). Finally, many women shared the belief that sexual health was less important than other medical issues to their oncologists; consequently, they felt that they were expected to focus on cancer-specific topics such as treatment and recurrence-related symptoms.

Shyness and discomfort discussing sexuality. Many felt that it would be embarrassing to discuss concerns about sexual health with peers and/or their health care team members. These women indicated that, in general, they were unaccustomed to discussing sexuality with others; this included health care professionals, friends, and sometimes romantic partners. Helen described her perception of a generational difference in comfort levels with regard to discussing sexuality,

> Total shyness. Don't forget we're of the age where we weren't given information when we were young. The kids today are more open...than we were. We were not given information from…I wasn't anyways, from my mother on anything... So you have to be able to open up and just tell all.

Practical barriers. When asked to explain what may discourage them from utilizing available resources, some women identified practical barriers. Many had financial struggles and were unable to pay additional parking fees on a weekly basis. Others had returned to work and were unable to attend daytime groups, and many had conflicting responsibilities such as the care of young children. Overall, these women felt that participating in such services, while potentially helpful, was not feasible.

Emotional avoidance.

Some women explained that they had not accessed support or informational services because they did not want to be exposed to any adverse emotional experiences. They explained that, as survivors, they wanted to focus on positivity and moving forward. Other women associated the hospital setting with their cancer experience, and felt that it would be unpleasant to receive post-treatment services in a hospital setting. Marquita, who emphasized her joy at the thought of "turning the page" after treatment, said,

> I didn't go to the support group mostly because... I was so overwhelmed with being at the hospital. I wanted to give myself a break from the hospital.

Potential subgroup differences in barriers.

While the qualitative nature of this study does not lend itself to making formal interpretations based on participant differences, it is interesting that an age difference was noted with regards to reported barriers to participation. The nine women who were pre-menopausal at diagnosis (i.e., younger women) were more likely to report practical barriers and emotional avoidance, while the six women who were post-menopausal at diagnosis were more likely to speak of expectations and stigma or shyness and discomfort. Further, it appears that relationship factors may play a role in women's desires to improve their own sexual health, and, therefore, to seek services. Nine of the fifteen participants reported making active

efforts to improve their sexuality through communication, open-mindedness, and resourcefulness. The other four women had resigned to their changed or inactive sexual lives, reporting longstanding couple communication difficulties leading to discomfort and avoidance of sexuality-related topics. These women felt misunderstood, isolated and/or rejected by their partners. Linda tearfully described her reaction when her husband refused to participate in management of her vaginal changes (e.g., vaginal dilation),

> He said, 'Well it's embarrassing for me, to mix medicine and sexuality, I don't like it, no.'… I felt sick. I felt like he was saying to me, 'Above all, above all that's how I see you. As a sick person.' That was what I thought. And I haven't opened up to him since then.

Discussion

The goal of this study was to explore patients' experiences of sexual health following gynecological cancer treatment. The interview was developed based on questions raised in the current literature and results will inform the development of future interventions offered to women following gynecological cancer treatment. Themes identified through the data analysis clustered around three dimensions: describing healthy sexuality, service suggestions, and barriers to requesting or utilizing sexual health-related services.

At the time the current study was developed, few published efforts to conceptualize sexuality in gynecological cancer survivors were identified. Interview questions were developed based on gaps in the literature, and were intended to be interpreted analytically then compared to Weijmar Schultz and Van de Wiel's work on sexual satisfaction (2003). During data analysis, a recent published work by Cleary and Hegarty (2011) proposed the Neotheoretical Framework of Sexuality, adapted from Woods (2011), which highlights a triangular relationship between sexual self-concept (body image, sexual esteem, and sexual

self schema), sexual relationships (communication and intimacy), and sexual functioning (desire, arousal, and orgasm). This framework provides practical guidance toward a more holistic conceptualisation of sexuality in patients.

The themes which emerged from this study can be understood within different aspects of these two models. The womens' descriptions of healthy sexuality (including intimacy, body image, sexual self-schema, and physiological function) are in sync with findings by Cleary and Hegarty which emphasize the combination of the sexual relationship, sexual self-concept, and sexual functioning. The variability in levels of distress despite similar symptoms across participants supports Weijmar Schultz and Van de Wiel's work, where personal perceptions, ideas and beliefs are crucial in their contribution to perceived sexuality and satisfaction.

Therefore, our findings were combined with the Cleary and Hegarty's Neotheoretical Framework of Sexuality (2011) and Weijmar Schultz and Van de Wiel's work on sexual satisfaction (2003). The upper left triangle of the adapted model (see Figure 1) illustrates the three categories listed in the Neotheoretical Framework of Sexuality, which are supported by our data. The two overlapping boxes and descriptions on the right hand side of the model are inspired by a combination of the current results with Wiejmar Schultz and Van de Wiel's model of sexual satisfaction. Finally, the lower left hand boxes (Unmet needs and Barriers to participation) illustrate the addition of the current study results. It is hoped that this model can guide the reader in understanding the complexity of, and relationships between, identified themes in this study. Further, it is hoped to guide researchers and clinicians in their evaluations and treatment of sexual health difficulties in this and other cancer populations, and possible future research in this domain.

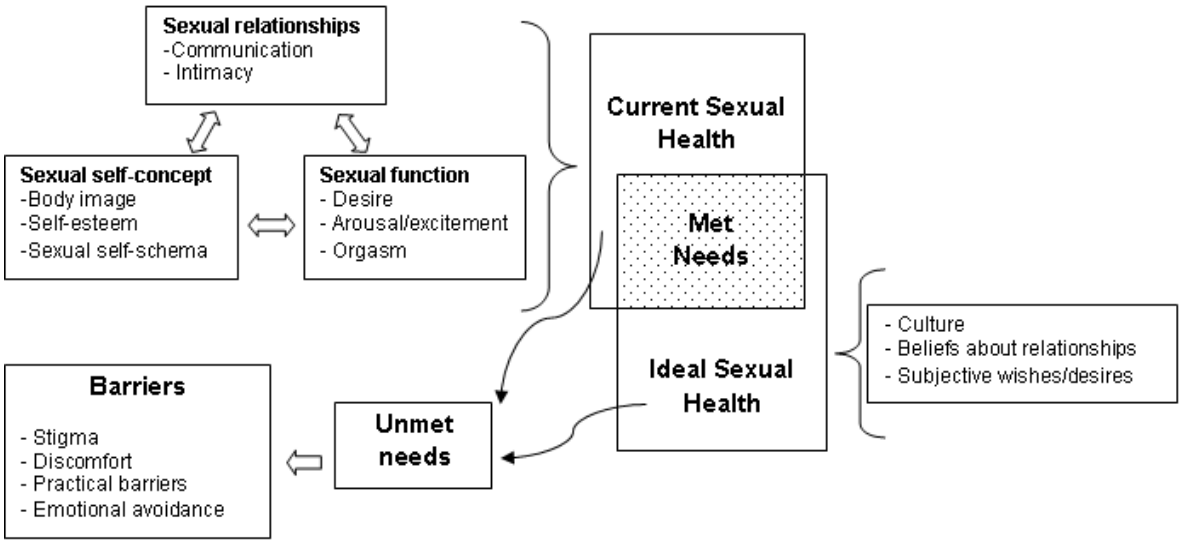

Figure 1. Model of sexual health needs. Adapted from Weijmar Schultz and Van de Wiel (2003) and Cleary and Hegarty (2011).

The qualitative nature of the current study allowed for a more in-depth understanding of the interaction between post-treatment symptoms, personal characteristics, and sexual health. Participants with similar post-treatment physical symptoms reported varying levels of distress and desire for support. This variability in symptom-related distress suggests that the extent to which treatment affects sexuality is moderated by a number of other factors, such as women's expectations and personal views on their "ideal" sexual health. A small number of subgroup differences were noted; for instance, age differences in barriers to participation, and body image-related difficulties in women reporting more post-treatment physical symptoms. No differences were noted with regard to cancer type and the themes identified. However, given the qualitative nature of our study, a larger quantitative study with a more representative sample is needed in order to explore significant subgroup differences in unmet sexuality needs post-treatment.

Women's descriptions of healthy sexuality were diverse and emphasized emotional intimacy, a positive body image and sexual self-schema, and physiological sexual response. The variability in descriptions of healthy sexuality support a trend toward a more comprehensive approach in defining and measuring sexual health as seen in recent studies (Robinson et al., 1999; Brotto et al., 2008). The women attached varying levels of importance to these themes, with no obvious association to age group, type of treatment, or cancer type. It is therefore possible that the women's preferences were affected by other unexplored factors including generational, personality, cultural and social variables (Weijmar Schultz & Van de Weil, 2003). Our results are in line with findings of these authors, who point to the importance of looking beyond the content and considering the context in conceptualising female sexuality. When screening for sexual health difficulties, it is therefore important that health care providers consider how such "context" variables such as cultural background and personal beliefs and characteristics will shape womens' current needs and desire for help.

As described by Weijmar Schultz & Van de Wiel (2003), the extent to which current and ideal sexual health overlap defines an individual's level of sexual satisfaction. Sexual satisfaction is nearly synonymous, then, to the state of having one's sexual expectations and needs met. On the other hand, when current experience differs from one's perception of ideal sexual health (i.e., where the two areas do not overlap), sexual dissatisfaction and unmet needs are reported. When asked about service suggestions for their unmet needs, participants' responses reflected current literature which highlights patients' desire for information on post-treatment symptoms, treatment effects on sexuality, and symptom management (Stewart et al., 2000). However, in past intervention studies, information-based programs have had no significant effect on sexual health (Robinson et al., 1994), as opposed

to more comprehensive and supportive psychological interventions (Brotto et al., 2008). This further supports a need for consideration of barriers which may make patients less likely to report a desire for psychological services, despite experiencing emotional struggles.

Participant's descriptions of barriers to participation support Steele & Fitch's (2008) findings that simply bearing an unmet sexual need does not necessarily translate into either motivation to seek change, nor a readiness to seek and receive help or support. Our findings contribute to the literature as they suggest that younger women may require more assistance in accessing services that are more convenient, flexible and affordable; further, they may be more likely to utilize services that are offered off-site. In contrast, older women may benefit from services that are offered in a manner that normalizes the experience of psychological and sexual health difficulties following cancer, and that explains the nature of services offered. Due to notable discomfort in discussing sexuality, which is viewed as a "taboo" subject, it is especially important for health care providers to initiate discussions about patient difficulties and resources. Finally, some reported no interest in receiving services due to an acceptance of, or perhaps resignation to, their current lack of sexual contact. These women reported peripheral longstanding couple issues (i.e., distress related to communication difficulties), and may benefit from information on couple therapy resources.

A number of study limitations are worth noting. Various forms of sexual dysfunction are reported by women in the general population; therefore, some sexual health difficulties may have been present prior to the women's cancer experience (e.g., hormone changes due to natural menopause, partners' physical conditions). Because baseline data (i.e., pre-diagnosis sexual function) could not be collected, the extent to which the cancer treatment directly affected current sexual health is unknown. The women interviewed were therefore asked to focus, to the best of their judgement, on sexual health difficulties they attributed to

the cancer experience. While this limitation is worth noting, it did not interfere with the research goal of understanding the women's current experiences and unmet needs.

Interpretations presented may not be reflective of all possible experiences women with gynecological cancer can manifest. However, the purposive sampling used in this study provided the means to present an array of possible experiences women with gynecological cancer can have. While not encompassing all possible sexual health difficulties experienced by women with gynecological cancers, we believe the findings can provide guidance to clinicians on possible aspects to explore with their patients. It is hoped that these efforts contributed to a richer understanding of sexuality in women with gynecological cancer. Finally, while a small number of observations were made with regard to noted subgroup differences in defining sexuality, service suggestions, and barriers to participation, the qualitative nature of this study did not allow for formal interpretations based on this information. Future quantitative research is needed in order to explore how unmet needs and readiness to seek and receive services may differ amongst these subgroups, and how different post-treatment difficulties (e.g., physical sequelae, emotional challenges) relate to varying levels of unmet needs and desire for help.

In sum, the current study results reveal an array of post-treatment difficulties, unmet needs, and definitions of healthy sexuality. The experience of healthy sexuality following treatment appears to be a combination of women's current sexual experiences and their perceptions of ideal sexual health. Most participants spontaneously described how services should be provided (i.e., in a comfortable environment, with a structured screening system) and focused less on specific types of service suggestions (e.g., group therapy). Based on patient feedback, it is possible that health care providers can help meet patients' needs by providing survivors with training in partner communication, information promoting physical

symptom management, and psychosocial support (e.g., cognitive-behaviour therapy) for psychological difficulties such as body image struggles and infertility-related distress. However, as these conclusions are not derived directly from participant feedback, further research is required in order to identify the types of services that these patients desire in improving their sexual health post-treatment. Future research is also mandated to identify subgroup differences (i.e., by cancer type, type of treatment), readiness to seek/receive help, and types of services desired in meeting sexual health needs. Finally, future research could explore whether the comprehensive model of sexual health needs presented is applicable to other cancer survivor populations.

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Study 2, Part 1

Filling in the Gaps: Sociodemographic and Medical Predictors of Supportive Care Needs and Desire for Help in Gynecological Cancer Survivors

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Abstract

Many gynecological cancer patient needs are met through standard care, while others require more extensive support. Health care providers currently have little evidence-based guidance as to how these vulnerable patients can best be identified and supported. Many intervention programs designed to meet gynecological cancer patients needs report low recruitment rates and high attrition, and research suggests women who do not receive services may be those who are most distressed. The study objective was to evaluate predictors of supportive care needs and readiness for help in a mixed gynecological cancer patient population. A sample of 113 women receiving follow-up services for gynecological cancer completed a comprehensive measure of needs and desire for help. Regression analyses were conducted to identify socio demographic and medical predictors of patient needs and desire for help. The three strongest predictors of higher unmet needs and greater readiness for help were younger age and shorter time since treatment. Younger age and receiving chemotherapy predicted greater readiness for help with sexual needs. Shorter time since treatment and younger age predicted greater readiness for help with social needs, and recent treatment predicted higher desire for help with emotional needs. These findings provide several implications. Patients who are younger and more recently treated may experience concerns regarding existential issues, anxiety, sexuality, and relationships. Post-treatment care must include support regarding sexuality and relationship concerns, which were most likely to remain unaddressed after treatment. Further research with a larger sample is required to better understand predictors of post-treatment needs and desire for help.

Filling in the gaps: Sociodemographic and medical predictors of supportive care needs and desire for help in gynecological cancer survivors

Well documented are the multifaceted sequelae of treatment for gynecological cancer, which often diminish women's quality of life indefinitely (Bergmark, Avall-Lundqvist, Dickman , Henningsohn, & Steineck, 2002; Auchincloss, 1995; Andersen, Anderson, & DeProsse, 1989a; Stead, 2004; Lagana et al., 2005; Burns, Costello, Ryan-Woolley, & Davidson, 2007; Gilbert, Ussher, & Perz J, 2011). Cancer care centres are increasingly adopting holistic, patient-centered mandates (Gamel, Grypdonck, Hengeveld, & Davis, 2001); unfortunately, health care providers have little scientifically-based guidance as to how gynecological cancer patients' post-treatment needs should be evaluated and addressed to maximize the quality of their care. This problem can be addressed through use of the supportive care need framework which encompasses physical, psychological, social, emotional, practical, spiritual, and informational needs (Fitch, 2008). The framework was developed as a tool for needs assessments and program planning and is a useful tool for education and model development.

Descriptive studies have shown great variability in levels of unmet needs (Steele & Fitch, 2008). Left unmet, these needs are linked to increased psychosocial distress and lower overall quality of life (Carpenter, Andersen, Fowler, & Maxwell, 2009). Most post-treatment needs appear to be non-physical in nature (Steele & Fitch, 2008; Beesley, Eakin, Steginga, Aitken, Dunn, & Battistutta, 2008; Hodgkinson et al., 2007); however, many health care providers feel they lack the resources, time, skills and knowledge to properly address psychosocial and sexual concerns (Stead, Brown, Fallowfield & Selby, 2003).

Currently, only two studies explore individual differences in unmet supportive care needs in gynecological cancer patients. First, Hodgkinson and colleagues (2007) reported

that higher anxiety and a later stage of cancer at diagnosis predicted reporting at least one unmet need. Second, Beesley and colleagues (Beesley et al., 2008) were the first to explore predictors of unmet supportive care needs using a socio-ecological perspective. Living in a rural location, limited ability to work due to illness and experiencing lymphedema were the most consistently significant community and health factors, while several demographic variables predicted some unmet needs; these included being partnered, vaginal or open bowel surgery, receiving chemotherapy, and shorter time since treatment. The authors emphasized the descriptive nature of their study and encouraged further research in this area to identify predictors. Both of these pioneer studies evaluated predictors of a dichotomous outcome variable (no need or one or more needs), which may have resulted in a significant loss of variability in needs as a construct.

Despite research indicating that a majority of women recovering from gynecological cancer treatment experience significant levels of sexual dysfunction (Gilbert et al., 2011), to date only Beesley and colleagues (2008) evaluated unmet sexual health needs as a unique domain. However, research has identified potential risk factors for sexual dysfunction and/or distress across all gynecological cancer sites; these include having radiation therapy and/or chemotherapy, being partnered, poor body image, and a negative sexual self-schema, or view of oneself as a sexual being (Lagana et al., 2005; Carpenter et al., 2009; Bruner et al., 1993; Jensen et al., 2004a; Lutgendorf et al., 2000; Schover, 2012). Further exploration of these potential predictors of unmet needs would help identify at risk patient groups that would benefit most from preventative and treatment interventions (Hodgkinson et al., 2007)

The current literature also provides interesting research directions with regard to patient readiness for help with unmet meets. Some women report moderate to high needs and low desire for help (Fitch, Gray, & Franssen, 2000), a finding that potentially complicates the

interpretation of distress screening tools and previous needs assessment. As per a recent review, several psychological intervention studies for sexual sequelae of cancer report low response rates and/or high attrition (Brotto, Yule, & Breckon, 2010), and another study reported that women who withdrew from a psychological intervention had higher distress rates at baseline than women who agreed to participate (Powell et al., 2008). Therefore, predicting readiness for help with needs could possibly assist health care providers in identifying patients who require assistance in overcoming certain barriers to accessing services; thereby, improving quality of care and the allocation of valuable and often limited program resources. To date, no needs assessment has examined predictors of desire for help with unmet supportive care needs in a gynecological cancer population.

To address the abovementioned shortcomings of the literature, the current study sought to comprehensively evaluate levels and predictors of gynecological cancer patient needs and desire for help in a mixed gynecological cancer population, while using a comprehensive framework and a validated measure of needs. Predictor variables were selected based on literature (in gynecological and other cancers) and available participant information. Two research questions were developed, and hypotheses regarding the predictor variables were based on available literature. When applicable, supporting references for hypotheses are provided below.

Research question 1: "Do sociodemographic and/or medical factors (i.e., age, time since treatment, radiation therapy, chemotherapy, surgery, civil status, menopausal status at cancer diagnosis) predict unmet supportive care needs?" For this question, three hypotheses were derived: (A) Younger age (Tangjitgamol et al., 2007; Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004; Schover, 1994; Stewart, Wong, & Duff; 2001) and shorter time since treatment (Beesley et al., 2008; Donovan et al., 2007) will predict higher supportive

care needs across multiple domains; (B) Radiation treatment will predict higher unmet physical needs (Jensen et al., 2003; Tangjitgamol et al., 2007); (C) Chemotherapy will predict higher unmet needs in the physical, psychological, and emotional domains (Lagana et al., 2005; Lutgendorf et al., 2000; Schover, 2012).

Research question 2: "Do sociodemographic and/or medical factors predict desire for help with unmet needs?" For this question, the authors developed a fourth hypothesis; (D) Younger age (McCallum, Lefebvre, Jolicoeur, Maheu, & Lebel, 2012) and shorter time since treatment (Donovan et al., 2007) will predict greater readiness for help with needs across several domains. For some independent variables (e.g., civil status, menopausal status) no formal hypotheses were drawn due to a lack of consistent findings in the literature. They were included in the analysis as exploratory variables.

Method

Participants

The current sample consisted of women who were: (a) diagnosed and treated for a gynecological cancer; (b) receiving post-treatment follow-up services at a regional cancer centre; (c) 18 years of age or older, and (d) fluent in spoken and written English or French. The gynecological clinic in the cancer centre offers services through the regional gynecologic oncology program, which is comprised of a multidisciplinary team of health care professionals.

Measures

The self-report questionnaire package included: (a) a 14-item sociodemographic and medical characteristics questionnaire (developed by the authors), (b) the Supportive Care Needs Survey – Gynecological Version (SCNS-gyne; Steele & Fitch, 2008), (c) the Sexual Function-Vaginal Changes Questionnaire (SVQ; Jensen, Klee, Thranov, & Groenvold,

2004b), (d) a "Format Preferences" questionnaire to evaluate the preferred format of help within supportive care need domains, and (e) an open "comments" section.

The SCNS-gyne was adapted from the Supportive Care Needs Survey (SCNS), which was developed and validated to assess cancer patients' global needs; it has demonstrated good test-retest and internal reliability and good face and construct validity (Bonevski et al., 2000). The SCNS-gyne was minimally altered from the SCNS and is said 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 5 point Likert scale ranging from 1 ("I did not experience this issue") to 5 ("I am experiencing a high level of difficulty with this issue"). A response of 3 or higher was scored as a need for the purpose of the regression analyses (low, moderate, or high level of difficulty with the item). In Part B, respondents are asked to rate their level of desire for help with each issue (when applicable) on a three point scale that includes, "No, I do not want any help", "I feel uncertain about wanting help", and "Yes, I would like help". The item scores for parts A and B are clustered into scores for seven supportive care need domains which were developed through factor analysis in previous studies (psychological, social, emotional, spiritual, information, practical, and physical needs; (Fitch, 2008). 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. This score was created due to a large body of literature highlighting the importance of sexuality-related difficulties post-treatment (Andersen, Anderson, & deProsse, 1989b; Lagana et al., 2005; Stead, 2004; Gilbert et al., 2011). With respect to internal reliability, Cronbach's alpha for the SCNS-gyne subscales in this study were .60 (practical needs), .69 (social needs), .82 (psychological and

physical needs), .84 (emotional needs), .87 (informational and spiritual needs) and .88 (sexual health needs).

Procedure

Study approval was obtained from the research ethics boards of all co-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 centre. 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 due to a low recruitment rate (approximately 12%) using the first strategy, consisted of direct recruitment through the nursing staff at the cancer centre. 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 pre-paid return envelope (see the study consent form in Appendix C). 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 medical care.

Data Analysis

Statistical analyses were conducted using SPSS 20. Univariate and multivariate assumptions for regression were verified, and data cleaning was conducted based on the guidelines of Tabachnick & Fidell, 2007. Based on the standard sample size recommendation of *50 + 8k observations* (k = #independent variables), the sample size of N=113 provided sufficient power to conduct regression analyses with seven predictors. The 8 need domain scores and one predictor, "time since treatment", were positively skewed. Square root transformation successfully normalized these variables except for "time since treatment" and "Practical needs", which underwent logarithmic transformation. Eight univariate outliers (*Z*

≤ 3.29) were capped to the next lowest (non-outlier) value. The two groups of participants recruited (i.e., mail-outs versus direct recruitment at the clinic) were compared using chi-square and independent T test analyses on all predictor variables as well as education and income. No significant differences were found. Four participants, likely neglecting the double-sidedness of the questionnaire, only filled out every second page of the questionnaire package. Due to already limited power, these participants were retained in the database and estimation maximization was employed for data imputation.. As part of the multiple regressions, the Mahalanobis distance for each case was calculated, and no multivariate outliers were found.

Research question #1 (Predicting unmet supportive care needs with sociodemographic/medical variables). To create need domain scores, the mean of participant responses was calculated for all items within the seven supportive care need domains. Eight hierarchical multiple regressions were employed between level of need (by domain) and the seven predictors in four blocks: (a) time since treatment (years), (b) age, (c) radiation and (d) chemotherapy, surgery, civil status, and menopausal status at diagnosis. Based on the literature review, variables shown to have stronger associations with unmet needs in gynecological and other cancer patients were entered in the first, second, and third blocks, while more exploratory variables were included in block four (see Table 2); for instance, time since treatment was, based on the available research, judged as the most commonly cited factor associated with a reduction of post-treatment symptoms and distress.

Research question #2 (Readiness to receive help with unmet needs). Due to a highly skewed distribution with a high frequency of "No help wanted" responses, a "readiness to receive help" variable was computed for each domain. Participants were attributed a value of 1 if they replied "Yes" or "Uncertain" on at least one item within the

need domain, and a value of 0 if they reported no desire for help on all items within a given domain. The group of "uncertain" women were included with those who responded "yes" to help because previous research (McCallum et al., 2012) suggests that many women with needs and a desire for help hesitate to access services due to various barriers; therefore, women reporting any amount of readiness to receive help should be conceptually considered as a patient that should be approached to offer further support. This is in line with the study's goal of facilitating the identification of vulnerable or at-risk patients.

In all, eight standard logistic regression analyses were performed with the "Readiness to receive help" variables and the seven predictors. To the knowledge of the authors, current literature provides little to no scientific evaluations of predictors of desire for help with unmet supportive care needs; consequently, predictors were not entered in a hierarchical order as in research question #1. For both research questions, since eight regressions were conducted per research question, a Bonferroni correction was applied during interpretation with a significant cut off level of .05/8= .006 for all regressions (Tabachnick et al., 2007).

Results

Participants

Table 1 presents the descriptive statistics for the sample. A total of 113 women treated for a gynecological cancer completed the questionnaire package. Age ranged from 27 - 89 (M = 60, SD = 13). Most participants were Caucasian (96%) and English-speaking (76%). Whereas endometrial is the most prevalent cancer type, ovarian cancer was the most prevalent cancer type in this sample.

Supportive Care Needs

Seventy-eight percent of the sample reported at least unmet need, and a range of 0 - 62% of the total 67 items were endorsed as unmet needs across the sample. To compare need

Table 1

Participant Characteristics, N=113

Variable	*M*	*SD*
Age (years)	61	13
Time since treatment (years)	2.7	5.8
	n	*%*
First language		
English	82	73
French	22	20
Other	9	8
Primary ethnic background		
Caucasian	109	97
Asian	2	2
African-Canadian	2	2
Civil status		
Married	76	67
Cohabitating	6	5
Single	9	8
Divorced/separated	10	9
Widowed	12	11
Education		
Primary school/High school	45	41
College	32	28
University	35	31
Income		
Less than 20,000	6	5
20 – 39,999	18	16
40 – 59,999	22	20
60 – 79,999	18	16
80 – 99,999	12	11
Over 100,000	21	19
Primary cancer site		
Uterus / Endometrium	26	23
Cervix	13	12
Ovary	60	53
Vulva / Vagina	9	8
Treatment regimen*		
Surgery	87	77
Chemotherapy	87	77
Radiation therapy	43	38
Menopausal status at diagnosis		
Pre-menopausal	33	29
Post-menopausal	70	62

Note. * Categories are not mutually exclusive.

domain scores, the individual items were summed and transferred to a 0-100 scale. When averaged across all participants, means were within a similar range for several domains (M = 38 - 41 for spiritual, psychological, sexual, emotional, and physical needs), while mean scores for social (M = 35), informational (M = 33), and practical (M = 29) need domains were slightly lower. The most prevalent unmet needs were in the psychological, social, and emotional domains as well as one physical domain item (e.g., fear of cancer recurrence and death and dying, concerns about the well-being of caregivers, coping with sexual changes, symptom management, and anxiety.

Predicting Needs

Hierarchical multiple regression analyses were employed to predict the eight need domain scores from the seven sociodemographic and medical characteristics; Table 2 presents the results of the 8 hierarchical multiple regressions analyzing predictions of supportive care need domain scores from the 7 sociodemographic and medical variables.

Time since treatment was entered as a first variable in step 1 of each regression. This predictor accounted for significant variance in emotional (F_{change} [1,111] = 8.67, $p \leq .006$), psychological (F_{change} [1,111] = 8.45, $p \leq .006$), and spiritual (F_{change} [1,111] = 11.9, $p \leq .006$) needs. Time since treatment alone predicted 7-10% of variance in these need domains, where shorter time since treatment was associated with increased unmet needs in these domains.

In step 2 of the regressions, age significantly predicted variance in the equations for emotional (F_{change} [1, 110] = 8.82, $p \leq .006$), social (F_{change} [1,110] = 17.33, $p \leq .006$), and sexual health (F_{change} [1, 110] =, $p \leq .006$) need domains. Younger age predicted increased

Table 2

Hierarchical Multiple Regression Analyses Predicting Supportive Care Need Domain Scores From Sociodemographic and Medical Variables, N=113

Predictor	Emotional		Psychological		Spiritual		Information		Practical		Sexual		Social		Physical	
	â	ÄR^2	*â*	ÄR^2	*â*	ÄR^2	*â*	ÄR^2	*â*	ÄR^2	*â*	ÄR^2	*â*	ÄR^2	*â*	ÄR^2
Step 1		.07***		.07***		.10***		.03*		.06**		.00		.02		.01
Time since tx	-..27		-.27***		-.31***		-.18*		-.24**		-.01		-.14		-.11	
Step 2		.07***		.04*		.03		.05**		.03*		.19***		.13***		.03
Time since tx	-.30		-.29***		-.33***		-.21*		-.26***		.05		-.18*		-.13	
Age	-.264		-.20*		-.17		-.23**		-.18*		-.44***		-.37***		-.16	
Step 3		.01		.01		.01		.001		.003		.004		.00		.00
Time since tx	-.31		-.31***		-.35***		-.21*		-.25***		-.04		-.18*		-.12	
Age	-.07		-.20*		-.16		-.23**		-.18*		-.44***		-.37***		-.16	
Radiation	-.03		-.11		-.11		-.03		.06		-.07		.01		.03	
Step 4		.05		.08*		.05		.06		.03		.10**		.06		.04
Time since tx	-.29		-.27***		-.32***		-.22*		-.26***		.01		-.14		-.09	
Age	-.31		-.33**		-.19		-.29*		-.21		-.39***		-.41***		-.21	
Radiation	-.04		-.08		-.08		.02		.09		.06		.01		.035	
Chemotherapy	.16		.15		.19*		.04		.02		.28***		.22**		.17	
Surgery	.11		.05		.11		.15		.07		.03		.04		.05	
Civil status	-.03		-.15		-.02		-.18		-.15		.15		.07		.04	
Menopause	.14		.22		.10		.13		.04		-.00		.11		.11	
Total R^2		.19		.20		.19		.15		.12		.29		.22		.08

Notes . tx = treatment.
**p≤.05. ** p≤.01. *** p≤.006*

unmet needs, contributing unique variances of 7% (emotional needs), 13% (social needs), and 19% (sexual needs) variance

In step 3, radiation treatment was entered as a third variable. This predictor did not add significant variance to any of the regression equations. After step 4, the four remaining predictor variables (i.e., civil status, chemotherapy, surgery, and menopausal status) predicted significant variance in sexual health needs, but at a less conservative alpha level, (F_{change} [1, 105] = 3.48, $p \leq .01$). This step is noteworthy, however, due to the significant variance contributed to the equation by the predictor chemotherapy ($B = .25$, $p \leq .001$). This predictor alone contributed 8% of variance to the equation, where having received chemotherapy was associated with higher sexual health needs.

Based on *R square* values, the seven variables as a set predicted the following variance in needs: sexuality (29%), social (22%), psychological (20%), emotional (19%), spiritual (19%) informational (15%), practical (12%), and physical (8%). A number of variables contributed variance to unmet needs which were significant at slightly less conservative alpha levels ($p \leq .05$, $p \leq .01$); these findings, which are illustrated in Table 2, are demonstrated due to their implications for future research with a larger sample size.

Readiness to Receive Help with Unmet Needs

Eight binary logistic regression analyses were conducted to evaluate if the seven predictors, as a group and/or individually, predicted a participant's readiness to receive help (i.e., 0 = no desire for help with all items within a need domain, 1 = "yes" or "uncertain" to at least one item within a need domain) in the 8 supportive care need domains. The results are summarized in Tables 3 and 4. A test of the full model with all seven predictors against a constant-only model was conducted for each need domain. The full model test was statistically significant for informational needs,

Table 3

Logistic Regression Analyses Predicting Readiness for Help with Unmet Informational, Sexual, Emotional, and Psychological Needs From Sociodemographic and Medical Variables, N = 113

Predictors	Informational domain			Sexual domain			Emotional domain			Psychological domain		
	B	Wald	*OR(CI .95)*	*B*	Wald	*OR(CI .95)*	*B*	Wald	*OR(CI .95)*	*B*	Wald	*OR(CI.95)*
Time since tx	-1.11	10.35***	.33(.17-.65)	.06	.02	1.06(.52-2.16)	-.74	5.48*	.48(.26-.89)	-.60	3.57	.55(.30-1.02)
Age	-.043	3.29	.96(.91-1.00)	-.08	6.9**	.92(.87-.98)	-.06	6.76**	.94(.90-.99)	-.05	3.96*	.96(.91-.99)
Radiation	1.12	5.27*	.33(.13-.85)	.10	.03	1.1(.39-3.03)	-.51	1.31	.60(.25-1.44)	-.77	2.96	.46(.19-1.12)
Chemotherapy	-.49	.98	.62(.24-1.61)	1.6	6.2**	5.02 (1.4-17.1)	.06	.015	1.1(.43-2.64)	.24	.261	1.3(.51-3.14)
Surgery	.43	.55	1.5(.50-4.7)	.57	.74	1.76(.49-6.4)	.57	1.11	1.8(.61-5.1)	1.0	3.51	2.8(.96-8.2)
Civil status	-.29	3.8	.74(.29-1.03)	-.97	2.6	2.64(.81-8.6)	.18	.14	1.2(.48-3.01)	.35	.559	1.4(.57-3.59)
Menopause	.50	.63	1.65(.48-5.69)	.23	.11	1.26(.32-4.9)	1.3	4.38*	3.6(1.09-12.1)	1.02	2.81	2.8(.84-9.12)

Notes:
* $p \leq .05$. **p≤.01. ***p≤.006. Wald=Wald Chi-Square. OR=Odds Ratio. CI.95=95% Confidence interval. tx = treatment.

Table 4

Logistic Regression Analyses Predicting Readiness for Help with Unmet Practical, Physical, Social, and Spiritual Needs From Sociodemographic and Medical Variables, N = 113

Predictors	Practical domain			Physical domain			Social domain			Spiritual domain		
	B	Wald	*OR(CI .95)*	*B*	Wald	*OR(CI .95)*	*B*	Wald	*OR(CI.95)*	*B*	Wald	*OR(CI.95)*
Time since tx	-.41	1.6	.67(.35-1.25)	-.21	.49	.81(.45-1.46)	-.46	2.24	.629(.34-1.15)	-.87	7.39**	.42(.22-.79)
Age	-.02	.54	.98(.94-1.03)	-.05	4.98*	.95(.91-.99)	.02	.74	.98(.94-1.02)	-.03	1.4	.98(.93-1.02)
Radiation	-.23	.26	.79(.32-1.96)	-.68	2.49	.50(.21-1.18)	-.53	1.4	.59(.25-1.4)	-.48	1.17	.62(.26-1.5)
Chemotherapy	.75	2.2	2.12(.78-5.7)	-.69	.44	1.35(.56-3.27)	.79	2.7	2.2(.86-5.6)	-.18	.16	.83(.34-2.1)
Surgery	.48	.72	1.6(.53-4.9)	.29	.32	1.34(.49-3.66)	1.12	3.8*	3.1(.99-9.48)	1.1	3.81*	3.0(.99-0.05)
Civil status	-.87	3.6	.42(.17-1.03)	.29	.28	.78(.31-1.95)	.04	.01	1.05(.42-2.59)	1.4	.09	1.2(.46-2.89)
Menopause	.19	.11	1.2(.39-3.82)	.61	1.11	1.8(.59-5.72)	.29	.25	1.3(.42-4.2)	.53	.80	1.7(.53-5.4)

Notes:
* $p \leq .05$. **p≤.01. ***p≤.006. Wald=Wald Chi-Square. OR=Odds Ratio. CI.95=95% Confidence interval. tx = treatment.

(χ^2 = 20.77 (7, N = 113, $p \leq .004$), indicating that the predictors, as a set, reliably distinguished between women who reported no desire for help from those who reported desire for help or uncertainty about wanting help. The model correctly predicted readiness for help classification in 74% of the sample. Time since treatment was the only statistically significant predictor of readiness for help with informational needs at the $p \leq .004$ level, where shorter time since treatment predicted greater readiness to receive help with informational needs.

The logistic regressions also examined which individual predictors significantly predicted readiness for help scores. Increased readiness for help with unmet sexual health needs was predicted by younger age ($p \leq .01$) and having received chemotherapy ($p \leq .01$). Increased readiness for help with emotional needs was also predicted by younger age ($p \leq .01$). Finally, increased readiness for help with spiritual needs was predicted by shorter time since treatment ($p \leq .01$). Whereas none of these findings met the Bonferroni-corrected alpha level ($p \leq .004$), many approached significance and offer directions for future research with a larger sample size and greater power.

Discussion

This study is the first to examine sociodemographic and medical predictors of both supportive care needs and desire for help using a validated measure of needs within a mixed gynecological cancer population, and the second to include sexual health needs as a unique domain. Contrary to previous studies which defined their outcome variable as "one or more unmet need", the current study measured needs as a continuous variable in order to preserve the richness of this data.

The most common unmet needs were consistent with previous needs assessments where existential concerns, lack of energy/tiredness, and concerns about worries of loved

ones were amongst the most frequent (Beesley et al., 2008; Hodgkinson et al., 2007). Based on the study results, Hypothesis A (i.e., younger age and shorter time since treatment will predict higher needs) was confirmed in several domains. Hypothesis B (i.e., radiation therapy will predict higher unmet physical needs) was rejected. Hypothesis C (i.e., chemotherapy will predict higher physical, psychological, and emotional needs) was rejected; however, chemotherapy was an important predictor of unmet sexual health needs. Hypothesis D (i.e., younger age and shorter time since treatment will predict higher desire for help with needs) was confirmed.

The findings on age as an important predictor of unmet needs in this population lend support to other research observing this association (Tangjitgamol et al., 2007; McCallum et al., 2012) and the multidimensional nature of the study provides a deeper understanding of the nature of younger women's concerns (e.g., fear of cancer recurrence, information on symptom management, changes in ability to have sexual intercourse, and worries about the struggles of loved ones). Younger women were experiencing greater difficulty with unmet emotional, sexual, and social needs, suggesting that themes such as fertility, relationships/intimacy, gender/family roles, and anxiety are prevalent. Some research indicates that many older women are able to adjust their expectations of sexual health to include more physical closeness rather than intercourse; on the other hand, many older women grieve changes to their sexuality but are uncomfortable discussing their sexuality with health care professionals (McCallum et al, 2012).

The finding that radiation therapy did not predict higher needs was surprising, given the well-populated literature on physical post-radiation vaginal changes (Jensen et al., 2004a; Tangjitgamol et al., 2007). To better understand this finding, medical characteristics of our sample were explored. Proportions of cancer types in the sample were compared to cancer

centre statistics for the year 2010-11, which reported the following proportions: Endometrial (42%), ovarian (32%), cervical (14%), and other (including vaginal/vulvar; 13%). Our proportions of cervical and vaginal/vulvar cancer were similar to the targeted population, but an over-representation of ovarian cancer patients was detected. Therefore, our results may be more applicable to women with ovarian cancer who receive chemotherapy treatment. Sub-groups of patients receiving radiation therapy as a primary treatment regimen were likely underrepresented in this sample.

To further explore this hypothesis, sample demographics for this study were compared to those reported by a recent needs assessment with 802 respondents who participated in a population-based survey (Beesley et al., 2008). The two samples are similar with regard to age and civil status. The current sample has a higher proportion of high-income families as well as a higher proportion of ovarian cancer patients and chemotherapy patients. However, since the authors reported that ovarian cancer patients were underrepresented in their sample, a comparison was not undertaken regarding cancer type.

The results regarding a null hypothesis for the prediction of radiation treatment may also be partially explained by a significant effort made in the current gyne-oncology program to develop informational services on post-treatment difficulties including sexual dysfunction for radiation patients; consequently, radiation patients may have more assistance with sexual health needs than other cancer types in the sample. Future research with a larger sample size and stratified sampling techniques would allow for the exploration of potential differences in post-treatment difficulties by specific treatment type and cancer type.

The results indicate that women recently treated are more likely to request help with informational needs (e.g., symptom management); on the other hand, they should also be offered support within the spiritual, psychological, and emotional domains, due to higher

reports of distress in these areas. Further, while research has identified that some post-treatment symptoms decrease or are met over time (Jensen et al., 2004) our study suggests that unmet sexuality and social needs persist in survivorship. This reinforces evidence that sexual health and interpersonal concerns are insufficiently addressed both by the patient and health care provider (Stead, 2004). Interestingly, while women recently diagnosed express a number of moderate to high needs (when probed), they are only more likely to report readiness to receive help with their emotional difficulties (e.g., anxiety, sadness). It is possible that women are more comfortable demonstrating readiness for help when their needs involve services that are familiar and involve fewer taboos (e.g., support groups, psychotherapy), compared to services they are less familiar with (e.g., support for spiritual or sexual concerns).

Due to the multidisciplinary collaboration in participant recruitment, it was impossible to track the number of potential patients approached and thereby calculate a recruitment rate. Also, the well-known limitations of cross-sectional research (i.e., no baseline level available) and self-report instruments (i.e., a lack of objectivity) apply. Despite these limitations, consistencies with previous needs assessments regarding top need domains, top items, and most significant predictors suggest that the sample represents those assessed in previous studies (Beesley et al, 2008; Hodgkinson et al., 2007; Steele & Fitch, 2008).

One notable difference was detected, however; whereas past needs assessments reported that 43% (Beesley et al., 2008) and 52% (Hodgkinson et al., 2007) of their samples experienced one or more moderate to high unmet needs, 78% of the current sample reported at least one moderate to high need. As women with ovarian cancer are often diagnosed at a later stage, and a previous study found that later stage of diagnosis predicted higher overall

needs in a univariate analysis, (Hodgkinson et al., 2007) it is therefore possible that the over-representation of ovarian cancer patients resulted in higher unmet needs.

The modest sample size contributed to some limitations in the analysis. Certain predictor variables of interest (i.e., cancer site, education) could not be included in the analysis. Further, in order to have a sufficiently high cell count for logistic regression, the response categories for desire for help (i.e., "no", "uncertain", and "yes") had to be dichotomized. This is less than ideal, since some women within the "no help wanted" category had a need, while others did not. Also, women who desire help may differ from those who are uncertain about wanting help. Notwithstanding, these results remain pertinent; certainly, it is useful for health care providers to better identify women who clearly want help as well as those who have needs and desire help but struggle with certain barriers (McCallum et al., 2012) or lack knowledge about available services. Studies with higher statistical power could address many of our study limitations by: (a) allowing a less stringent alpha level, possibly allowing for the observation of more significant relationships; (b) calculating predictors with more homogenous categories, and (c) exploring other predictors such as socioeconomic variables (e.g., rural/urban settings, work status), gynecological cancer type, education, and baseline psychological factors such as sexual self-schema (Carpenter et al., 2009).

The current study offers important implications and directions for further research. The link between treatment and unmet needs remains uncertain, and future research could explore the validity of our results, conservatively suggesting that chemotherapy patients may have higher needs for support regarding sexual function, and could benefit from increased patient and caregiver support focusing on symptom management (e.g., menopause) and understanding/coping with changes in sexual function. Younger women may experience a

greater need for more support and education on sexual and relational aspects of cancer and survivorship (e.g., infertility, relationships, family). Needs within the sexual and social domain appear to persist, which highlights that they are not being adequately addressed by the patients and their health care teams. Finally, as unmet needs and readiness for help are not synonymous, it is vital that health care providers evaluate patient needs as well as barriers to accessing services. As research efforts in this domain multiply, health care providers will hopefully have access to guidelines for developing screening and intervention strategies that identify vulnerable patients and improve their access to services and improved long-term quality of life.

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RUNNING HEAD: SEXUAL HEALTH NEEDS AND DESIRE FOR HELP

Study 2, Part 2.

Supportive Care Needs After Gynecological Cancer: Where Does Sexual Health Fit in? Evaluating Unmet Needs and Desire for Help.

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Abstract

There currently exists little empirically supported guidance on effective interventions for sexual health difficulties after treatment for gynecological cancer. Research on patients' sexual health needs and their desire for help is urgently required to inform program development for gynecological cancer survivors. The study objective was to describe sexual health needs within the framework of supportive care needs, as well as desire for help and service format preferences for needs. The goal was to inform the development of post-treatment screening and intervention services in a gyne-oncology program. A total of 113 women receiving follow-up care after treatment for gynecological cancer completed a questionnaire package. Descriptive and correlation statistics were conducted to observe levels of need and desire for help as well as associated variables (e.g., sociodemographic and medical factors). Forty percent of the sample was worried about the status of their sex life. Few women said "yes" when asked if they desired help with unmet sexual health needs, but twice as many indicated an interest in receiving help when they were able to identify a desire to meet one-on-one with a health professional. Younger age, pre-menopausal status at diagnosis, and greater sexual satisfaction and vaginal changes after treatment were associated with greater sexual health needs and desire for help. Health care providers should proactively encourage discussions of the patient perceptions of their needs and their views of healthy sexuality, and develop a treatment plan collaboratively. Ambivalence about receiving help is high, and barriers to accessing services must be individually assessed to improve quality of care, as well as response and participation rates.

Supportive care needs after gynecological cancer: Where does sexual health fit in?

Evaluating unmet needs and desire for help

Gynecological cancer and its treatment are associated with changes in the physical, psychological, and social dimensions such as mood, fertility, body image, bladder/bowel dysfunction (Pearman, 2003; Gilbert, Ussher, & Perz, 2011; 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 (see Abbott-Anderson & Kewkkeboom for a recent review); yet, discussions about sexuality between gynecological cancer patients and their health care providers are sparse (Lindau, Gavrilova, & Anderson, 2007; Stead 2004; Gott, Hinchliff, & Galena, 2004).

Awareness of survivorship needs is increasing along with nation-wide efforts to implement systematic screening for distress in cancer survivors (Bultz et al., 2011).To maximize the quality of patient care, it is important that health care teams provide treatment and/or the appropriate referrals to assist patients who have been identified. Unfortunately, there exist little empirically supported interventions for sexual problems post-treatment. Only a handful of published intervention studies have shown favorable effects on symptom-management behaviours that are understood to improve sexuality (e.g., increasing compliance to vaginal dilation recommendations; Robinson, Faris, & Scott, 1999). A recent systematic review of sexual concerns in thiuls 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 gynecological cancer survivors (Abbott-Andersen & Kwekkeboom, 2012).

In light of these challenges, additional research on patient needs and preferences for services directed to meeting their needs is urgently needed. A literature review revealed a number of studies investigating only one or two need domains in gynecological cancer patients post-treatment; for example, some explored a need for increased patient-physician communication about sexuality, while others pay 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, Pittman, & Strong, 2003; Stewart et al., 2000). Only a small number of needs assessment studies explored comprehensive supportive care needs in gynecological cancer patients post-treatment (Steele & Fitch, 2008; Beesley et al., 2008; Hodgkinson et al., 2007). The inclusion of a wider spectrum of types of needs led to a consistent broader observation that patients' post-treatment unmet needs are most often non-physical in nature, with existential and interpersonal concerns at the forefront.

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

In sum, currently, no needs assessments have comprehensively explored unmet needs, desire for help with unmet needs, and service format preferences in a mixed gynecological cancer population (i.e., with all gynecological cancer sites); furthermore, only one study has included sexuality needs as a unique domain. The current study describes a needs assessment conducted at a regional cancer centre with the objective of directly informing program development as well as addressing gaps in the literature on gynecologic oncology patients' needs. The evaluation questions included: (a) What are the unmet supportive care and sexual health needs of women treated for gynecological cancer 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 to portray sexual health needs within the larger schema of supportive care needs.

Method

Participants

The current sample consisted of women who were: (a) diagnosed/treated for a gynecological cancer and receiving follow-up care at the designated regional cancer centre; (b) 18 years of age or older, and (c) fluent in spoken and written English or French. The gynecological clinic in the cancer centre offers services through the regional gynecologic oncology program, which is comprised of a multidisciplinary team of health care professionals. In general, women who are in remission are seen in follow-up and screening for recurrence every 3-4 months to yearly for up to 5 years. In this center, most endometrial cancer patients who receive surgery are followed in the community by their primary care providers; therefore this subgroup could not be recruited. Those who were

treated with radiation therapy are transitioned back to the primary care provider after 2 years.

Measures

The self-report questionnaire package included a 14-item sociodemographic and medical characteristics questionnaire, the Supportive Care Needs Survey – Gynecological Version (SCNS-gyne; Steele & Fitch 2008), the Sexual Function-Vaginal Changes Questionnaire (SVQ; Jensen, Klee, Thranov, & Groenvold, 2004a), a "Format Preferences" questionnaire to evaluate the preferred format of help within domains, and an open "comments" section. In the latter measure, 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". All measures administered to the patients are found in Appendix D.

The SCNS-gyne was adapted from the Supportive Care Needs Survey (SCNS), which was developed and validated to assess cancer patients' global needs (Bonevski et al., 2000). The SCNS-gyne was minimally altered from the SCNS and retained its psychometric properties, with demonstrated good construct, content, and face validity (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 5 point Likert 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's alpha for the SCNS-gyne subscales in this study were .60 (practical needs), .69 (social needs), .82 (psychological and physical needs), .84 (emotional needs), .87 (informational and spiritual needs) and .88 (sexual health needs).

The SVQ is currently the only validated tool intended to measure cancer/treatment-specific sexual function and vaginal difficulties in gynecological cancer patients (Jensen et al., 2004a). It consists of 24 items with responses on a numeric rating scale (e.g., "not at all" to "very much"). Its conceptualisation of sexual function is based on four main dimensions of sexuality: sexual interest, sexual arousal, orgasm, and pain (Basson et al., 2000). Item responses were summed to create one of four validated subscales; Intimacy scale, Global Sexual Satisfaction Scale, Vaginal Changes Scale, and Sexual Functioning Scale. A fifth existing subscale called "Sexual interest" was not utilized as a subscale since it includes only one item. In Jensen and colleagues' validation study (2004a), Cronbach's alpha was satisfactory for subscales, with a range of .76–.83. In the current study, moderate to high reliability was demonstrated with the following Cronbach's alpha: .69 (Intimacy scale), .61 (Global sexual satisfaction scale), .90 (Sexual function scale), and .93 (Vaginal changes scale).

Procedure

Study approval was obtained from the research ethics boards of all co-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 centre. 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 due to a low recruitment rate (approximately 12%) using the first strategy, consisted of direct recruitment with full nursing staff assistance at the cancer centre. 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 pre-paid 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 20. Frequency analyses measured levels of supportive care needs, sexual health and vaginal changes, and service format preferences. The low number of sexually active women (N=36) limited power for a regression analysis. An exploratory analysis of correlations between socio demographic and medical variables (e.g., age, civil status), sexual health needs (SCNS-gyne), desire for help with sexual health needs (SCNS-gyne), and the SVQ subscales (Intimacy scale, Global Sexual Satisfaction Scale, Vaginal Changes Scale, and Sexual Functioning Scale) was conducted.

Results

Participants

Table 1 presents sociodemographic and medical characteristics of the sample. Data were collected from 113 patients at a gynecological cancer follow-up clinic. Age ranged from 27-89 years (M = 61, SD = 13), with the majority of the sample (76%) aged 50 to 79 years. Most women were of Caucasian background, and ovarian cancer was the most common cancer type, with a variety of treatment modalities.

Table 1.

Participant Characteristics, *N*=113

Variable	*M*	*SD*
Age	61	13
Years since treatment	2.7	5.8
	n	*%*
Primary cancer site		
Uterus / Endometrium	26	23
Cervix	13	12
Ovary	60	53
Vulva / Vagina	9	8
Treatment regimen*		
Surgery	87	77
Chemotherapy	87	77
Radiation therapy	43	38
First language		
English	82	73
French	22	20
Other	9	8
Primary ethnic background		
Caucasian	109	97
Asian	2	2
African-Canadian	2	2
Civil status		
Married	76	67
Cohabitating	6	5
Single	9	8
Divorced/separated	10	9
Widowed	12	11
Education		
Primary school/High school	45	41
College	32	28
University	35	31
Income		
Less than 20,000	6	5
20 – 39,999	18	16
40 – 59,999	22	20
60 – 79,999	18	16
80 – 99,999	12	11
Over 100,000	21	19
Menopausal status at diagnosis		
Pre-menopausal	33	29
Post-menopausal	70	62

Notes. * Categories not mutually exclusive

Unmet Supportive Care and Sexual Health Needs

Table 2 displays the top unmet needs across all domains; most are psychosocial and highlight existential struggles (e.g., fear of cancer recurrence), concerns about caregivers/loved ones, and difficulty with sexual health changes. About one quarter of the sample reported moderate to high levels of difficulty with changes in their ability to have intercourse (24%) and changes in sexual feelings (22%). The SVQ measures difficulties with sexual function and vaginal changes commonly associated with gynecological cancer and treatment. Most participants reported a moderate level of satisfaction with their appearance (on a scale of 1-7; $M = 4$, $SD = 1.6$) and sex life ($M = 4.2$, $SD = 2.1$).

On the SVQ, 40% of the sample reported feeling worried about their sex life and 67% of the women reported at least one sexual health need. Thirty-five percent of the women reported that they had been sexually active in the past month. Table 3 illustrates the sexual health and vaginal changes reported by the participants. Low or no sexual interest was reported in three quarters of the entire sample.

Amongst the sexually active women (n=39), 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% of the sexually active participants, with 50% reporting distress. Almost half of the sexually active women reported their vagina “felt too small” (42%), and 64% reported achieving orgasm either “never” or “occasionally” in sexual interactions over the past month.

Table 3 also summarizes patient perceptions of changes in sexual function since their cancer diagnosis. 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%). Further, 38% reported that their partner experienced problems with sexual arousal.

Table 2.

Most Prevalent Unmet Needs (SCNS-gyne) and Proportions of Desire for Help, N = 113

Item	Low need (%)	Moderate-High need (%)	Want help (%)	Uncertain (%)	No help wanted (%)
Fear about the cancer returning	31	44	23	15	57
Fear about the cancer spreading	33	33	23	9	62
Lack of energy/tiredness	21	26	18	6	74
Concerns about the worries of those close to you	30	25	18	12	64
Changes in ability to have sexual intercourse	12	24	11	10	71
Feelings about death and dying	25	23	17	11	68
Uncertainty about the future	32	23	17	9	67
Not able to do the things I used to do	19	23	12	7	74
Fear about physical disability	17	22	17	6	74
Changes in sexual feelings	14	22	10	11	74
Changes in sexual relationships*	10	19	12	8	71
To be given information about sexual relations*	7	8	11	3	76

Notes. * These two items were not among the most frequent unmet needs; their results are displayed to better inform the reader on participant responses to the four sexual health-related needs of the SCNS-gyne

Desire for Help

Table 2 illustrates that, across domains, many patients did not desire help with their identified needs. Of those who experienced difficulty with their "ability to have sex" (as measured on the SCNS), 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/fatigue).

Table 3.

Sexual Health – Vaginal Changes Questionnaire Results

	Responded (%)	Not at all (%)	A little (%)	Quite a bit-very much (%)	Distress (%)
Interested in sex	92	44	32	16	-
Vaginal dryness*	32	25	39	36	67
Dyspareunia*	32	44	33	22	50
Vagina feels too small*	32	58	22	19	-
	Responded (%)	Never (%)	Occasionally (%)	Often-Always (%)	
Ability to reach orgasm*	32	22	42	36	
Perceived changes **	Responded (%)	Decreased (%)	Unchanged (%)	Increased (%)	
Interest in sexual contact	89	41	48	0	
Vaginal dryness	43	1	18	25	
Dyspareunia	35	4	13	18	
Change in vaginal size	43	50	27	0	
Partner's interest in sexual contact	73	12	59	1	

Notes.* These percentages represent the responses of sexually active women (*n*=39)
**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 (*N*=113)

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, between 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) 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 health care professional, and 17% indicated that written information could help meet their sexual health needs. Only 1% 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 examine the relationship between higher sexual health needs and sociodemographic/medical characteristics? Correlation results for two of the SVQ

Table 4

Service Format Preferences by Domain, N = 113

Format	Sexual (%)	Spiritual (%)	Practical (%)	Physical (%)	Emotional (%)	Psychological (%)	Social (%)	*M* (%)
Group	1	7	6	1	12	7	8	6
Written	17	13	11	15	22	17	10	15
1-on-1	24	8	9	18	27	21	21	18
No help	64	76	79	73	53	52	71	67

Notes.
M = mean of desire for the service format across all need domains

subscales (Vaginal Changes Scale and Sexual Function Subscale) only apply to women who were sexually active within the past month (n=39), and other columns apply to the full sample (N=113). Sexual health needs and desire for help were highly, but not perfectly, correlated ($r = .65$, $p \leq .001$). Greater sexual health needs were positively associated with several SVQ subscales, including higher scores on the Vaginal Changes Subscale ($r = .61$, $p \leq .001$) and decreased scores on the Sexual Function Subscale ($r = 0.59$, $p \leq .001$). Greater sexual health needs were also associated with socio demographic and medical variables, including younger age ($r = -.42$, $p \leq .001$), chemotherapy treatment ($r = .23$, $p \leq .01$), and pre-menopausal status ($r = -.27$,$p \leq .01$).

As with sexual health needs, greater desire for help with unmet sexual health needs was associated with higher scores on the Vaginal Changes Scale ($r = .48$, $p \leq .01$), younger age ($r = -.36$, $p \leq .001$) and pre-menopausal status ($r = -.23$, $p \leq .05$), as well as lower scores on the Global Sexual Satisfaction Scale ($r = -.33$, $p \leq .001$).

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 = .434,$p \leq .01$), and lower scores on the Global Sexual Satisfaction Scale (r = -.22, $p \leq .05$), and Sexual Function Scale (r = -.34, $p \leq .05$).

Table 5

Correlation Matrix of Sexual Health, Sociodemographic, and Medical Variables, N = 113[3]

		1	2	3	4	5	6	7	8	9	10	11	12
1	Sexual needs[1]	-											
2	Help with sexual needs[1]	.65***	-										
3	Chemo	.23*	.09	-									
4	Civil status	.20*	.09	-.06	-								
5	Menopause	-.27***	-.23*	.06	-.01	-							
6	Years since tx	-.04	-.05	-.19	.06	-.20*	-						
7	Intimacy[2]	-.01	-.13	.16	.26**	.00	.12	-					
8	Satisfaction[2]	-.51***	-.33***	-.22*	.12	.13	.10	.07	-				
9	Vaginal changes [2]	.61***	.48***	.43**	-.07	-.11	-.20	-.28	-.51***	-			
10	Sexual function[2]	-.59***	-.30	-.34*	.15	-.25	.05	.23	.46***	-.46**	-		
11	Sexual interest[2]	-.05	-.08	-.13	.18	-.21*	.23*	.38***	.12	-.43**	.58***	-	
12	Age	-.42***	-.36***	-.03	-.10	.64***	.05	-.19	.19	-.26	-.29	-.25*	-

Notes
* p ≤.05. **p<.01. *** p<.001. Correlates of the variable "Radiation" and "Surgery" are not displayed due to a lack of significant relationships between the variables of interest.
1 Sexual health needs domain score and desire for help with at least one sexual health item (Supportive Care Needs Survey – Gyne)
2 Subscales and items of the Sexual Health – Vaginal Changes Questionnaire
3 Subscales "Vaginal Changes" and "Sexual Function" had n=39 (sexually active women only)

Discussion

The current needs assessment explored unmet supportive care and sexual health needs, desire for help with needs, and service format preferences. Our results confirmed previous findings that psychosocial struggles are the most common unmet needs post-treatment (Steele & Fitch, 2008; Beesley et al., 2008; Hodgkinson et al., 2007). 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 I 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 ten unmet needs. On the SVQ, three quarters of the sample reported low or no sexual interest, and over half of sexually active participants experienced problems with, and distress related to, sexual function.

Symptoms Versus Need

As recommended by Bancroft, Loftus, and Long (2003), our measurement of sexual health needs 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. First, whereas 67% of the sample reported at least one sexual health problem on the SVQ, a smaller proportion (40%) reported they felt "worried" about their sex life, and a similar proportion (36%) reported difficulty with sexual health changes on the SCNS-gyne. Second, 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 50% were bothered by it. Individual factors such as utilisation of symptom management strategies and resources may explain this difference; for instance, perhaps the 20% who experienced dyspareunia but were not distressed since they utilized lubrication as needed.

Many assessments and intervention studies in the general and oncologic population have focused on single measures of sexual function (e.g., frequency of intercourse) without assessing distress. Qualitative work has also 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, Lefebvre, Jolicoeur, Maheu, & Lebel, 2012); findings from this 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 factors) and their perception of "ideal" sexual health (based on personal characteristics and beliefs, cultural factors, etc.). Finally, recent qualitative work by Sekse, Gjengedal & Raheim (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

Our study is the first published effort to evaluate desire for help with supportive care and specific sexual health needs in a mixed gynecological cancer population. As demonstrated in Table 2, there was a high level of ambivalence toward receiving help with many needs; this was especially true with unmet sexual health needs as well as difficulties with not being able to "do the things I used to do". It seems that a relatively small number of women were open to receiving help, in comparison to the proportion of women who were worried about their sex life (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 health care provider(s), patients may be led to believe it is inappropriate to discuss these needs in the medical context (Hordern & Street, 2007; Butler, Banfield, Sveinson, & Allen, 1998); an impression that is not entirely unfounded, since many health care 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 health care team in initiating discussions about sexuality with patients as a regular part of cancer care (Wilmoth & Spinelli, 2000).

Research on help-seeking behaviour for sexual problems in the general female population may also be of assistance in interpreting these data. In the Global Study of Sexual Attitudes and Behaviors (GSSAB; Moriera et al., 2005), 79% of women did not seek help for a sexual problem; many women reported they assumed their problems were a normal part of ageing, or did not think their problem was medically-based and could be

improved through intervention. Along similar lines, gynecological cancer patients may feel that sexual dysfunction is beyond the scope of the oncologic team's mandate, and thereby feel it is inappropriate to discuss such issues in follow-up care. As help-seeking behaviours may depend on both health beliefs and cultural factors, it is the responsibility of the health care team to communicate readiness to assist the patient in obtaining a better quality of life in the physical, psychosocial, and sexual realms.

Participants in this study described a strong preference for one-on-one consultations, especially 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 higher sexual health needs and desire for help with unmet sexual health needs are associated with younger age, pre-menopausal status at diagnosis, and greater 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 for this is that women may assume that this is not a medically-based problem worth discussing with the health care 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, there was a significant association between the Global Sexual Satisfaction Scale (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 their actual level of sexual response.

The observed relationship between age and sexual interest is not unique to women with cancer. With the exception of low sexual interest (which tends to increase with age in women), younger women may be more likely to experience sexual problems, possibly related to inexperience and a higher frequency of new and developing relationships (Laumann, Paik, & Rosen, 1999). Understandably, younger women with cancer experiencing these factors as well as treatment-induced menopause and vaginal changes may experience high distress. Due to 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.

Our data show effects of chemotherapy on sexuality, but not radiation. While it is known that radiation causes significant vaginal changes, perhaps the over-representation of ovarian cancer patients (who typically receive surgery and chemotherapy) masked this association. Further, the radiation therapy 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 and Future Directions

Unfortunately, information on the women who declined participation was not collected. However, our findings regarding sexual difficulties are similar to recent studies

(Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004; Jensen et al., 2004b), which suggests that our results are generalizable to the targeted population. Given our participant demographics, our results are likely limited to a middle class, middle aged Caucasian population. 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 due to its concise and specific evaluation of sexual problems, distress, and perceived changes in sexuality since the cancer diagnosis. The higher proportion of women with ovarian cancer may mean that higher rates of difficulties and distress were measured (due to more advanced stages at diagnosis).

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 physiological sexual response. Also, pre-diagnosis 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 recent study of sexual health in vulvar cancer survivors found that optimism significantly predicted sexual function (Hazewinkel et al., 2012). Previous literature has also identified enduring post-treatment physical symptoms (e.g., chronic fatigue, Vistad, Fossa, Kristensen, & Dahl, 2007; lymphedema, Bergmark, Avall-Lundqvist, Dickman, Henningsohn, & Steineck, 2002) and other distressful practical concerns (e.g., family roles, finances; McCallum et

al., 2012) which may affect sexual health variables (such as desire/arousal) and desire for help. These results emphasize the importance of evaluating patient needs within a comprehensive network. Finally, partner's sexual response is an important factor. Over one third (38%) of the women indicated their partner had experienced difficulty with sexual arousal, and one-fifth indicated their partner had no desire for sexual contact. Future research with higher statistical power could explore the relative contribution of these groups of predictors.

Conclusion and Implications

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. Whereas many of the patient services in the program are group-based (e.g., workshops, support groups), patients clearly described a preference for discussions with a health care professional. . Our 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.

Given the nature of their contact with gynecological cancer patients through treatment and follow-up care, nursing staff have an invaluable role in assessing and addressing patient needs. Wilmoth & 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, while all members of the health care 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.

This assessment of sexual health needs as a unique supportive care need domain was fruitful and reiterated the importance of comprehensive evaluations. Screening and intervention planning should focus on a wide spectrum of post-treatment difficulties. The currently administered screening tool (Edmonton Symptom Assessment Scale; Chang, Hwang, & Feuerman, 2000) at the involved institution is a brief measure of common physical symptoms as well as subjective depression, anxiety, and well-being. While this form includes space for "another problem", the current study findings and 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 health care professional about sexual health needs. As needs were higher closer to treatment, a more comprehensive screening tool designed specifically for patients terminating treatment (for example, the Pearlman Mayo Survey of Needs; Schlairet, Heddon, & Griffis, 2010) could be administered at the transition between end of treatment and follow-up care.

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 of sexual health may be discussed, for instance, with an emphasis on expanding one's views of intimacy beyond the scope of intercourse.

To maximize quality of care, health care providers should receive training on (a) effective and efficient procedures for initiating conversations about sexuality and normalizing difficulties (Wilmoth, 2007; Fitch, 2003), and (b) the most frequent post-

treatment needs, desire for help and potential barriers (the current study, McCallum et al., 2012; Steele & Fitch, 2008), and (c) potentially at-risk populations (Donovan et al., 2007; Andersen, Woods, & Copeland, 1997; Hodgkinson et al., 2007; Beesley et al, 2008). In order to facilitate referrals to specialists in sexual health care, a general knowledge base of etiology and treatment modalities would also be helpful (e.g., as described in Krychman & Millheiser, 2013). While all members of the health care team should have a basic knowledge of these dimensions, to ensure the quality and continuity of care and it would be helpful to provide advanced training to specific individuals (e.g., selected nurses) who would be responsible for evaluating and addressing patient concerns.

Whereas these recommendations are tailored to the specific cancer centre in question, these findings on sexual health needs, within the framework of supportive care needs, are certainly applicable to a wider context and they have implications for the advancement of research on the screening and treatment of post-treatment difficulties in the gynecological cancer survivor. It is hoped that these results and directions for further research will be helpful in the continued movement toward comprehensive care in cancer survivorship.

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General Conclusion

Review of Context and Study Rationale

These three manuscripts report findings on data from a mixed-methods study exploring gynecological patients' needs following treatment, with a focus on sexual health. This research was conducted in collaboration with a team of health care professionals and researchers at the Gyne-Oncology Program of The Ottawa Hospital. This program's mandate is to provide holistic patient care with a commitment to understanding quality of life issues; along these lines, this work was part of a multidisciplinary effort to evaluate patient needs and inform the development of services provided in cancer survivorship.

Prior to developing this plan of study, a thorough literature review explored various facets of gynecological cancer survivorship including overall quality of life, sexuality, predictors of unmet needs, and intervention studies to improve sexual health in gynecological cancer survivors. This study was then designed with the intention of addressing gaps in this literature which included; (a) inconsistent descriptions of sexual health which focused on physiological aspects of sexual response; (b) a limited understanding of patient's sexual needs relative to other supportive care needs; (c) a paucity of information on barriers to accessing services (i.e., unexplained low response rates and high attrition); (d) little research exploring desire for help with supportive care needs; (e) no research on format preferences for supportive care and sexual health needs; (f) limited research on predictors of supportive care and sexual health needs and desire for help with these needs. In view of the Gyne-Oncology Program's mandate and these identified gaps, this study was conducted with the intention of providing clinical implications for program development while making a meaningful, original contribution to the literature on supportive care and sexual health needs in gynecological cancer

patients. The current conclusion will reflect upon an amalgamation of the findings, followed by a consideration of the study's strengths, limitations, and research and clinical implications.

Sexual Health and Supportive Care Needs: Symptoms Versus Needs

Both studies' results illustrated the advantages of evaluating a complete spectrum of supportive care needs following cancer. Whereas follow-up care generally focuses on patients' physical well-being, in these studies women's difficulties appeared to be predominantly psychosocial and sexual. In the survey study, existential worries about cancer recurrence, death, and dying were the most prevalent unmet needs, followed by different concerns about adapting to changes in daily living and in interpersonal/sexual relationships. The comprehensive assessment of sexual health needs within the Supportive Care Framework allowed for a clearer portrait of the relational and sexual health challenges potentially experienced after treatment.

The presence of significant fear of cancer recurrence may overlap with problems in the sexual realm; for instance, some women fear that sexual intercourse may increase their chance of having a recurrence, or of transmitting the cancer to their sexual partner (Tangjitgamol et al., 2007; Saewong & Choobun, 2005). Unmet physical needs may also overlap with sexual health difficulties; for instance, 65% of the sample reported difficulty due to lack of energy and/or fatigue. In another study, chronic fatigue was significantly associated with higher reports of vaginal dryness and dyspareunia, sexual inactivity, and depression and anxiety after gynecological treatment (Vistad, Fossa, Kristensen, & Dahl, 2007), demonstrating the co-morbidity of post-treatment symptoms.

Whereas many health care practitioners assume that physical sequelae of treatment decrease gradually over time, our findings suggest that unmet sexual and social needs endure. While this interpretation is limited by the cross-sectional design used in the

survey study, women with both shorter and more extended times since treatment reported similar (moderate to high) levels of unmet sexual health and social needs. These results support findings that cancer patients' psychosocial and sexual needs are often neglected (Gott, Hinchliff, & Galena, 2004). Longitudinal research on supportive care needs over time could further explore these findings.

Results from both studies point to the importance of evaluating and treating sexual health difficulties with patient perceptions of the symptom and their distress at the forefront. In study 1, each participant provided a unique description of healthy sexuality and its physical, interpersonal, and emotional facets. While sexual response was a necessary component of sexual health for many participants, having a sense of connection, a healthy body image, and a positive sexual self-schema was of equal or superior importance for most participants in the qualitative study.

Furthermore, whereas women of all ages reported a similar level of sexual health needs, younger age predicted desire for help with sexual health needs. This suggests that experiential and contextual factors related to individual factors such as age contribute significantly to the sexual satisfaction and perception of need for help. Finally, in line with these results, some women reported significant sexual function and vaginal changes, but little or no related distress. Therefore, women with comparable physical post-treatment symptoms reported different interpretations of the symptoms as being problematic or not with regard to their sexual relationships and well-being, again highlighting the subjective nature of satisfaction and needs. Together, these findings reflect the importance of one's personal beliefs, characteristics, context, and expectations and 'ideals' of sexual health in the development of a perceived need.

Previous quality of life research has demonstrated that, throughout the cancer jouney, many patients experience a response shift where their internal standards and core

values shift significantly; for example, some patients who experience significant physical limitations report a quality of life that is similar to the quality of life reported in the general population (Sprangers & Schwartz, 1999). This constitutes further evidence that individual perceptions, expectations and characteristics are closely related to well-being and distress. The transactional model of stress and coping (Lazarus & Folkman, 1984) may also be useful in understanding the symptom/need discrepancy. The model delineates a process in which each situation undergoes a primary appraisal regarding the meaning of a situation and its potential threat (limitations, suffering, loss, consequences) followed by a secondary appraisal of one's perceived capacity to overcome this challenge and/or to obtain adequate resources to overcome it. Based on this model of stress and coping, women may experience higher distress (and, therefore, a perceived unmet need) when post-treatment symptoms are considered more invasive and threatening, and/or when the patients feel incapable of managing their symptoms and obtaining adequate help. Further research integrating the response shift and/or transactional model of stress and coping would be helpful in understanding the patients' journey.

The practice of evaluating distress as a vital component of sexual dysfunction is young, both in the oncologic and general populations. Based on a large-scale prevalence study in the United States, the American Foundation of Urologic Disease has recently stressed the importance of including symptom-related distress as a criterion in diagnosing sexual dysfunction (DeRogatis & Burnett, 2008). In the field of psychosocial oncology, a small number of manuscripts have promoted the application of a multifaceted conceptualisation of sexuality in gynecological cancer patients (Weijmar Schultz & Van de Wiel, 2003; Cleary & Hegarty, 2011). Despite these efforts, little published work demonstrates the practical application and validation of such models. This study's comprehensive approach is coherent with these conceptualisations of sexuality and the

results led to an amalgamation of two models of sexuality, Weijmar Schultz and Van de Wiel's conceptualisation of sexuality (2003), and Cleary and Hegarty's Neotheoretical Framework of Sexuality (2011). It is hoped that this model can be applied, 1) in education to promote health care provider awareness of sexual health needs and their complexity, 2) as a model for research on predictors of sexual health needs, and 3) In the development of future interventions.

Describing and Predicting Needs and Desire for Help

Our qualitative and quantitative studies provided complementary findings regarding levels and predictors of need and desire for help with unmet needs. Sexual health needs were reported by many patients, but several other concerns also persisted with regard to existential struggles and adapting to daily life after treatment. As fear of cancer recurrence is well-documented as a primary concern of many cancer survivors, several authors involved in this study are also currently piloting an intervention to assist gynecological cancer survivors with fear of cancer recurrence.

Based on the interview and survey data, many women with sexual health needs desired help but were not accustomed to discussing sexuality; some women reported they were uncomfortable discussing sexuality even with their partner. Given these qualitative findings, paired with an obvious preference for one-on-one consultations, it is unsurprising that group-based services and programs experience recruitment challenges. Patients expressed a need for a more personalized, intimate atmosphere in which patients can discuss problems that are meaningful to them.

The most consistent and significant predictor of sexual health needs was age, with the younger participants being at a higher risk for post-treatment morbidity. In our multivariate analyses, younger women reported more difficulty with issues in the psychosocial, informational and spiritual domains, and were significantly more likely to

desire help with emotional and sexual health needs. Along similar lines, in our correlational analysis in sexually active women, younger age was significantly associated with lower sexual interest, but not specific vaginal changes, suggesting that the meaning or implications of vaginal and sexual health changes may differ in younger women.

Our qualitative work suggested that women's distress related to sexual and vaginal changes varies considerably based on personal factors, such as attributions of the relative importance of physical contact, emotional intimacy and sexual intercourse. In the needs assessment, women of all ages experienced sexual function and vaginal changes, but only a third described a clear desire for help. Whereas some felt uncertain, others did not want to seek help. In the qualitative study, some reportedly had adapted their expectations surrounding sexuality and were satisfied with intimacy that involved other forms of physical and emotional closeness. Therefore, when exploring patient barriers to accessing services, it is crucial to consider whether the patient is motivated in seeking help and faced with barriers, or if they are content as they are. Some patients may simply want information to manage the physical discomfort of vaginal changes, while others may be more emotionally distressed about psychological and sexual facets (e.g., loss of femininity, body image, not fulfilling one's role as a sexual partner). Measures of coping strategies used to manage post-treatment distress may provide a clearer understanding of differences between patients who desire help and those who don't as well as patients who are most likely to surrender to barriers. For instance, perhaps patients who adopt a problem-focused approach may be more likely to overcome (or not experience) barriers; while others who apply emotion-focused strategies may be less likely to seek help and overcome barriers.

From a medical perspective, time since treatment is intuitively a likely predictor of post-treatment symptoms, since the more obvious physical symptoms related to cancer

and its treatment are expected to naturally subside over time (e.g., nausea, hair loss). A recent review of overall quality of life concluded that, approximately one year post-treatment, most gynecological cancer survivors demonstrate an overall quality of life that is comparable to non-cancer controls (Pearman, 2003). However, as previously mentioned, other studies have indicated that more specific aspects of post-treatment suffering (e.g., fear of cancer recurrence; Crist & Grunfeld, 2012) can persist long after treatment. It is possible that portraits of patient distress over time may vary depending on the approach chosen in evaluating patient well-being (i.e., patient quality of life versus unmet supportive care needs and specific concerns or worries).

Despite the lack of longitudinal data, it was interesting to observe levels of need domains at varying intervals of time since treatment to understand the different needs that may be expressed across the cancer survivorship trajectory. In our multivariate analysis, time since treatment most significantly predicted spiritual, emotional, and psychological needs. On the other hand, levels of physical, sexual, and social needs were not significantly associated with time since treatment. Physical needs were lower compared to other need domains in women at all post-treatment time points, which suggests physical needs were probably addressed after treatment and in follow-up. On the other hand, the more frequently endorsed sexual and social domains were relatively equally elevated in women across the distribution, suggesting these issues remained present and unaddressed. Whereas one would expect the presence of vaginal changes and other problems to be higher in women recently treated, results of study 2, part 2 suggested that only sexual interest was correlated with time since treatment (where recent treatment was associated with lower sexual interest). Overall, these findings suggest that patients experience a significant need for support in many non-physical domains following

treatment, and, despite their cross-sectional nature, results point to the presence of sexual and social unmet needs up to several years after treatment.

A third noteworthy predictor variable identified in this research was chemotherapy treatment. Interpretations of these results are made with caution, since significance at a Bonferroni-corrected level was not attained; however, many results approached significance and point to a need to further investigate the unmet needs of this patient subgroup. While some research has explored post-chemotherapy struggles (most with a focus on induced menopause, infertility, and other effects of the chemotherapy; Lagana et al., 2005; Schover, 2012) radiation has been a more popular focus of post-treatment distress given considerable evidence of vaginal stenosis, atrophy, and related sequelae (Jensen et al., 2004) . In the current study, chemotherapy predicted more unmet sexual health needs and increased readiness for help with sexual health needs; moreover, it was associated with scores on the SVQ subscales measuring sexual satisfaction and vaginal changes. Due to our conservative alpha level, further research is required to validate these findings. Radiation therapy, on the other hand, did not correlate with sexual health or vaginal changes, nor did it predict needs or desire for help in multivariate analysis. As described in our discussions, it is possible that many of these patients' needs were addressed by staff, given a significant increase in attention paid to these difficulties in radiation patients in the program. Further, radiation therapy alone was a rare treatment modality in this sample, which had an over-representation of ovarian cancer patients. These results may better represent the needs and preferences of women treated for ovarian cancer, and/or with chemotherapy.

Despite these careful interpretations, these findings suggest that chemotherapy has important implications regarding women's sexual and social concerns. Most common themes related to chemotherapy in the literature are coping with a changing self-concept

following premature menopause and physical changes such as weight gain; furthermore, the fatigue and physical challenges of chemotherapy are likely to affect women's abilities to fulfill their roles as mothers, workers, and partners in the same way they did pre-diagnosis. Paired with the finding that worries about the concerns of loved ones are endorsed amongst the top needs, these recurring themes of distress demonstrate that women are considerably affected by the implications of cancer on their ability to fulfill their roles in the interpersonal and family realms.

Overall, our findings on predictors can possibly be further understood with consideration of some important work which was published while the current study was being conducted. Carpenter, Andersen, Fowler, and Maxwell (2009) explored determinants of post-treatment sexual and psychological morbidity (e.g., depression), and reported that that sexual self-schema (i.e., a cognitive representation of one's sexual self) significantly predicted patient reports of sexual behaviour, responsiveness, and satisfaction following treatment; that is, women who had more positive self-schemas were less likely to report sexual problems after treatment.

These findings corroborate with reports from large-scale studies in the general female population, where women who placed greater importance on sexuality were less likely to experience low desire, low arousal, and low orgasmic function (Hayes et al., 2008). These authors proposed that these women may be more motivated to seek solutions to sexual concerns that arise; alternatively, perhaps women who have lower sexual response adapt by placing greater importance on other aspect of their lives and relationships. Indeed, this phenomenon was observed in our qualitative study, where some participants indicated they had chosen to accept their changes in sexual arousal and focused instead on physical and emotional intimacy. Together, these findings emphasize

the utility of further exploring psychological predictors in describing needs and desire for help post-treatment.

Limitations and Future Research Directions

From this study proliferated a rich description of the experiential facets of sexual health and the path toward wellness after cancer. Our needs assessment is the first to examine sociodemographic and medical predictors of both supportive care needs and desire for help, and the second to observe supportive care and sexuality needs within a mixed gynecological cancer population. Contrary to previous studies which defined their outcome variable as "one or more unmet need", the current study measured needs as a continuous variable in order to preserve the variability and richness of this data.

Recruitment of participants receiving follow-up at the cancer centre was challenging and the anticipated timelines for recruitment were significantly extended. Regulations surrounding patient confidentiality prohibited graduate students and volunteers from approaching potential patients in order to introduce the study. Therefore, health care providers (i.e., nurses) were requested to include patient recruitment in their systematic follow-up care. Unfortunately, some found the task cumbersome and several adjustments were made over time to sustain motivation and enhance recruitment while minimizing interference with the daily routine of the health care team. Moreover, since the study was conducted at one cancer centre, saturation occurred every few months, where nurses reported that the patients they were seeing had already participated in the study, or had already declined participation. Therefore, recruitment was postponed for a period of time and, concurrently, motivation of the recruiters waned.

Given the multidisciplinary and challenging nature of participant recruitment, information on response rates are unavailable. Reasons non-participants declined participation are not available for analysis. Our comparison of cancer type proportions in

the sample and targeted population demonstrated an over-representation of ovarian cancer patients; these women may have been more likely to accept the offer to participate in the study. Characteristics potentially related to participation and non-participation in this study (e.g., higher distress, lower distress, sociodemographics) are unknown. However, sample demographics for this study were compared to those reported by a recent needs assessment with 802 respondents who participated in a population-based survey (Beesley et al., 2008). The two samples are similar with regard to age and civil status. The current sample has a higher proportion of high-income families and chemotherapy patients. Overall, our findings regarding the most prevalent unmet needs (e.g., fear of cancer recurrence, psychosocial and sexual concerns) are consistent with results in past needs assessments (surveying patients with all gynecological cancer types; Hodgkinson et al., 2007, Beesley et al., 2008; Steele & Fitch, 2008). Further, our findings on sexual function and vaginal changes (i.e., dyspareunia, vaginal dryness) very closely match reports of sexual difficulties in past studies of sexuality in larger samples of cervical (N=173; Jensen et al., 2004) and ovarian (N=232; Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004) cancer patients, suggesting that many sexual health difficulties are not contained to one single gynecological cancer type. Given these comparisons with the current literature, the current results are believed to be relatively representative of the targeted population. Due to the sample size achieved in the needs assessment, some initial research objectives had to be altered. It was hoped that cancer type would be included as a predictor of needs and desire for help, but too few women with the less common cancer types (e.g., vulvar cancer) were recruited to have adequate statistical power. Fortunately, we were able to include type of treatment in the analysis; it is possible that this variable accounts for a significant portion of variance that would have been shared by cancer type, which essentially dictates the treatment modality of patients.

Nonetheless, an exploration of cancer subtypes as predictors of patient needs and desire for help may have important implications regarding screening and treating patient distress.

Cross-sectional methods are commonly associated with a lack of information on baseline levels (e.g., pre-diagnosis sexual function) and on changes in observations over time. We must therefore rely on the patient perceptions of cancer and treatment-related changes. However, since the objective of the study was to evaluate perceived needs and distress (and not to document prevalence of sexual dysfunction), this reduces the concern of bias associated with this inherent limitation in the context of the current study.

Our findings on sexual health needs and desire for help have some differences, but many commonalities, with the general female population. A number of studies comparing gynecological cancer patients to matched controls reported that the former reported significantly lower frequency of sexual intercourse, lower sexual satisfaction, lower sexual arousal (evidenced by reduced vaginal blood flow), and greater reproductive concerns (Andersen, Lachenbruch, Anderson, & deProsse, 1986; Gershenson et al., 2007; Lindau, Gavrilova, & Anderson, 2007; Maas et al., 2004). Based on findings of the National Health and Social Life Survey (NHSLS; Laumann, Paik, & Rosen, 1999), the current sample reported higher rates of sexual impairment than those reported in the general population. On the NHSLS, women aged 50-59 reported fewer problems with low sexual interest (27%, compared to our rate of 76%), and vaginal dryness (27%, compared to our rate of 75%) and lower rates of pain (8%, compared to our rate of 55%). On the other hand, rates of difficulty reaching orgasm were similar (23%, compared to 22%). Our results on sexual difficulties cohere with a number of studies comparing gynecological cancer patients to healthy controls which suggest that, indeed, the former

report lower sexual responsiveness, lower sexual satisfaction, and greater sexual problems.

However, the above referenced prevalence studies failed to address self-identified sexuality problems, or symptom-related distress. Women in our study reported specific symptom related distress at levels which are higher than reports of the symptom's presence in the general population (e.g., 50% of women were "bothered by pain"); however, overall, only 36% reported moderate to high difficulty with sexual health changes, and 40% reported they were worried about their sex life. On the other hand, in Bancroft and colleague's study of sexual distress in healthy women (2003), only 15% reported "moderate" amount or "great deal" of stress or worry about their sexuality.

With this respect, it indeed appears that women in our sample were more distressed about their sexuality than women in the general population. However, the study by Bancroft, Loftus, and Long. (2003) also demonstrated that sexual distress was best predicted, not by reported sexual response, but by a lack of emotional well-being (e.g., depression) and negative feelings during sexual interactions. Considering the higher number of co-occurring concerns and worries reported by women in our studies (e.g., fear of cancer recurrence, worries about fulfilling one's roles), it is difficult to decipher which factors led them to report such a high level of worry and distress. Further investigation of the relationship between psychological and sexual well-being in women with gynecological cancer is a worthwhile research avenue.

The current study's modest sample size means we were limited in our choice of predictor variables to be explored. It is possible that some associations (e.g., with civil and/or menopausal status) were not detected due to the limited power in this analysis. Studies with higher statistical power could explore whether these factors as well as other types of predictors such as socioeconomic variables (e.g., rural/urban settings, work

status), education, and baseline psychological factors such as sexual self-schema add predictive value to these analyses.

Implications

Research Implications. Our analysis of predictors revealed some sociodemographic and medical predictors of unmet needs and desire for help and pointed to a need to further explain the remaining variance in needs and desire for help. Based on the literature, a future needs assessment could include measures of depression and anxiety (e.g., the Beck inventories; Beck, Steer, & Carbin, 1988; Steer, Beck, & Zalaquett, 1997), sexual self-schema (e.g., The Sexual Self Schema Scale for Women; Andersen & Cyranowski, 1994), relationship factors (e.g., Dyadic Adjustment Scale; Spanier & Thompson, 1982), and sociodemographic questions on cancer, stage of cancer at diagnosis, and socioeconomic variables. A short form of the SCNS (Schofield, Gough, Lotfi-Jam, & Aranda, 2012) could be administered to allow more time for the completion of these other measures without compromising response rates. To improve response rates, individuals who will be implicated in patient recruitment should be involved in one or more formal research team meetings where the study rationale and the significant value of their role are emphasized. In order to obtain greater statistical power for these analyses, a larger sample would be required; given the unavoidable phenomenon of participant saturation in a single center, a multi-center study would be ideal.

In data analysis, the associations between these predictors could be structured in grouping variables by type. These groups could be entered in steps (e.g., medical variables, sociodemographic variables, psychological variables) to better comprehend the predictive value of each block; if steps are significant, the individual predictive value of specific variables (e.g., cancer type) could be investigated. This type of research would further clarify the importance of contextual, relational and psychological factors in

predicting needs and desire for help, thereby facilitating the identification of at-risk patients an developing services to target their needs.

Clinical Implications. The goal of this work was to develop and test a group intervention. An unexpectedly long recruitment period as well as the described results pointed our research team in a new direction. Women's unique and varying definitions of sexuality as well as their clear preference for one-on-one and written forms of support demonstrated a need to not only screen for, but treat, each patient's needs individually.

It would be beneficial to offer patients greater assistance with spiritual, sexual, and psychosocial needs immediately following treatment, when they are in a "transition" between the treatment and follow-up phase. An example of a tool specifically designed for assessments at this point in the cancer trajectory has been provided (Pearlman Mayo Survey of Needs; Schlairet Heddon, & Griffis, 2010). Depending on the center's model of care, a member of the patient's health care team (e.g., a registered nurse) could be designated the task of meeting these patients, screening for needs, and discussing any identified problems. Whereas some sexual problems may qualify as symptoms of sexual dysfunction and can be a result of treatment, other sexual impairments are related to relationship, psychological, and other peripheral difficulties for which patients require help. If the nature of these problems is beyond the scope of nursing, the nurse can offer empathetic guidance toward the appropriate services, with the patients' preferences and identified barriers in mind.

Since patients may express needs at any point in the cancer trajectory, the entire health care team should be aware of the variability in needs, including the impact of treatment on women's' self-concepts, gender roles, and interpersonal relationships. Younger women and chemotherapy patients may be more likely to struggle with these themes, which shape their identity as women, mothers, and partners. It is imperative that

health care providers recognize these challenges which transcend the physical symptoms that women experience in terms of distress and duration. Anxiety surrounding these themes may affect women at any point of the trajectory (e.g., in deciding treatment modality, which may impact fertility), so it may be necessary to detect these struggles and provide support before and/or after treatment. Given the significant and enduring nature of sexual and social needs, it would be pertinent for health care providers to offer patients the opportunity to include their partners in informational and supportive services, as well. This possibility could be introduced during one-on-one discussions of the patients needs.

Finally, many women may not desire help from their health care team; some participants associated the hospital with the traumatic cancer experience and reported the hospital setting had become aversive. Certainly, supportive care can be provided not only by health care providers but also community agencies, and family and friends. As such, the health care system can play the role of acting like a hub by referring patients not only to other health professionals but also connecting them to different community resources. However, to be able to accomplish this task, health care providers must be able to recognize and address patient needs. Further dissemination of these study results will center on assisting physicians and nurses in developing communication skills to effectively and empathetically identify a problem and, when appropriate, refer the patient to the appropriate services. Overall, these findings have made a meaningful, concrete contribution to survivorship care in the Gyne-Oncology Program of The Ottawa Hospital, and it is hoped that these findings will promote further research on comprehensive care in cancer survivorship.

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Appendix A

Consent Form, Study 1

uOttawa

The Ottawa Hospital
L'Hôpital d'Ottawa

Informed Consent Form for Participation in a Research Study

Defining and improving sexuality in women treated for gynecological cancers: A qualitative exploration

Principal investigator: Dr. Monique Lefebvre, *The Ottawa Hospital*

Introduction

- The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time.
- In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the **informed consent process**.
- Please ask the interviewer to explain any words you don't understand before signing this consent form. **Make sure all of your questions have been answered** to your satisfaction before signing this document.

Purpose

- This study is designed to explore how the experience of gynecological cancer and its treatment influence women's lives.
- **We hope to gain a better understanding of how women's quality of life and sexuality are affected by the cancer experience.** This information will contribute to the development of educational and psychotherapeutic interventions for women treated for gynecological cancer.

Procedures

- You will be asked to participate in an interview with a member of the research team. During the interview, the interviewer will ask about your experience with cancer and treatment and their impact on your life.
- **Duration of interview**: 30 -60 minutes
- The interview will be audiotaped in order to allow for the transcription of the interview.
- **If you consent to being re-contacted**, the researchers will offer you the opportunity to read and comment on a summary of the study findings.

Risks

- **Psychological support is available** in the program for any participant who is having difficulties. If you feel you need psychosocial support at any point in time, you may contact Dr. Monique Lefebvre, who is staff psychologist in the Gyne-Oncology Service (see end of consent form for contact information).
- You will be asked questions about your personal experiences with cancer and issues revolving around your sexuality. There is very little risk associated with this study

- However, most patients experience mild discomfort or shyness at discussing their cancer experience or sexuality.

Benefits

- There are no medical or financial benefits from your participation in this study. However, individuals with health problems sometimes find it helpful to think and talk about their disease and its impact on their lives in the context of interviews relating to these issues.
- Information learned from this study will contribute to the development of effective educational and psychotherapeutic interventions for women who have been treated for a gynecological cancer at the Ottawa Hospital. Your answers, combined with those of others, will help inform our team on the emotional experience of cancer and will help health care professionals provide more compassionate care.

Participation

- ***Your participation in this study is voluntary.*** *You are free to abstain from answering any questions or to withdraw from the study at any time without affecting your health care. If you choose to terminate the interview earlier or withdraw from the study, you are under no obligation to provide the investigator with a reason. You will receive the same high quality medical care regardless of whether you participate in this study or not.*

Confidentiality

- All personal information obtained during the study will be held in strict confidence, unless release is required by law. Your consent form will be kept separately from your interview transcript and no identifying information will be added to your transcript.
- Your records will never leave the hospital. No names or identifying information will be used in any publication or presentations, and you will be identified with a study number.
- Representatives of the Ottawa Hospital Research Ethics Board, the Ottawa Health Research Institute, and the Social Sciences and Humanities Research Ethics Board of the University of Ottawa may review your record for audit purposes. The study data will be kept for 15 years after termination of the study.

Questions:

If you have any questions about the study, please call the principal investigator of the study, Dr. Monique Lefebvre. If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at XXX-XXX-XXXX. The Chairperson is not involved with the research project in any way, and calling him will not affect your participation in the study.

Contact Information:
Dr. Monique Lefebvre: XXX-XXX-XXXX
Dr. Sophie Lebel: XXX-XXX-XXXX

uOttawa

The Ottawa Hospital

Defining and improving sexuality in women treated for gynecological cancers: A qualitative exploration

Participant Consent:

I have read this 3-page consent form and have had the opportunity to discuss this study. My questions have been answered to my satisfaction. I consent to take part in the study with the understanding that I may withdraw at any time without affecting my medical care. I will receive a signed copy of this consent form. I voluntarily consent to participate in this study.

_____	_____	_____
Participant's Name *(Print)*	**Participant's Signature**	**Date**

I would like to receive a summary of the study's final results.

_____	_____	_____
Participant's Name *(Print)*	**Participant's Signature**	**Date**

Investigator/Delegate Section:

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

_____	_____	_____
Investigator/Delegate *(Print)*	**Investigator/Delegate Signature**	**Date**

Appendix B

Interview Guide, Study 1

Defining and improving sexuality in women treated for gynecological cancers: A qualitative exploration
Interview Guide

Note: The following questions are a general guide to topics that should be addressed within the interview. The interviewer is not limited to the following order or exact phrasing of the questions.

1. Introduction: questions about general demographics, diagnosis/treatment, their perception of "how they are doing" now to gain a basic understanding of their current level of functioning (e.g., occupation, household work, social network) and overall perceived quality of life.

2. As you know, this study is about sexual health changes after treatment for a gynecological cancer. Can you tell me about any impact that this experience might have had on you?

3. *Reflect the main points they mentioned*. How did or do you/the two of you deal or cope with this?

4. Ideally, what would you like your sexuality to look like now? Or: "What does it mean to you, to be 'sexually healthy'?"

5. For many patient populations the hospital offers a variety of informational services like pamphlets or information sessions for patients and their family. What types of informational services do you think would be helpful to women who have been diagnosed with and treated for a gynecological and have difficulties similar to yours?

6. The hospital also offers psychological or emotional support services such as individual therapy or support groups. What types of psychological services do you think would be helpful to women who have been diagnosed with and/or treated for a gynecological cancer?

7. Can you tell me about some things that discouraged you or might discourage you (or someone else; adapt based on their story) from participating in these types of services, or that might act as barriers to participation? (Prompt about sexual health services specifically if not addressed)

Appendix C

Consent Form, Study 2

uOttawa

The Ottawa Hospital
L'Hôpital d'Ottawa

Informed Consent Form for Participation in a Research Study

Women treated for a gynecological cancer: Support and intimacy needs

Principal investigator: Dr. Monique Lefebvre, *The Ottawa Hospital*

Introduction

The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study, as well as your right to choose not to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process.

Please call the research assistants if you have any questions or concerns about the study and make sure that all questions have been answered to your satisfaction before completing this questionnaire. By completing and returning this questionnaire to the research team, you are indicating that you have read, understood, and agree with the content of this informed consent form.

Purpose

This study is designed to measure unmet needs expressed by women who have received treatment for a gynecological cancer at The Ottawa Hospital.

Study Procedures

You will be asked to complete a questionnaire package including: 1) General questions about yourself (e.g. age, marital status, cancer site, etc.), 2) questions about your unmet needs (e.g. information, psychological support, etc.), and 3) questions about sexual health-related difficulties experienced after treatment. The questionnaire will take approximately 30 minutes to complete. You will be provided an addressed and pre-stamped envelope in which you may to return your completed questionnaire.

Risks

You will be asked questions about your personal experiences with cancer and issues revolving around your sexuality. Some patients experience mild discomfort or shyness at discussing their cancer experience or sexuality. You are under no obligation to answer any questions that make you uncomfortable. Psychological support is available in the program for any participant who is having difficulties. If you feel you need psychosocial support at any point in time, the research assistant will provide you with a referral to Dr. Monique Lefebvre, who is staff psychologist in the Gyne-Oncology Service (see end of consent form for contact information).

Benefits

There are no medical or financial benefits from your participation in this study. However, individuals with health problems sometimes find it helpful to think and talk about their disease and its impact on their lives in the context of interviews relating to these issues. Your answers, combined with those of others, will help inform our team in making improvements to patient care.

Participation

Your participation in this study is voluntary. You are free to abstain from answering any questions or to withdraw from the study at any time without affecting your health care. If you withdraw from the study, you are under no obligation to provide the investigator with a reason. You will receive the same high quality medical care regardless of whether you participate in this study or not.

Confidentiality

No identifying information (e.g., names) will be obtained during the study. As such, you may ensured that your rights to confidentiality and anonymitity will be protected. The received questionnaire packages will never leave the hospital. No identifying information will be used in any publications or presentations.

Representatives of the Ottawa Hospital Research Ethics Board, the Ottawa Hospital Research Institute, and the Social Sciences and Humanities Research Ethics Board of the University of Ottawa may review our study documents for audit purposes. The study data will be kept by the Principal Investigator in a secure location at The Ottawa Hospital for 15 years after termination of the study, after which all data will be electronically deleted or shredded.

Questions

If you have any questions about the study, please call the research assistants, Megan McCallum and Lyzon Babchishin, at: XXX-XXX-XXXX ext.XXXXX. For other concerns, including a request for psychological services, please contact the principal investigator of the study, Dr. Monique Lefebvre, at XXX-XXX-XXXX.

If you have any questions about your rights as a research participant, you may contact the Chairperson of the Ottawa Hospital Research Ethics Board at XXX-XXX-XXXX. The Chairperson is not involved with the research project in any way, and calling him will not affect your participation in the study.

Implied Consent

By completing the attached questionnaire and returning it to the research team, you are indicating that:

- You have read the Patient Information Sheet and this three-page Consent Form.
- You understand you have been asked to participate in a research study about supportive care and intimacy needs in gynecological cancer patients.
- You have contacted the research assistants in regards to any confusion, concerns, or questions you had about the study and they have resolved these issues and/or answered your questions to your satisfaction.
- You are aware that participation is voluntary, which indicates 1) you may chose to skip any questions you do not want to answer.
- You voluntarily agree to participate in this study.

Please keep this consent form for your records.

Appendix D

Needs Assessment Questionnaire Package

uOttawa

Part 1: Demographics

The Ottawa Hospital
L'Hôpital d'Ottawa

Please check the box corresponding to your answer or write your responses on the lines corresponding to each question.

1. What is your age? _____ years

2. What is your first language? _____

3. What do you consider to be your primary ethnic background?
   - ❑ White (Caucasian , European)
   - ❑ Black (African, Caribbean, American)
   - ❑ Native (Indian, Inuit, Métis)
   - ❑ Asian (Chinese, Japanese, Korean)
   - ❑ South Asian (East Indian, Pakistani)
   - ❑ South or Central American
   - ❑ Other_____

4. What is your civil status?
   - ❑ Single
   - ❑ Married
   - ❑ Cohabiting/living with intimate partner
   - ❑ Separated/divorced
   - ❑ Widowed

5. Do you have children?
   - ❑ No
   - ❑ Yes

   If you have answered "Yes", please answer the following questions:
   a) How many children do you have? _____
   b) How old are they presently?_____
   c) Do your child(ren) presently live at home with you? Yes___ No___

5. What is your main activity
   - ❑ Caring for my family (homemaker)
   - ❑ Working (paid or volunteer) and caring for family
   - ❑ Looking for work
   - ❑ Retired
   - ❑ Unable to return to my normal activity due to my illness
   - ❑ Other_____

6. What is the highest level of education you have completed?
   - ❑ No formal schooling
   - ❑ Primary school
   - ❑ Secondary or high school
   - ❑ College/professional program
   - ❑ University

7. In which of the following ranges does your total household income lie (before tax)?
   - ❑ Less than $20,000
   - ❑ $20,000-$39,999
   - ❑ $40,000-$59,999
   - ❑ $60,000-$79,999
   - ❑ $80,000-$99,999
   - ❑ over $100,000

8. In which region do you live? _____

9. You were diagnosed with which of the following type(s) of cancer?
   - ❑ Ovarian
   - ❑ Vulva
   - ❑ Endometrium
   - ❑ Cervix
   - ❑ Uterus
   - ❑ Other
     Please describe _____

10. Date of cancer diagnosis _____

11. Treatment received (please check all that apply)
    - ❑ Radiation
    - ❑ Chemotherapy
    - ❑ Surgery
    - ❑ Other

12. Prior to your cancer diagnosis, were you:
    - ❑ Pre-menopausal (still having menstruations)
    - ❑ Post-menopausal (no longer having menstruations)

13. End of treatment date _____

Part 2: Supportive Care Needs Survey

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
1. Vaginal Discharge e.g. blood, mucous	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue. ❑	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
2. Change in appetite	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
3. Abdominal Discomfort e.g. pressure, gases, bloating, increase in size	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
4. Pain	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
5. Lack of energy/tiredness	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
6. Nausea/vomiting	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
7. Leg edema (leg swelling)	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
8. Change in bowel pattern **e.g. diarrhea, constipation**	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
9. Changes in urinary function **e.g. frequency, pain, urgency**	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
10. Not being able to work around the home	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
11. Not being able to do the things you used to do	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
12. Clinic staff to convey a sense of hope to you and your family	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
13. The opportunity to talk to someone who understands and has been through a similar experience	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
14. To be given written information about the important aspects of your care	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
15. To be given information (written, diagrams, drawings) about aspects of managing your illness and side effects at home	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
16. To be given explanations of those tests for which you would like explanations	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
17. To be adequately informed about the benefits and side effects of treatments before you choose to have them	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
18. To be informed about your test results as soon as possible	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
19. To be informed about cancer that is under control or diminishing (that is, remission)	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
20. To be informed about things you can do to help yourself get well	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
21. To be informed about support groups in your area	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
22. To have access to professional counseling if you/family/friends need it	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
23. To be treated like a person, not just another case	❑ I did not **experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
24. To be treated in a clinic that is as physically pleasant as possible	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
25. To be given choices about when you go in for tests or treatment	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
26. To have one member of clinic staff with whom you can talk to about all aspects of your condition, treatment, and follow-up	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
27. Waiting a long time for clinic appointments	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
28. Family or friends to be allowed with you in clinic whenever you want	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
29. More fully protected rights to privacy when you're at the clinic	❑ I did **not experience**` this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
30. More choice about which cancer specialist you see	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
31. More choice about which clinic you attend	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
32. Reassurance by medical staff that the way you feel is normal	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
33. Clinic staff to attend promptly to your physical needs	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
34. Clinic staff to acknowledge and show sensitivity to your feelings and emotional needs	❑ I did not **experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
35. Talking to other people about cancer	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
36. Changes in people's attitudes and behaviour towards you	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
37. Concerns about your financial situation	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
38. Concerns about paying for prescription medications	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
39. Concerns about getting to and from the clinic	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
40. Changes in sexual feelings	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
41. Changes in your ability to have sexual intercourse	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
42. Changes in sexual relationships	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
43. To be given information about sexual relations	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
44. Fears about losing your independence	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
45. Confusion about why this has happened to you	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
46. Feeling bored and/or useless	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
47. Anxiety	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
48. Feeling down or depressed	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
49. Feelings of sadness	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
50. Fears about the cancer spreading	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
51. Fears about the cancer returning	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
52. Fears about pain	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
53. Anxiety about having any treatment	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
54. Fears about physical disability or deterioration	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
55. Accepting changes in your appearance	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
56. Worry that the results of treatment are beyond your control	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
57. Uncertainty about the future	❑ I did not **experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
58. Concerns about your care-giving role (i.e. being a mother, caring for elderly parents)	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
59. Concerns about fulfilling your role as a partner	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
60. Learning to feel in control of your situation	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
61. Making the most of your time	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
62. Keeping a positive outlook	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
63. Finding meaning in this experience	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
64. Feelings about death and dying	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help .
65. Concerns about the worries of those close to you	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Issue	Part A	Part B
	Are you experiencing this issue as a result of your cancer?	**Would you like help with this issue?**
66. Changes in usual routine and lifestyle	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
67. Concerns about the ability of those close to you to cope with caring for you	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.
68. Other _____	❑ I did **not experience** this issue. ❑ I experienced this issue but it has been **looked after**. ❑ I am experiencing a **low** level of difficulty with this issue. ❑ I am experiencing a **moderate** level of difficulty with this issue. ❑ I am experiencing a **high** level of difficulty with this issue.	❑ **No**, I do not want any help. ❑ **Yes**, I would like help. ❑ I feel **uncertain** about wanting help.

Part 3: Sexual Health – Vaginal Changes Questionnaire

Physical contact and sexual relations can be an important part of many people's lives. People who suffer from illnesses involving their pelvic region may experience changes in their sex life.

The questions below refer to this. The information you provide will remain strictly confidential.

Please answer all the questions yourself by circling the number that best applies to you.

Part A

During the past month:

		Not at all	A little	Quite a bit	Very much
1.	Have you been interested in close physical contact (a kiss and a cuddle)?	1	2	3	4
2.	Have you had close physical contact with your family and close friends?	1	2	3	4
3.	Have you had any interest in sexual relations?	1	2	3	4

		Yes	No
4.	Do you have a partner? (If not, please continue to **question 8**)	1	2

		Not at all	A little	Quite a bit	Very much
5.	Has your partner wanted to have sexual relations?	1	2	3	4

		No	Yes, 1-2 times a month	Yes, 3-4 times a month	Yes, 1-2 times a week	Yes, more than twice a week
6.	Have you had sexual relations? (If you have answered no to this question, please continue to **question 8**)	1	2	3	4	5

		Not at all	A little	Quite a bit	Very much
7.	Did your partner have difficulty achieving sexual arousal (i.e., lubrication/erection)?	1	2	3	4
8.	Has your sex life/lack of sex life made you worry?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you.

During the past month:

9. How satisfied or dissatisfied have you been with your sex life/lack of sex life

1	2	3	4	5	6	7
Very dissatisfied						Very satisfied

10. How satisfied or dissatisfied have you been with your appearance?

1	2	3	4	5	6	7
Very dissatisfied						Very satisfied

Please complete **Part B** if you have been sexually active during the past month.
If you have not been sexually active during the past month, please go on to P**art C**.

Part B
During the past month:

		Not at all	A little	Quite a bit	Very much
11.	Did you feel that your vagina was dry during intercourse?	1	2	3	4
11a.	If yes, has it bothered you?	1	2	3	4
12.	Have you had any pain during intercourse?	1	2	3	4
12a.	If yes, has it bothered you?	1	2	3	4
13.	Have you experienced bleeding during intercourse?	1	2	3	4
13a.	If yes, has it bothered you?	1	2	3	4
14.	Did you feel that intercourse was bothersome because your vagina felt too small	1	2	3	4
		Never	Occasionally	Often	Always
15.	Were you able to complete sexual intercourse?	1	2	3	4
16.	Have you reached orgasm?	1	2	3	4
		Not at all	A little	Quite a bit	Very much

17.	Did you feel relaxed after having sex?	1	2	3	4

Part C

The following questions are about your experience of any changes in your feelings and/or your sex life today compared to before you were diagnosed with cancer:
Please answer all the questions yourself by circling the number that best applies to you

		I am less interested now	It is unchanged	I am more interested now
18.	Has your interest in close physical contact changed since you were diagnosed with cancer?	1	2	3
19.	How much close physical contact do you have with your family and close friends compared to before you were diagnosed with cancer?	1	2	3
20.	Has your interest in sexual relations changed since you were diagnosed with cancer?	1	2	3

The following questions apply to you only if you have a partner:

		(S)he is less interested now	It is unchanged	(S)he is more interested now
21.	Has your partner's interest in sexual relations changed since you were diagnosed with cancer?	1	2	3

The following questions apply to you only if you are sexually active:

		It is less dry now	It is unchanged	It is dryer now
22.	Has the dryness of your vagina changed compared to before you were diagnosed with cancer?	1	2	3

		It is smaller now	It is unchanged	It is larger now
23.	Do you feel that the size of your vagina has changed since you were diagnosed with cancer	1	2	3

The following question apply to you only if you have experienced any pain during intercourse:

		I have less pain now	It is unchanged	I have more pain now
24.	Has the pain you experience during intercourse changed since you were diagnosed with cancer?	1	2	3

Part 4: Format Preferences

Part A. General Issues

Please circle the format of help you would prefer for the following issues (circle all that apply):

	No help wanted	Help in written form (e.g., brochures, pamplets)	One-on-one with a health professiona l	Group format (e.g., support groups)
1. Dealing with my spiritual difficulties (e.g., search for meaning, hope)	**1**	**2**	**3**	**4**
2. Dealing with my sexual difficulties (e.g., sexual changes, sexual desire)	**1**	**2**	**3**	**4**
3. Dealing with my practical difficulties (e.g., daily home help, financial needs, employment)	**1**	**2**	**3**	**4**
4. Dealing with my physical difficulties (e.g., pain, nausea, and/or other symptoms)	**1**	**2**	**3**	**4**
5. Dealing with my emotional difficulties (e.g., sadness, fear, uncertainty)	**1**	**2**	**3**	**4**
6. Dealing with my psychological difficulties (e.g., anxiety, depression, body image)	**1**	**2**	**3**	**4**
7. Dealing with my social difficulties (e.g., with social network, family, partner)	**1**	**2**	**3**	**4**

Part B. Use of a Vaginal Dilator

1. Was the use of a vaginal dilator recommended? Yes ____ No____
2. Would you have needed any specific help with the use of the dilator? Yes ____ No____
3. **If yes,** please check the format of help you would have preferred (check all that apply):
   - □ No help wanted
   - □ Help in written form (e.g., brochures, pamphlets)
   - □ One-on-one with a health professional

Part C. Comments or Suggestions

Do you have any comments or suggestions on ways to improve the experience of women diagnosed and treated with gynecological cancers?

Please take a moment to review the survey to ensure that you have completed all the pages.

Thank you very much for your help!