Sexuality in Irish Women With Gynecologic Cancer

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Purpose/Objectives: To investigate sexual self-concept, sexual relationships, and sexual functioning, and the relationship between these and certain demographic variables of Irish women, following a diagnosis of gynecologic cancer.

Design: Descriptive, correlational.

Setting: Outpatient gynecologic oncology clinic in a large university hospital in Southern Ireland.

Sample: 106 women with a diagnosis of and treatment for various gynecologic cancers (cervical, ovarian, endometrial, and vulvar).

Methods: The Body Image Scale, Sexual Esteem Scale, and Sexual Self-Schema Scale were administered to women a minimum of six weeks postdiagnosis of any form of gynecologic cancer to measure sexual self-concept; the Intimate Relationships Scale to measure sexual relationships; and the Arizona Sexual Experiences Scale to measure sexual functioning.

Main Research Variables: Sexual self-concept, body image, sexual esteem, sexual self-schema, sexual relationships, and sexual functioning.

Findings: Participants reported negative changes in relation to their sexual self-concept, sexual relationships, and sexual functioning. Participants reported negative changes in relation to all stages of the sexual response cycle.

Conclusions: Gynecologic cancer has the potential to negatively affect a woman's sexual self-concept, sexual relationships, and sexual functioning. Sexuality is a multidimensional construct and must be measured in this way.

Implications for Nursing: Healthcare professionals must use a holistic approach when providing information and support to patients with gynecologic cancer. Information must be provided to women on how cancer and its treatment has the potential to affect their sexual self-concept, sexual relationships, and sexual functioning, including information on how to overcome these alterations.

Advancements in cancer detection and treatment have led to increased survival rates among patients with cancer (Tierney, 2008), but cancer survivorship is associated with distressing long-term side effects that can negatively influence patients' sexual health (Stilos, Doyle, & Daines, 2008). According to the National Cancer Institute (2010), sexual dysfunction is the most common side effect of cancer treatment, affecting 50% of gynecologic cancer survivors. However, Sheerin and McKenna (2000) proposed that the nursing literature is lacking in a holistic conceptualization of sexuality that has contributed to a dominant focus on the physical aspect of sexual functioning with a neglect of broader dimensions of sexuality in nursing research. Nursing research exploring the sexuality of patients with a diagnosis of cancer within an Irish context is scarce (Lavin & Hyde, 2006). In addition, traditional Irish culture and the influence of strong religious beliefs may have contributed to the consideration of sexuality as a taboo subject among Irish women (Lavin & Hyde, 2006). However, since the mid-1990s, the influence of the Catholic Church has declined, resulting in a change of attitudes toward sexuality (Higgins, Barker, & Begley, 2009; Lavin & Hyde, 2006), enabling nurses and healthcare professionals in Ireland to address sensitive issues such as sexuality more easily.

Literature Review

A review of the literature surrounding the construct of sexuality in female cancer care highlights a lack of consensus. Although numerous definitions of the term sexuality exist (Butler, Banfield, Sveinson, & Allen, 1998; Krebs, 2006; Thaler-DeMers, 2001; Tierney, 2008), few theoretical frameworks aim to provide a deeper understanding of the construct of sexuality in cancer care. However, Woods' (1987) conceptualization of sexuality has been acknowledged by various researchers in cancer-related studies (Bruner & Boyd, 1999; Butler et al., 1998; Gamel, Hengeveld, & Davis, 2000). Woods (1987) proposed a multidimensional view of sexuality composed of three inter-related concepts: sexual self-concept, sexual relationships, and sexual functioning. Through an examination of empirical and theoretical literature surrounding sexuality in a female cancer

context, Woods' framework of sexuality was further developed by the current study's authors to create a neotheoretical framework of sexuality (see Figure 1). In this framework, sexual function was perceived to include the dimensions of the sexual response cycle (desire and arousal, excitement, and orgasm) (Kaplan, 1979); sexual self-concept was further divided into the dimensions of body image (Price, 1990), sexual self-schema (Andersen & Cyranowski, 1994), and sexual esteem (Snell & Papini, 1989). Finally, sexual relationships were perceived to include communication (Tierney, 2008) and intimacy (Hughes, 2000).

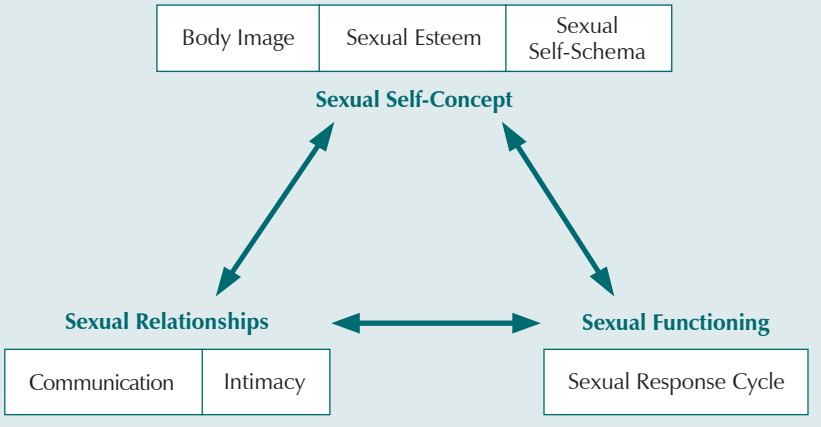

Figure 1. Neotheoretical Framework of Sexuality

Note. Based on information from Andersen & Cyranowski, 1994; Hughes, 2000; Kaplan, 1979; Price, 1990; Snell & Papini, 1989; Tierney, 2008; Woods, 1987.

Sexual Self-Concept

The negative effect that a gynecologic cancer diagnosis and its treatment can have on a woman's body image has been highlighted in many qualitative (Ekwall, Ternestedt, & Sorbe, 2003; Juraskova et al., 2003) and quantitative studies (Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004; Green et al., 2000; Liavaag et al., 2008; Stewart, Wong, Duff, Melancon, & Cheung, 2001). Issues relating to loss of femininity also have been highlighted (Chan et al., 2001; Juraskova et al., 2003), which is not unexpected because surgery for a gynecologic cancer could mean the loss of the uterus and associated structures that represent femininity, motherhood, and, ultimately, sexuality. Age has been found to be an important variable when assessing the body image of patients with gynecologic cancer. Juraskova et al. (2003) and Stewart et al. (2001) have noted that issues relating to altered femininity and body image were more common in younger patients with gynecologic cancer.

Physical changes caused by gynecologic cancer or its treatment can undermine a woman's self-esteem (Stilos et al., 2008). However, the concept of self-esteem is not unique to sexual behavior, which led Snell and Papini (1989) to focus on sexual esteem. Wiederman and Allgeier (1993) proposed that sexual esteem is a person's evaluation of him- or herself as a sexual partner; an important variable when assessing sexuality in patients with prostate cancer (Garos, Kluck, & Aronoff, 2007). Literature is limited regarding the examination of sexual esteem in patients with gynecologic cancer. Stead, Brown, Fallowfield, and Selby (2003) made reference to the devastating effects that gynecologic cancer has on a woman's sexual self-esteem; however, researchers used the terms self-esteem and sexual self-esteem interchangeably.

Sexual self-schemas refer to "cognitive representations about sexual aspects of the self" (Cyranowski & Andersen, 1998, p. 241). Few studies have investigated the sexual self-schemas of patients with gynecologic cancer (Andersen, Woods, & Copeland, 1997; Donovan et al., 2007; Gershenson et al., 2007). However, researchers agree that women with negative sexual self-schemas (i.e., negative thoughts about the sexual aspects of themselves) experienced worse sexual functioning than those women with positive sexual self-schemas, thus highlighting the importance of investigating this variable in research pertaining to the sexuality of patients with gynecologic cancer (Carpenter, Andersen, Fowler, & Maxwell, 2009; Donovan et al., 2007).

Sexual Relationships

Lack of communication between couples can cause unnecessary distress within relationships and emerged as an important theme in a grounded theory study conducted by Maughan, Heyman, and Matthews (2002). Unstructured interviews conducted with patients with gynecologic cancer and separate interviews conducted with their partners (N = 6) revealed that, since the cancer diagnosis, men waited for their wives to initiate sexual relations. However, lack of communication often can cause that hesitancy to be misinterpreted by their partners as disinterest or rejection. That is supported by the findings of Juraskova et al. (2003), in which semistructured interviews revealed that women felt their partners were afraid to commence sexual activity, which they attributed to fear or rejection. A quantitative study conducted by Bourgeois-Law and Lotocki (1999) (N = 73) also revealed that 33% (n = 24) of women felt that communicating feelings to their partner was the most difficult aspect of learning to deal with the effects of their illness and treatment on sexuality.

In addition to communication issues, intimacy within relationships can be affected by a gynecologic cancer diagnosis. Semistructured interviews with patients

with gynecologic cancer (N = 17) conducted by Butler et al. (1998) revealed that sexual intercourse was not the only expression of intimacy wanted by women; many women wished for intimate acts, such as holding hands, kissing, and cuddling. However, although that intimacy was desired, many women felt that it was not enough to sexually satisfy their partners (Juraskova et al., 2003).

Sexual Functioning

Undoubtedly, the majority of publications relating to the sexuality of patients with gynecologic cancer focus on the sexual functioning of the women. According to results from various studies, each stage of the sexual response cycle has the potential to be affected by gynecologic cancer and its treatment. Numerous studies highlight the negative effects that women experienced with regard to sexual desire and arousal (Carmack Taylor et al., 2004; Frumovitz et al., 2005; Green et al., 2000; Jensen et al., 2004; Liavaag et al., 2008; Lindau, Gavrilova, & Anderson, 2007; Nunns, Williamson, Swaney, & Davy, 2000), lubrication (Carmack Taylor et al., 2004; Carter et al., 2005; Frumovitz et al., 2005; Green et al., 2000; Jensen et al., 2004; Kylstra et al., 1999; Liavaag et al., 2008), and orgasm (Carmack Taylor et al., 2004; Carter et al., 2005; Frumovitz et al., 2005; Jensen et al., 2004; Kylstra et al., 1999; Lindau et al., 2007).

Much research has been conducted to examine the effects of a diagnosis of and treatment for a gynecologic cancer on a woman's sexuality. However, a holistic view of sexuality is not encompassed within research publications pertaining to sexuality in patients with gynecologic cancer. Research generally focuses on the physical aspects of sexuality (Bergmark, Avall-Lundqvist, Dickman, Henningsohn, & Steineck, 2002; Grumann, Robertson, Hacker, & Sommer, 2001; Leake, Gurrin, & Hammond, 2001; Lindau et al., 2007; Nunns et al., 2000). A large proportion also examined the link between gynecologic cancer and sexual self-concept (Andersen et al., 1997; Donovan et al., 2007; Gershenson et al., 2007; Juraskova et al., 2003; Stead et al., 2003; Stewart et al., 2001), and a smaller proportion focused on sexual relationships (Bourgeois-Law & Lotocki, 1999; Butler et al., 1998; Corney, Everett, Crowther, & Howells, 1992; Juraskova et al., 2003).

Despite an extensive literature search, only one quantitative study was sourced (Donovan et al., 2007) that encompassed the majority of the dimensions (with the exception of sexual-esteem) included in Figure 1, thus highlighting a gap in the literature pertaining to sexuality in women with gynecologic cancer. In addition, no studies were sourced exploring the sexuality of women with gynecologic cancer within an Irish context. Irish culture has been shown to affect the willingness of healthcare professionals to broach the topic of sexuality with patients with cancer. In a qualitative study conducted by Lavin and Hyde (2006), the views of oncology nurses working with patients with breast cancer in Ireland were explored in relation to addressing sexuality as an important aspect of nursing care (N = 10). The effect of religion and Irish culture was a dominant theme that emerged from in-depth interviews with oncology nurses. Participants spoke of the Catholic Church as a major influence on attitudes toward sexuality, resulting in what they termed as "sexual repression." However, the powerful influence of the Catholic Church has decreased steadily since the 1960s and has been particularly challenged in the mid-1990s because of reports of clerical sexual abuse (Hilliard, 2003; Lavin & Hyde, 2006). Therefore, attitudes toward sexuality have changed (Higgins et al., 2009), allowing nurses and healthcare professionals to more easily address sensitive issues such as sexuality with patients (Lavin & Hyde, 2006). Despite this, research is limited regarding the sexuality of women in Ireland with gynecologic cancer.

The primary aim of the current study was to investigate the sexuality of women in Ireland following a diagnosis of and treatment for gynecologic cancer. The specific objectives were to identify (a) the sexual self-concept, sexual relationships, and sexual functioning, and (b) the relationship between these and certain demographic variables.

Methods

Study Design

A descriptive, correlational, cross-sectional approach was used in this study. The theoretical framework was developed by the researchers based on an amalgam of empirical and theoretical literature (Andersen & Cyranowski, 1994; Hughes, 2000; Kaplan, 1979; Price, 1990; Snell & Papini, 1989; Tierney, 2008; Woods, 1987).

Setting and Sample

The study was conducted in an outpatient gynecology clinic of a large university hospital in Southern Ireland. The hospital provides care to public (those without private health insurance) and private patients (those with private health insurance); however, participants were recruited from the public outpatient clinic because private clinics could not be accessed by the researchers. In total, 136 questionnaires were distributed to patients who met the following inclusion criteria: older than 18 years, at least six weeks postdiagnosis for any form of gynecologic cancer, and treated with surgery, chemotherapy, or radiotherapy. In total, 106 questionnaires were returned, yielding a response rate of 78%.

Instruments

The sexual self-concept of participants was measured using the Body Image Scale (Hopwood, Fletcher, Lee, & Al Ghazal, 2001), the Sexual Esteem Scale (Snell &

Papini, 1989), and the Sexual Self-Schema Scale (Andersen & Cyranowski, 1994). The **Body Image Scale** (Hopwood et al., 2001) is a 10-item scale developed specifically to measure body image in patients with cancer. Responses to each item are summed to provide an overall summary score for each patient, ranging from 0–30, with increasing scores indicating more symptoms or distress. The scale includes clinical validity and discriminant validity (Hopwood et al., 2001). In the current study, the Cronbach alpha for the Body Image Scale was 0.91. The scale has been used to assess the body image of an ovarian cancer population (Liavaag et al., 2008).

The **Sexual Esteem Scale,** a 10-item Likert-type scale that is a subscale of the Sexuality Scale (Snell & Papini, 1989), was used to measure the sexual esteem of participants. When summed, scores range from –20 to 20, with higher scores corresponding to greater sexual esteem. In the current study, the Cronbach alpha for the Sexual Esteem Scale was 0.88. Validity of the scale includes discriminant validity (Wiederman & Allgeier, 1993). Although no studies were sourced that used this scale in the gynecologic cancer or female population, it has been used in a study of patients with prostate cancer (Garos et al., 2007).

The **Sexual Self-Schema Scale** (Andersen & Cyranowski, 1994) consists of 25 trait adjectives that respondents rate on a seven-point scale, ranging from 0 (not at all descriptive of me) to 6 (very much descriptive of me). Factor-analytic research has indicated that the scale includes three factors: passionate or romantic self-views (factor 1), directness or openness (factor 2), and embarrassment or conservatism (factor 3) (Cyranowski & Andersen, 1998). Total Sexual Self-Schema scores are calculated by summing respondent ratings for factors 1 and 2 and subtracting respondent ratings for factor 3. Therefore, scores can range from –42 to 114, with higher scores corresponding to more positive self-schemas. A Cronbach alpha of 0.97 was calculated for the Sexual Self-Schema Scale in the current study. The scale also has been shown to have content, construct, and convergent validity (Andersen & Cyranowski, 1994). In addition, the scale has been used in several studies that examined the sexuality of patients with gynecologic cancers (Andersen et al., 1997; Donovan et al., 2007; Gershenson et al., 2007).

The **Intimate Relationship Scale** (Hetherington & Soeken, 1990) was used to operationalize the concept of sexual relationships. It consists of a 12-item Likert-type scale in which participants check response options that most accurately describe their views of changes in their sexual relationships since their cancer diagnosis. Participants choose from five response options ranging from "much less" to "much more." When summed, scores range from 12–60, with a higher score indicating a greater degree of positive change in the relationship. Factor analysis was performed to develop three subscales: emotional, physical, and cognitive. The emotional component includes areas such as satisfaction, desire, and feelings. The physical subscale incorporates items related to intimacy, such as stroking, holding, touching, and sexual intercourse. The cognitive subscale is composed of items related to communication, such as quiet conversations or talks about sex (Hetherington, 1998). In the current study, a Cronbach alpha of 0.84 was calculated for the Intimate Relationship Scale, and it has been shown to have content validity (Hetherington, 1998). Although this scale has not yet been used in patients with gynecologic cancer, it was included in a study that examined the effects of a hysterectomy (in non-cancer patients) on sexuality and intimacy in intimate relationships (Biddle, Hetherington, & Soeken, 1987).

The **Arizona Sexual Experience Scale** (McGahuey et al., 2000) was used to measure sexual functioning. This five-item, six-point Likert scale measures the core aspects of sexual function (including the three phases of the sexual response cycle): sexual drive and desire, arousal, lubrication, ability to reach orgasm, and satisfaction. When summed, scores range from 5–30, with higher scores indicating poorer sexual functioning. The scale demonstrates reliability with a Cronbach alpha of 0.94 in the current study, and content and convergent validity has been established (McGahuey et al., 2000). Although the scale has not been used previously for patients with gynecologic cancer, it has been used to assess sexual functioning in similar populations, including patients with breast cancer (Mathias et al., 2006) and patients posthysterectomy (Kiziltepe, Tüfekçi, Öcal, Batur, & Kiziltepe, 2007).

Following each section of the questionnaire, participants were asked to rate the overall change in their sexual self-concept, sexual relationships, and sexual functioning from before to after their cancer diagnosis using a single researcher-developed Likert-type scale. Respondents chose from five response options: "extremely negative change," "moderately negative change," "no change," "moderately positive change," and "extremely positive change." A researcher-developed demographic questionnaire determined the age, diagnosis, type of treatment, relationship status, and treatment status of each participant. Participants who indicated that they were not currently involved in an intimate relationship did not complete the sexual relationships or sexual functioning sections of the questionnaire.

All scales used in the constructed questionnaire have been used in previous research with similar populations and have demonstrated adequate validity and reliability. However, because some modifications were made in certain questions, measures were undertaken by the researcher to increase the psychometric properties of the instrument. Content validity was established through the completion of an in-depth literature review and examination of the questionnaire by a panel

of experts in research and sexuality. Cronbach alpha was calculated for each scale, and each was shown to be highly reliable.

Procedures

The study was approved by the Clinical Research Ethics Committee of the University Teaching Hospitals. Participants who fulfilled the inclusion criteria were approached by the investigator at their outpatient appointments. The investigator explained the study to the prospective participants and provided written information. Written consent was obtained, and patients completed the questionnaire, which took about 20 minutes, while waiting to be seen in the clinics. To ensure privacy, participants were advised that they could complete the questionnaire at home and return it in a stamped, addressed envelope provided; however, the majority of women chose to complete the questionnaire while waiting to be seen in the clinic. Data collection took place over a period of four months.

Data Analysis

All data obtained were entered into SPSS®, version 15. Measures of central tendency, including the mean, were used to determine typical responses. Analysis of variance (ANOVA) was used to measure the relationship between demographic variables and measures of sexual self-concept, sexual relationships, and sexual functioning. Tukey's post-hoc test was used with one-way ANOVA to identify the pairs of groups that significantly differed. This study was preliminary in nature with a limited sample size; therefore, multiple regression analysis was not performed.

Results

Subjects

Participants were age 24–79 years, with a mean age of 53.8. They were diagnosed with varying forms of gynecologic cancer; the most common diagnosis was cervical, followed by ovarian, endometrial, and vulvar. The mean time since diagnosis was 48.1 months (range = 2–456 months). Women had experienced varying types of treatment, including surgery, chemotherapy, and radiotherapy. The majority of respondents had finished treatment at the time of completing the questionnaire. However, 24% were on treatment when they completed the questionnaire. For those not on treatment, the mean time since finishing treatment was 44.9 months (range = 1–271 months) (see Table 1).

Respondents also indicated whether they were involved in an intimate relationship. This question was included because certain sections of the questionnaire were not applicable to women who were not involved in an intimate relationship. Results revealed that 72% (n = 76) of respondents were involved in an intimate relationship, with 28% (n = 30) reporting that they were not. Therefore, the section in the questionnaire pertaining to sexual self-concept was applicable to all participants; however, the sections related to sexual relationship and sexual functioning were only applicable to 76 participants.

Table 1. Demographic Characteristics

Characteristic	$\bar{X}$	SD	Range
Age (years)	53.8	12.2	24–79
Time since diagnosis (months)	48.1	65	2–456
Time since completion of treatment (months)	44.9	56.7	1–271

Characteristic	n	%
Treatment status		
On treatment	25	24
Completed treatment	81	76
Type of cancer		
Cervical	51	48
Ovarian	36	34
Endometrial	16	15
Vulvar	3	3
Type of treatment		
Surgery only	32	30
Chemotherapy only	4	4
Radiotherapy only	3	3
Surgery and chemotherapy	23	22
Surgery and radiotherapy	16	15
Chemotherapy and radiotherapy	12	11
Surgery, chemotherapy, and radiotherapy	16	15
Currently involved in an intimate relationship		
Yes	76	72
No	30	28

N = 106

Sexual Self-Concept

Respondent scores to the various measures of sexuality are outlined in Table 2. With regard to sexual self-concept, the mean scores on three scales indicated that participants experienced a relatively positive body image, sexual self-schema, and sexual esteem. However, responses to individual items of the Body Image Scale indicated the negative effects that women had experienced relating to their body image was a result of the cancer and its treatment. Surprisingly, 49% of participants (n = 52) indicated that their femininity had not been affected by their cancer diagnosis and its treatment. Fifty-one percent (n = 54) noted that their cancer diagnosis had affected their femininity, with responses varying from "a little" (n = 29, 27%), "quite a bit" (n = 13, 12%), and "very much" (n = 12, 11%). Therefore, in total, a slightly greater proportion of women (n = 54) reported a greater loss in their femininity than those

Table 2. Respondent Scores on Various Measures of Sexuality

Scale	Possible Range	N	Range of Scores	$\bar{X}$ Score	SD
Arizona Sexual Experience Scale	5–30; higher scores equate to poorer sexual functioning.	74	5–30	20.01	6.4
Body Image Scale	0–30; higher scores equate to worsening body image.	106	0–29	7.6	7.7
Intimate Relationship Scale	12–60; higher scores equate to a greater degree of positive change in relationship.	75	14–45	30.3	7
Sexual Esteem Scale	–20 to 20; higher scores equate to higher sexual esteem.	103	–20 to 20	0.9	8.6
Sexual Self-Schema Scale	–42 to 114; higher scores equate to more positive sexual self-schemas.	103	0–87	49.4	19.8

who reported no change in their femininity (n = 52). In addition, 51% (n = 54) of the participants reported that they had been feeling self-conscious about their appearance as a result of their disease and treatment. A large proportion of women (n = 54) noted that treatment had contributed to a feeling of something missing (feeling "less whole") from their body. Strikingly, 55% (n = 59) of participants reported that the disease and its treatment had left them feeling less sexually attractive than before their diagnosis of and treatment for gynecologic cancer.

Sexual Relationships

Scales relating to sexual relationships and sexual functioning were completed only by women involved in an intimate relationship. The mean score of 30.3 (SD = 7) on the Intimate Relationship Scale indicated that the majority of women experienced some degree of negative change in the sexual relationship with their partner since their cancer diagnosis. With regard to communication, 33% (n = 25) of women found more time for quiet conversation with their partner since their cancer diagnosis, 49% (n = 37) said that time for communication remained unchanged, and 17% (n = 13) indicated they had less time for quiet conversation since their cancer diagnosis. Thirty-five percent (n = 26) of women were less comfortable talking about sexual matters with their partner, whereas 55% (n = 41) indicated that their comfort in discussing these issues remained unchanged.

Seventy-three percent (n = 55) of participants indicated that the frequency of intercourse with their partner had decreased since their cancer diagnosis. However, 59% (n = 50) of participants indicated that, since their cancer diagnosis, the frequency in which they initiated sexual activity had decreased. In addition, 43% (n = 32) of participants reported that the frequency with which their partner initiated sexual activity that led to intercourse had decreased since their diagnosis. As a result, 56% (n = 42) of women indicated that their feelings of sexual fulfillment had decreased since before their cancer diagnosis.

Although the frequency of intercourse had decreased for the majority of participants, 27% (n = 20) stated that their desire to be held, stroked, and touched had increased since their cancer diagnosis. That highlights the need for intimacy within relationships that is not solely limited to the physical act of sexual intercourse. On a positive note, 47% (n = 35) of women felt that their feelings of closeness with their partner were unchanged, and 28% (n = 21) stated that their feelings of closeness with their partner had increased since their diagnosis of cancer.

Sexual Functioning

The mean score of 20.01 (SD = 6.4) on the Arizona Sexual Experience Scale indicates that the women who participated in this study experienced poor overall sexual functioning. Sixty percent (n = 44) reported difficulties with sexual arousal. In response to a question about vaginal wetness during sex, 64% (n = 47) reported difficulty becoming lubricated.

Similarly, 35% (n = 26) of women experience difficulty reaching orgasm, and 23% (n = 17) indicated that they never reached orgasm.

Change in Sexuality Since Cancer Diagnosis

In addition to the aforementioned scales, respondents were asked to rate the change in their sexual self-concept, sexual relationships, and sexual functioning from before cancer diagnosis to after cancer diagnosis using a five-point Likert-type scale (see Table 3). With regard to sexual self-concept, half of the participants (n = 52) who completed this question indicated some degree of negative change. In total, 53% (n = 37) of the participants indicated some degree of negative change in their sexual relationship, and 64% (n = 48) indicated a negative change in their sexual functioning.

Relationship Between Demographics and Main Research Variables

In addition to measuring the mean score on the various scales and the frequency of responses to individual questions, the relationship between demographic information and the sexual self-concept, sexual relationships, sexual functioning, and change in sexuality also was determined. For the analysis, age was categorized into three groups (less than 45 years, 45–59 years, greater than 60 years) and months since diagnosis was divided into four categories (less than one year, one to less than three years, three to less than five years, and five years or more).

Regarding sexual self-concept, age was found to be a highly significant variable influencing body image; a more positive body image was associated with increasing age ($p < 0.001$). Patients with endometrial cancer scored significantly higher than patients with cervical cancer in relation to the Sexual Esteem Scale ($p = 0.007$). The mean age of patients with cervical cancer was younger than patients with endometrial cancer; therefore, alterations in their sexuality may have affected their sexual esteem more acutely than their older counterparts.

No significant relationship was found between total scores on the Intimate Relationship Scale and age, relationship status, type of cancer, type of treatment, time since diagnosis, and treatment status. With regard to sexual functioning, no significant relationship was found between age, relationship status, type of cancer, type of treatment, time since diagnosis, and total scores on the Arizona Sexual Experience Scale. However, a significant difference was found in the scores of those who were on treatment ($\bar{X} = 23.4$, SD = 6.2) and those who had completed treatment ($\bar{X} = 19.1$, SD = 6.2) ($p = 0.015$). In general, patients on treatment tended to have higher scores, equating to poorer sexual functioning.

A highly significant association was found between age and reports of a negative change in sexual self-concept. Two-thirds of women younger than age 60 experienced negative change, but only 25% of women older than age 60 reported a similar change ($p < 0.001$). No evidence pointed to an association between age, treatment status, type of cancer, time since diagnosis, and type of treatment and negative change in sexual relationships and sexual functioning.

Discussion

This study was the first to investigate all elements of the neotheoretical framework of sexuality in patients with gynecologic cancer. This also was the first study to quantitatively examine the multidimensional construct of sexuality of women with gynecologic cancer within an Irish context. Participants experienced a relatively positive body image, sexual self-schema, and sexual esteem; surprising, but perhaps related to the Theory of Response Shift (Sprangers & Schwartz, 1999), which involves accommodating to illness by changing internal values and standards. The find is comparable to previous literature (Gershenson et al., 2007; Liavaag et al., 2008; Stewart et al., 2001); however, to the authors' knowledge, the current study is the first to examine the sexual esteem of patients with gynecologic cancer.

The study participants did report negative changes in relation to their femininity and feelings of sexual attractiveness. Chan et al. (2001) found deterioration in femininity associated with surgical treatment, which the authors speculated was the result of the female sexual organs being important symbols of motherhood, femininity, and sexuality. Although no association was found between surgical treatment and body image in the current study, 51% of the sample (n = 54) indicated that treatment had contributed to the feeling of their body being "less whole." The results are supported by Juraskova et al. (2003). In addition, when asked to rate the change in their sexual self-concept from before to after their cancer diagnosis, half of the participants indicated some degree of negative change. The results are in keeping with negative responses to individual questions gleaned from the Body Image Scale related to appearance, feelings of sexual attractiveness, femininity, and feeling "less whole." Not surprisingly, decreasing age was associated with more negative reports of

Table 3. Responses to Questions Pertaining to a Change in Sexuality From Before to After Cancer Diagnosis

	Extremely Negative Change		Moderately Negative Change		No Change		Moderately Positive Change		Extremely Positive Change	
Variable	n	%	n	%	n	%	n	%	n	%
Change in sexual self-concept (N = 104)	18	17	34	33	36	35	10	9	6	6
Changes in sexual relationships (N = 70)	13	19	24	34	23	33	4	6	6	9
Changes in sexual functioning (N = 75)	22	29	26	35	21	28	3	4	3	4

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

changes in sexual self-concept and body image, suggesting that a gynecologic cancer diagnosis affects the sexual self-concept of younger women more acutely than that of their older counterparts. This supports findings from Stewart et al. (2001) and Juraskova et al. (2003).

Participants indicated a negative change in their sexual relationships since their cancer diagnosis. On a positive note, findings indicate that communication within sexual relationships remained largely unchanged since the diagnosis, important because difficulties within relationships often are heightened through failure to communicate feelings (Manne, 1998). However, with regard to the intimate aspects of the couples' relationships, the frequency of sexual intercourse had decreased, with women reporting that they and their partners initiated sexual intercourse less often since the cancer diagnosis. Although additional qualitative research is needed to investigate the reasons for the finding, published research has suggested that hesitancy to initiate sexual intercourse often can be mistaken for disinterest or rejection (Juraskova et al., 2003; Tierney, 2008), highlighting the need for healthcare professionals to encourage open communication within relationships and provide relevant education. More than half of respondents indicated some degree of negative change in their sexual relationship since their cancer diagnosis. That may be explained by results gleaned from the Intimate Relationships Scale, in which a majority of women were experiencing a decrease in intercourse frequency and feelings of sexual fulfillment, whereas a minority reported a decrease in feelings of closeness with their partner and comfort in talking with their partner about sexual issues.

The final aspect of a woman's sexuality measured in the current study was that of sexual functioning. Wilmoth and Spinelli (2000) stated that sexual functioning is the dimension of sexuality that is directly affected by treatment provided for gynecologic cancers. Not surprisingly, the current study's participants experienced poor overall sexual functioning, with difficulties related to each stage of the sexual response cycle. The findings are in agreement with numerous published studies (Carmack Taylor et al., 2004; Carter et al., 2005; Donovan et al., 2007; Green et al., 2000).

Responses to the question asking women to rate the change in their sexual functioning from before to after their cancer diagnoses concur with findings gleaned from the Arizona Sexual Experience Scale. Unfortunately, 64% of women experienced some degree of negative change in their sexual functioning since their cancer diagnosis. That is not surprising because of the devastating effects of gynecologic cancer treatment and is in keeping with findings from Stewart et al. (2001).

Healthcare professionals do not routinely broach the subject of sexuality with women with gynecologic cancer (Corney et al., 1992; O'Mahony, 2002; Stead et al., 2003). Lavin and Hyde (2006) suggested that Irish culture and the Catholic Church's associated influence led to a generation of women who are uncomfortable with discussing sexual issues. In recent years, Ireland has become increasingly multicultural, and the influence exerted by religion has declined (Lavin & Hyde, 2006). However, Lavin and Hyde (2006) suggested that women born in the mid-20th century may have been reared in a climate of sexual repression, which makes discussing sexual issues difficult. According to the results of this study, women with gynecologic cancer experience alterations in all aspects of sexuality; therefore, information and support must be provided.

Limitations

Convenience sampling leads to a level of subjectivity in participant selection because only those who are available are included. The researcher also was the data collector, which could have introduced bias. In addition, the study sample was very heterogeneous in relation to diagnosis, time since diagnosis, treatment status, and relationship status. Time and resources constrained the accessible sample size; as a result, women with all forms of gynecologic cancer were included to obtain a sufficient sample size. However, the generalizability of results is limited to specific subgroups of patients with gynecologic cancer. In addition, women who were on treatment and those who had finished treatment were included in the sample. For women who are on treatment, "life or death" issues such as cure and prognosis may be considered more important than sexuality. The full extent of the effects of cancer and its treatment may not yet have been realized by the women included in the study who were currently on treatment, thus having implications for data collected.

The study had a relatively small sample size (N = 106), with even fewer participants (n = 76) qualified to complete all sections of the questionnaire, thus limiting generalizability of findings. Furthermore, in the study sample, only three women were diagnosed with vulvar cancer. Because of the limited number, this type of cancer was omitted from correlational analyses. In addition, generalizability is limited further because the participants were Irish. Irish culture, in particular the Catholic Church, has been shown to be an important influence on sexuality resulting in "sexual repression" (Lavin & Hyde, 2006), so the framework of sexuality that guided the current study would have to be tested in other cultures to determine its relevance and generalizability to women in other countries. Finally, because the study was not longitudinal, information relating to the sexuality of participants prior to cancer diagnoses and treatment was not obtained. Therefore, the altered sexuality experienced by women in this

study may have existed prior to diagnosis and may not have been experienced as a consequence of the cancer and its treatment. Future research in this area should be conducted to address the aforementioned limitations.

Conclusions

Sexuality is a multidimensional construct that must be addressed by healthcare professionals. The neotheoretical framework of sexuality was found to be a relevant and suitable framework to address the construct of sexuality in a holistic manner. This study showed that sexuality is a multidimensional construct composed of the concepts of sexual self-concept, sexual relationships, and sexual functioning. Those concepts can be divided further into numerous dimensions, such as body image, sexual esteem, sexual self-schema, intimacy and communication within relationships, and the elements of the sexual response cycle. According to results of this study, women with gynecologic cancer diagnoses are at risk for experiencing alterations in each of the aforementioned dimensions of sexuality. To the authors' knowledge, this study is the first to incorporate such a holistic view toward sexuality by examining all of the dimensions of body image, sexual self-schema, sexual esteem, sexual relationships, and sexual functioning within a gynecologic cancer context. That has important implications for health care and emphasizes the need to encompass a multidimensional approach to sexuality in this patient population.

Nurses and other healthcare professionals must provide information on the potential effects of diagnosis and treatment on all aspects of sexuality to women with gynecologic cancers. The assessment of sexuality following a cancer diagnosis should encompass this holistic view so women experiencing alterations in sexuality can be referred to appropriate resources, such as counselors and support groups. This framework could guide future research to address some of the limitations of the study and explore the sexuality of patients in other cultures and specific patient groups to determine its generalizability. Because previous research has highlighted the influence of religion and spirituality on sexuality (Lavin & Hyde, 2006; Lewis & Bor, 1994), future research should explore the relationship between religion or spirituality and sexual health outcomes following a cancer diagnosis. Results from this study highlight the negative consequences of a gynecologic cancer diagnosis and its subsequent treatment on women's sexuality, and underlines the need for healthcare professionals to address this important issue using a holistic approach.

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References

Andersen, B., & Cyranowski, J. (1994). Women's sexual self-schema. *Journal of Personality and Social Psychology, 67,* 1079–1100. doi: 10.1037/0022-3514.67.6.1079

Andersen, B., Woods, X.A., & Copeland, L.J. (1997). Sexual self-schema and sexual morbidity among gynecologic cancer survivors. *Journal of Consulting and Clinical Psychology, 65,* 221–229. doi: 10.1037/0022-006X.65.2.221

Bergmark, K., Avall-Lundqvist, E., Dickman, P.W., Henningsohn, L., & Steineck, G. (2002). Patient-rating of distressful symptoms after treatment for early cervical cancer. *Acta Obstetricia et Gynecologica Scandinavica, 81,* 443–450.

Biddle, K., Hetherington, S., & Soeken, K. (1987). Post-hysterectomy effects on sexuality and intimacy. In *Proceedings from the 21st International Congress* (pp. 87–90). The Hague, Netherlands: International Conference of Midwives.

Bourgeois-Law, G., & Lotocki, R. (1999). Sexuality and gynaecological cancer: A needs assessment. *Canadian Journal of Human Sexuality, 8,* 231–240.

Bruner, D.W., & Boyd, C.P. (1999). Assessing women's sexuality after cancer therapy: Checking assumptions with the focus group technique. *Cancer Nursing, 22,* 438–447.

Butler, L., Banfield, V., Sveinson, T., & Allen, K. (1998). Conceptualizing sexual health in cancer care. *Western Journal of Nursing Research, 20,* 683–705. doi: 10.1177/019394599802000603

Carmack Taylor, C.L., Basen-Engquist, K., Shinn, E.H., & Bodurka, D.C. (2004). Predictors of sexual functioning in ovarian cancer patients. *Journal of Clinical Oncology, 22,* 881–889.

Carpenter, K.M., Anderson, B.L., Fowler, J.M., & Maxwell, G.L. (2009). Sexual self schema as a moderator of sexual and psychological outcomes for gynecologic cancer survivors. *Archives of Sexual Behavior, 38,* 828–841. doi: 10.1007/s10508-008-9349-6

Carter, J., Rowland, K., Chi, D., Brown, C., Abu-Rustum, N., Castiel, M., & Barakat, R. (2005). Gynecologic cancer treatment and the impact of cancer-related infertility. *Gynecologic Oncology, 97,* 90–95. doi: 10.1016/j.ygyno.2004.12.019

Chan, Y.M., Nagan, H.Y.S., Yip, P.S.F., Li, B.Y.G., Lau, O.W.K., & Tang, G.W. (2001). Psychosocial adjustment in gynecologic cancer survivors: A longitudinal study on risk factors for maladjustment. *Gynecologic Oncology, 80,* 387–394. doi: 10.1006/gyno.2000.6093

Corney, R., Everett, H., Crowther, M., & Howells, A. (1992). The care of patients undergoing surgery for gynaecologic cancer: The need for information, emotional support and counselling. *Journal of Advanced Nursing, 17,* 667–671.

Cyranowski, J., & Andersen, B. (1998). Sexual Self-Schema Scale—Women's version. In C. Davis, W. Yarber, R. Bauserman, G. Schreer, & S. Davis (Eds.), *Handbook of sexuality-related measures* (pp. 241–244). Thousand Oaks, CA: Sage.

Donovan, K.A., Taliaferro, L.A., Alvarez, E.M., Jacobsen, P.B., Roetzheim, R.G., & Wenham, R.M. (2007). Sexual health in women treated for cervical cancer: Characteristics and correlates. *Gynecologic Oncology, 104,* 428–434. doi: 10.1016/j.ygyno.2006.08.009

Ekwall, E., Ternestedt, B.M., & Sorbe, B. (2003). Important aspects of health care for women with gynecologic cancer. *Oncology Nursing Forum, 30,* 313–319. doi: 10.1188/03.ONF.313-319

Frumovitz, M., Sun, C.C., Schover, L.R., Munsell, M.F., Jhingran, A., Wharton, J.T., . . . Bodurka, D.C. (2005). Quality of life and sexual functioning in cervical cancer survivors. *Journal of Clinical Oncology, 23,* 7428–7436. doi: 10.1200/JCO.2004.00.3996

Gamel, C., Hengeveld, M., & Davis, B. (2000). Informational needs about the effects of gynecologic cancer on sexuality: A review of the literature. *Journal of Clinical Nursing, 9,* 678–688. doi: 10.1046/j.1365-2702.2000.00416.x

Garos, S., Kluck, A., & Aronoff, D. (2007). Prostate cancer patients and their partners: Differences in satisfaction indices and psychological variables. *Journal of Sexual Medicine, 4,* 1394–1403. doi: 10.1111/j.1743-6109.2007.00545.x

Gershenson, D.M., Miller, A.M., Champion, V.L., Monahan, P.O., Zhao, Q., Cella, D., & Williams, S.D. (2007). Reproductive and sexual function after platinum-based chemotherapy in long-term ovarian germ cell tumor survivors: A Gynecologic Oncology Group study. *Journal of Clinical Oncology, 25,* 2792–2797. doi: 10.1200/JCO.2006.08.4590

Green, M.S., Naumann, R.W., Elliot, M., Hall, J.B., Higgins, R.V., & Grigsby, J.H. (2000). Sexual dysfunction following vulvectomy. *Gynecologic Oncology, 77,* 73–77. doi: 10.1006/gyno.2000.5745

Grumann, M., Robertson, R., Hacker, N.F., & Sommer, G. (2001). Sexual functioning in patients following radical hysterectomy for stage IB cancer of the cervix. *International Journal of Gynecological Cancer, 11,* 372–380. doi: 10.1046/j.1525-1438.2001.01051.x

Hetherington, S. (1998). Intimate Relationship Scale. In C. Davis, W. Yarber, R. Bauserman, G. Schreer, & S. Davis (Eds.), *Handbook of sexuality-related measures* (pp. 501–593). Thousand Oaks, CA: Sage.

Hetherington, S., & Soeken, K. (1990). Measuring changes in intimacy and sexuality: A self-administered scale. *Journal of Sex Education and Therapy, 16,* 155–163.

Higgins, A., Barker, P., & Begley, C. (2009). Sexuality and mental health in nursing in Ireland: Weaving the veil of socialised inhibition. *Nurse Education Today, 29,* 357–364. doi: 10.1016/j.nedt.2008.07.003

Hilliard, B. (2003). The Catholic Church and married women's sexuality: Habitus change in late 20th century Ireland. *Irish Journal of Sociology, 12,* 28–49.

Hopwood, P., Fletcher, I., Lee, A., & Al Ghazal, S. (2001). A body image scale for use with cancer patients. *European Journal of Cancer, 37,* 189–197. doi: 10.1016/S0959-8049(00)00353-1

Hughes, M.K. (2000). Sexuality and the cancer survivor: A silent coexistence. *Cancer Nursing, 23,* 477–482. doi: 10.1097/00002820-200012000-00011

Jensen, P.T., Groenvold, M., Klee, M.C., Thranov, I., Petersen, M.A., & Machin, D. (2004). **Early-stage cervical carcinoma, radical hysterectomy, and sexual function. A longitudinal study.** *Cancer, 100,* 97–106.

Juraskova, I., Butow, P., Robertson, R., Sharpe, L., McLeod, C., & Hacker, N. (2003). Post-treatment sexual adjustment following cervical and endometrial cancer: A qualitative insight. *Psycho-Oncology, 12,* 267–279. doi: 10.1002/pon.639

Kaplan, H.S. (1979). *Disorders of sexual desire and other new concepts and techniques in sex therapy.* New York, NY: Simon and Schuster.

Kiziltepe, A., Tüfekçi, E., Öcal, A., Batur, O., & Kiziltepe, H. (2007). Comparison of sexual functioning in women who have history of total hysterectomy with women of similar age without history of hysterectomy. *Medical Journal of Bakirköy, 3*(1), 23–28.

Krebs, L. (2006). What should I say? Talking with patients about sexuality issues. *Clinical Journal of Oncology Nursing, 10,* 313–315. doi: 10.1188/06.CJON.313-315

Kylstra, W.A., Leenhouts, G.H., Everaerd, W., Panneman, M.J., Hahn, D.E., Weijmar Schultz, W.C., . . . Heintz, A.P. (1999). Sexual outcomes following treatment for early stage gynecological cancer: A prospective multicenter study. *International Journal of Gynecological Cancer, 9,* 387–395. doi: 10.1046/j.1525-1438.1999.99052.x

Lavin, M., & Hyde, A. (2006). Sexuality as an aspect of nursing care for women receiving chemotherapy for breast cancer in an Irish context. *European Journal of Oncology Nursing, 10*(1), 10–18. doi: 10.1016/j.ejon.2005.03.013

Leake, R.L., Gurrin, L.C., & Hammond, I.G. (2001). Quality of life in patients attending a low-risk gynaecological oncology follow-up clinic. *Psycho-Oncology, 10,* 428–435. doi: 10.1002/pon.539

Lewis, S. & Bor, R. (1994). Nurses' knowledge of and attitudes toward sexuality and the relationship of these with nursing practice. *Journal of Advanced Nursing, 20,* 251–259.

Liavaag, A.H., Dørum, A., Bjøro, T., Oksefjell, H., Fosså, S.D., Tropé, C., & Dahl, A.A. (2008). A controlled study of sexual activity and functioning in epithelial ovarian cancer survivors. A therapeutic approach. *Gynecologic Oncology, 108,* 348–354.

Lindau, S.T., Gavrilova, N., & Anderson, D. (2007). Sexual morbidity in very long term survivors of vaginal and cervical cancer: A comparison to national norms. *Gynecologic Oncology, 106,* 413–418.

Manne, S. (1998). Cancer in the marital context: A review of the literature. *Cancer Investigation, 16,* 188–202. doi: 10.3109/07357909809050036

Mathias, C., Cardeal Mendes, C., Pondé de Sena, E., Dias de Moraes, E., Bastos, C., Braghiroli, M.I., . . . del Giglio, A. (2006). An open-label, fixed-dose study of bupropion effect on sexual function scores in women treated for breast cancer. *Annals of Oncology, 17,* 1792–1796. doi: 10.1093/annonc/mdl304

Maughan, K., Heyman, B., & Matthews, M. (2002). In the shadow of risk. How men cope with a partner's gynaecologic cancer. *International Journal of Nursing Studies, 39*(1), 27–34.

McGahuey, C.A., Gelenberg, A.J., Laukes, C.A., Moreno, F.A., Delgado, P.L., McKnight, K.M., & Manber, R. (2000). The Arizona Sexual Experience Scale (ASEX): Reliability and validity. *Journal of Sex and Marital Therapy, 26*(1), 25–40. doi: 10.1080/009262300278623

National Cancer Institute. (2010). Sexual and reproductive issues: The prevalence and types of sexual dysfunction in people with cancer. Retrieved from http://www.cancer.gov/cancertopics/pdq/supportivecare/sexuality/Healthprofessional

Nunns, D., Williamson, K., Swaney, L., & Davy, M. (2000). The morbidity of surgery and adjuvant radiotherapy in the management of endometrial carcinoma. *International Journal of Gynecological Cancer, 10,* 233–238. doi: 10.1046/j.1525-1438.2000.010003233.x

O'Mahony, M. (2002). Perceptions of nurses working in oncology in providing care regarding sexuality to women with ovarian cancer. *Cancerwise, 1*(4), 14–19.

Price, B. (1990). A model for body image care. *Journal of Advanced Nursing, 15,* 585–593. doi: 10.1111/j.1365-2648.1990.tb01858.x

Sheerin, F., & McKenna, H. (2000). Defining sexuality for holistic nursing practice: An analysis of the concept. *All Ireland Journal of Nursing and Midwifery, 1*(3), 94–99.

Snell, W., & Papini, D. (1989). The Sexuality Scale: An instrument to measure sexual-esteem, sexual-depression, and sexual-preoccupation. *Journal of Sex Research, 26,* 256–263.

Sprangers, M.A., & Schwartz, C.E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science and Medicine, 48,* 1507–1515.

Stead, M.L., Brown, J.M., Fallowfield, L., & Selby, P. (2003). Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *British Journal of Cancer, 88,* 666–671. doi: 10.1038/sj.bjc.6600799

Stewart, D.E., Wong, F., Duff, S., Melancon, C.H., & Cheung, A.M. (2001). "What doesn't kill you makes you stronger": An ovarian cancer survivor survey. *Gynecologic Oncology, 83,* 537–542.

Stilos, K., Doyle, C., & Daines, P. (2008). Addressing the sexual health needs of patients with gynecologic cancers. *Clinical Journal of Oncology Nursing, 12,* 457–463. doi: 10.1188/08.CJON.457-463

Thaler-DeMers, D. (2001). Intimacy issues: Sexuality, fertility, and relationships. *Seminars in Oncology Nursing, 17,* 255–262. doi: 10.1053/sonu.2001.27919

Tierney, D.K. (2008). Sexuality: A quality-of-life issue for cancer survivors. *Seminars in Oncology Nursing, 24,* 71–79.

Wiederman, M.W., & Allgeier, E.R. (1993). The measurement of sexual esteem: Investigation of Snell and Papini's (1989) Sexuality Scale. *Journal of Research in Personality, 27*(1), 88–102.

Wilmoth, M.C., & Spinelli, A. (2000). Sexual implications of gynecologic cancer treatments. *Journal of Obstetric, Gynecologic, and Neonatal Nursing, 29,* 413–421. doi: 10.1111/j.1552-6909.2000.tb02064.x

Woods, N.F. (1987). Toward a holistic perspective of human sexuality: Alterations in sexual health and nursing diagnoses. *Holistic Nursing Practice, 1*(4), 1–11.