

Representations of nurses regarding sexuality of women treated for breast cancer in Brazil

Representações das enfermeiras sobre a sexualidade de mulheres tratadas de câncer de mama

Concepciones de enfermeras sobre la sexualidad de las mujeres tratadas por cáncer de mama

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Abstract

The development of new treatments has improved survival and quality of life among cancer patients. Nurses are expected to answer questions and to provide orientation regarding patients' sexuality since it is an important aspect of life. The main objective of this paper is to understand the representations of sexuality among nurses working with women who survive breast cancer after diagnosis and during treatment assuming that their representations may affect communication with the patient. This is a qualitative study using an in-depth guideline which involved interviews with 28 nurses living and working in the southeast of Brazil. The narratives were submitted to a content analysis and categories of representations were identified and are discussed here. Several representations of sexuality were found in the nurses' discourses. Some of the nurses' representations may be expected to hinder their ability to provide helpful orientation regarding the sexual lives of these patients.

Breast Neoplasms; Sexuality; Nurses

Resumo

O desenvolvimento de novos tratamentos melhorou a sobrevivência e a qualidade de vida dos pacientes de câncer. Espera-se que as enfermeiras forneçam orientações sobre a sexualidade dos pacientes, considerada importante aspecto da vida. O principal objetivo deste artigo é compreender as representações da sexualidade entre as enfermeiras que trabalham com as mulheres sobreviventes ao câncer de mama depois do diagnóstico e durante o tratamento, considerando que estas representações possam afetar a comunicação com o paciente. Este é um estudo qualitativo que entrevistou 28 enfermeiras que vivem e trabalham no Sudeste do Brasil. As narrativas foram submetidas à análise de conteúdo e as categorias das representações foram identificadas e discutidas. Várias representações sobre sexualidade foram encontradas nos discursos das enfermeiras. Algumas delas podem ocultar a habilidade de transmitir orientação em relação à vida sexual desses pacientes.

Neoplasias da Mama; Sexualidade; Enfermeiras

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Introduction

Breast cancer represents the most prevalent cancer in women in the world. Annually it constitutes 22% of all new cancer diagnoses in women and 7% of the 7.6 million cancer-related deaths internationally¹.

Breast cancer has been the type of malignant neoplasm of greatest incidence and mortality among Brazilian women. In 2012 52,680 new cases were estimated, i.e., 52 new cases per 100,000 women². Over recent years, a significant increase has been reported among young women up to 35 years of age³. Similarly in the United States it is the most common cancer in women, but due to the advances of therapy and the participation in screening programs, mortality rates are now decreasing. The survival of women with breast cancer is considered a process that begins at diagnosis and does not cease, lasting until the end of life⁴, so the rehabilitation of the survivors of breast cancer takes place permanently and requires attention in all spheres of daily life⁵. Studies have shown that survival is associated with several changes impacting upon different phases in the lives of women, each phase with its specific demands^{6,7}.

Sexuality is one of the areas potentially affected after breast cancer and because of its impact and significance in the patient's life, demands attention alongside that given to diagnosis and treatment⁸. Sexuality encompasses intimate feelings of individuality and is central to a person's sense of wellness and health⁹. The majority of research on breast cancer is focused on the period of diagnosis and treatment and few publications are dedicated to investigating the impact of cancer upon sexuality and sexual life after treatment⁵. A literature review concerning the sexuality of women with cancer has identified important gaps in the research of the subject. According to some authors this has led sexuality-related breast cancer interventions to be based more upon anecdotal experience and the predispositions of the specialist than upon sound evidence from the social sciences⁸. Some studies have reported that health professionals do not usually address sexual issues among breast cancer survivors^{10,11}.

Among professionals of the health team, nurses are given an important role since they are required to answer questions and provide orientation in several aspects of their patients' lives including their sex lives. Some authors emphasize the need to improve communication on sexuality between nurses and patients in order to deliver better care^{12,13}. Representations about sexuality can affect communication since nurses can put more or less emphasis upon different aspects

or even ignore some aspects of sexuality which may be important to patients. Such varied communication is likely to be based on nurses' own assumptions, concepts and beliefs pertaining to the subject^{14,15}. In order to understand these important representations we developed the present study having in mind the following question: how do nurses address sexuality as part of the health care for women recovering from breast cancer?

The objective of this study was to understand the representations of how sexuality of women undergoing treatment of breast cancer is understood by the nurses responsible for those patients after diagnosis and during treatment.

Methods

This is an exploratory qualitative study carried out with 28 nurses living and working in the Southeast of Brazil. We identified all nurses working in cancer clinics (ambulatories and hospitals) in Ribeirão Preto, a city in São Paulo State with a population of half a million people, and conducted interviews. Only two nurses refused to be interviewed. All but one nurses in the sample were women, aged between 23 and 60 years old, with between two and 30 years of work experience with breast cancer patients. The majority, 16 of them were married with children. Only one was cohabiting, nine were single and two were divorced or separated. Regarding sexual orientation, one was homosexual. 20 of them had attended a "specialization course" including 12 in oncologic care, four had a Resident Certificate and four had just a nursing degree. Only one reported she had cancer. We used a semi-structured interview guideline developed by a similar collaborative study conducted in France¹⁴. A deliberately open and broad trigger question was used to start the interview: "*How do you deal with sexuality in your professional practice?*". It is important to note that the interview explored both nurses general feelings about sexuality in their working practice, as well as its more specific bearing upon dealing with the sexuality of patients being treated for cancer (thus some quotations presented below include reference to male patients).

The research project was approved by the Committee of Ethics in Research at the Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo in August, 2009 (protocol n. 1019/2009). All participants were asked to read and sign a form detailing terms of consent and their free will in participating in the interview, in which confidentiality and privacy of informa-

tion were guaranteed, according to *Resolution n. 196/96* of the Brazilian National Health Council.

The interviews were audio-tape recorded and transcribed in full. Afterwards they were subjected to a content analysis and thematic categorization in which the following range of representations were identified and labeled.

In order to analyze the data, the following sequence of content analysis was used: preparation of the material through the interview transcripts, coding based on the previously defined thematic script and data interpretation and description of each category¹⁶. After reading and identifying each category in the transcriptions of interviews we organized similar narratives under each label. We developed seminars for interpretation and analysis, defining the meaning of each category, with the research team discussing each interpretation. A review of the relevant social science literature was undertaken in order to link the meanings of each category identified to themes in the more general research.

Results

The representations of sexuality found in the nurses' discourses were interpreted and organized according to the following six sets of meanings.

Sexuality as dangerous and risky for diseases

Some nurses shared representations of sexuality that were limited to sexual function (sexual activity or intercourse) and linked to the functioning of genital organs (or breasts) in a spectrum from the normal to the pathological. So, this concept of sexuality is focused on the body, especially on the genitals, and can be considered as a subject pertaining to sexual disorders or as a means for disease transmission. These are concepts associated with the risk of contamination and disease transmissions (STI and AIDS). On the other hand, this representation also involves the concept of health prevention and the orientation for condom and contraceptive use. In this sense sexuality is seen in terms of the traditional, rather narrowly focused, biomedical model.

"How do I approach sexuality? I do the prevention of STI and orientation about sexual pathology, right? It would also be an interesting area of how to deal with the patient when he/she reaches the hospital and you have to give him a swab, you have to examine the [genitals], right?" (Nurse 1).

Holistic sexuality: sexuality as a basic human need for health and wellbeing

In this category representations of sexuality were included that are similar to the World Health Organization (WHO) definition stated in 2002¹⁷ (p. 4): *"[Sexuality is] an integral part of the personality of everyone: man, woman, and child. It is a basic need and an aspect of being human that cannot be separated from other aspects of life. Sexuality is not synonymous with sexual intercourse, it is not about whether we have orgasms or not, and it is not the sum total of our erotic lives. These may be part of our sexuality but equally they may not. Sexuality is so much more: it is in the energy that motivates us to find love, contact, warmth and intimacy; it is expressed in the way we feel, move, touch and are touched; it is about being sensual as well as being sexual"*.

Nurses' discourses which presented conceptions about sexuality as being more than merely a physical aspect of the body, not limited to sexual intercourse or the physiological response of genital organs were classified in this category. From this perspective, sexuality also includes sexual orientation, sexual behavior, feelings of love and what may be thought of as sexual comportment according to sexual scripting. This category also presents the idea of sex as being healthy, important for wellbeing, connected to affection and human development, and such discourses are expressed with words such as desire, expectations, wellbeing, self-esteem, happiness, being a man or woman, feelings and self-image.

"...I understand that sexuality is not only sexual intercourse, it is everything, the way people dress, how they act, behavior...all this is part of sexuality...very important for wellbeing and self-esteem" (Nurse 2).

Sexuality as a prerogative of youth

For some nurses women's age is the main determinant of the consequences breast cancer produces on sexuality. Several ideas presented by them involved reference to age. Some nurses believed that younger women suffer more sexual alterations due to cancer than older women since the former have more sexual desire. For many of these nurses sexual desire was considered to decrease as people grow older with sexuality becoming less important to elderly people. Some nurses argued that sexual activity could be unpleasant in mature age and for this reason they reported that some women use the treatment of breast cancer as an excuse to interrupt sexual activities.

Women who had finished their reproductive cycle would suffer fewer consequences to their sexuality after breast cancer than younger women who are still “building” their reproductive life. So from this perspective the meaning of sexual life for younger women is centered around reproduction and thus sexuality should be more important to them. So, sexuality is represented as reproductive sexuality.

Such nurses also felt age to be a factor to influencing women's freedom to express concerns about sexuality. For some nurses younger women would express their concerns about sexuality more easily than older women, since they considered the latter would have greater difficulties with the subject, due to their adherence for instance to more traditional religions norms, cultural barriers and taboos. So, these nurses place a priority on orienting younger women on sexual matters because in their view they would need more advice and ask more directly for such orientation, which in a sense authorizes the nurse to talk about the subject. Nurses feel that it is more difficult to approach the subject with older women because of the cultural barriers, and they feel that to do so is to be invasive of the patient's privacy and modesty.

The link between youth and sexuality is also expressed when considering the need for breast reconstruction after mastectomy. Some nurses think that young women have more need to reconstruct their breasts than older women. They say that there are older women who do not want breast reconstruction.

“Old ladies have more barriers to talk about sex...I think so...with young people it is different... to have cancer is much worse for young people than old people because those already have had children...” (Nurse 3).

Sexuality as beauty and body image

In this representation sexuality appears to be as an expression of an idealized pattern of beauty being connected to body image and self-esteem. So this representation comprises some ideas related to the consequences of how breast cancer will deeply affect sexuality because it will affect beauty, body-image and women's behavior. Some aspects such as self-esteem, wellbeing and embarrassment were also included here. Although having a social and psychological dimension it may be linked to the category of holistic sexuality noted above, though the emphasis here is put on the body image and mental wellbeing aspects. The testimonies reveal women's behaviors and symptoms observed by the nurses including depression or acceptance of losing the breast and

hair, which are seen as symbols of femininity and sexuality. They also mentioned partner rejection, divorce or separation and social isolation. The breast reconstruction and the use of prostheses are considered important resources in restoring identities as well as a form of coping with the disease and treatment.

“Even patients who therefore refused to do a mastectomy because of the same image, self-image, then also lose their hair, you know? They face a lot of these difficulties, the limitations of the arm, mastectomy, all this seems to bother them. Also the person did not want a mastectomy in any way because of the impact it would cause in her life” (Nurse 4).

Sexuality and love

In this category the representation of sexuality is clear: love and sex must be experienced together, with sex being considered a complement to love. For these nurses love (in a relationship) is more important than sex. There is a sense of a clear devaluation of the significance of sexual intercourse. There is also something of an expression of gender roles and sexuality, with an emphasis that while women value love and romance, men would place a more primary value upon sex. From this perspective love and sex must be experienced together. Some discourses express the idea that sex is a complement to love and in most cases sex without love is unacceptable. The presence of love will determine the level of social support the woman will receive after breast cancer. The chances of the future continuation of the partnership of the couple is considered to increase when there is love, as well as the commitment of care between partners and there is more assistance to the partner during treatment. There is the acknowledgment that the treatment of breast cancer has an influence beyond sex, affecting the relationship and the quality of the affection between partners.

“I think so, even if there is not sex, or the sex act, but at least one is living a good life, loved, feeling loved, to love, a husband's touch, the family's touch. Many times when this does not happen, it hinders all treatment. I think it is not necessary to have the act, sex itself, but that rather that coexistence [in the relationship] is pleasant, healthy, feeling loved, feeling that people are worried about her, with her treatment and improvement from it” (Nurse 6).

Erotic and sexual fantasy

Nurses reveal that in the exercise of their profession, sexuality appeared sometimes as erotic fan-

tasy for patients, especially when they are manipulating their bodies. They also express patients' reactions as expressions of sexuality. Nurses talked about manipulation of patients' bodies and their own sexuality facing certain situations.

"Sexuality? I think so, part of dealing with the naked [patient], [their] being naked, touching, exposure of intimate parts, of talking pertaining to sexuality, subjects such as erections, wanting to make love, sex. Sometimes there can be a misunderstanding that in providing care for the patient, it is construed as tenderness, a closeness that can be seen as sexual, though, is pretty much it, so I play, you know?" (Nurse 7).

"...and when you change a diaper, if you have to perform some such procedure...then, at times like this, we respect [the patient] a lot and you see that side of not wanting to invade the privacy of the patient, maintaining an appropriate facial expression and respecting him while we are providing this care" (Nurse 8).

Discussion

Following the outline of the six thematic dimensions of the representations of sexuality identified in the interviews with nurses we now turn to an attempt to synthesize these findings. The findings are thus discussed in relation to general health and medicine discourses, Brazilian sexual culture and broader social theories regarding sexuality. From the outset of this discussion it may be noted that there is both a wide range of expressions as presented in the findings above, and that nurses sometimes expressed more than one of these representations of sexuality. The main themes that emerged from the analysis of the transcripts may be viewed on two levels. On the first level there are the expressions of their nursing role regarding sexuality, variously expressed in terms of the traditional biomedical model and the broader psychosocial holistic model. On the second level there are the themes pertaining to the sexuality of cancer patients, which have been summarized as pertaining to wellbeing and body image, sex as sexual intercourse, sex as the prerogative of youth, and some specific reference to love and relationships.

The findings may most usefully be considered within the light of two structuring prisms, firstly the contested and competing discourses of the bio-medical and holistic, such as the WHO concept of sexual health, and the personal sexual philosophies and predispositions of individual nurses. The nurses can be divided fairly evenly between those who expressed a primarily bio-medical model of sexual health and those

who shared a more holistic and personal perspective¹³. This range testifies to the diversity in the sample, and highlights the scope for an exploration of the differences.

The full interviews obviously presented a much fuller perspective of the nurses' ways of thinking about the sexuality issues among patients recovering from breast cancer, than this necessarily condensed presentation of findings and quotations.

It is important to analyze the findings keeping in mind that the particularities of Brazilian sexual culture can influence the findings (health system and nurse training). For instance it is crucial to consider sexuality and the life course, gender constructions, the importance of the "body beautiful" and the personal and emotional conduct of relationships¹⁸.

Furthermore Giddens' ¹⁹ notion of "plastic sexuality" with its emphases on reflexivity and dynamism provides another useful theoretical basis. For instance, in historical terms Brazil has only relatively recently passed through the demographic transition from high to low fertility, with its attendant separation of sex for reproduction and pleasure that is so basic to "plastic sexuality". Thus with reference to the gender structuring of sexual expectations although we can find modern liberal and reflexive tendencies, there is also clear evidence of what may be thought of as more traditional sexual cultural values and dispositions.

Individual nurses' sexual propensities and dispositions and the ways they impact upon their approach to addressing the sexual dimensions of patient care may also be most usefully explored in relation to Fisher's et al. ²⁰ notion of the "erotophilia-erotophobia" continuum. In brief nurses that feel more open towards, and comfortable with their own sexuality would be expected to be more proactive towards, and caring of, the sexuality dimension of patients recovering the treatment of breast cancer.

As in all countries probably the greatest sexually-related issues following mastectomy and chemotherapy for women were the implications for body image and sense of wellbeing^{8,21}. Both the loss of breasts and hair as symbols of femininity are potentially traumatic in their effects on self-image. It is possible to surmise that given the enormous importance accorded to the "body beautiful" in Brazilian culture these concerns are felt especially strongly here. These matters were explicitly raised and discussed by two thirds of the nurses interviewed. Many of the nurses showed a rich appreciation of the negative effects on their patients' sense of body image. They variously alluded to the effect on self-esteem,

even depression, general wellbeing and the loss of confidence in sexual interaction.

In general, not surprisingly, they discussed the negative impacts, although some nurses went on to talk more positively about the way they had noticed some women had been able to cope surprisingly well with, and adjust to, the changes. Nurses reported that many women also expressed anxieties regarding the possible effects on their relationship, and fear of losing their partner. Some authors reported that separations were initiated by men unable to cope with their partner's cancer, but also reported a proportion of patients and their partners who have been shown that breast cancer created a greater sense of closeness^{22,23}.

About half of the nurses interviewed discussed sex solely in terms of sexual intercourse. They discussed patients' anxieties concerning whether and in what ways their treatments may result in lasting impacts on their engaging in intercourse. It has to be recalled here that treatment does involve suspending intercourse for a period of one month. Some nurses commented that when asked such questions they felt at a loss, feeling unable or unsure as to how to answer. Some of them revealed that they need more information and training on this subject.

The third most common theme (found in 11 of the 28 cases) recurring in the nurses' interviews was that the main sexual repercussions of cancer treatments depended upon the age of the patient. Some nurses expressed the view that it was unnecessary or even invasive to raise sexual matters with older patients. This point also links with the previously mentioned theme of 'sex as sexual intercourse', as some nurses seemed to forget that sex is far broader than intercourse or even genital activity, and that they should have a role in assisting their patients to continue to enjoy intimacy, warmth, caressing and so on in their relationships, rather than "closing down" that very important dimension of their lives. The second rationale (reinforcing the first) was that younger women find it easier to express their sexual concerns than older women. Part of the rationale expressed here was that older women are more inhibited by a range of religious and cultural taboos. Thus nurses prioritized the discussion of sexual matters with younger patients because they believed they have both a greater need, and find it easier to discuss such matters. The third rationale that expressed this "ageism" was that young women have a much greater need for possible breast reconstruction after mastectomy, and that older women do not want such corrective surgery. The fourth rationale concerned sexuality and fecundity, that

sexuality was a much less important matter for women who had finished their reproductive career, rather than those younger women who are still building their life. This idea of sexuality being primarily concerned with reproduction reflects more traditional views, and may well be related to the relative recentness of Brazil's demographic transition and reproductive revolution. Giddens's¹⁹ notion of a modern reflexive "plastic sexuality" is predicated on this massive cultural transformation, which for the first time in human history has allowed women to separate sex for reproduction and sex for pleasure.

Running through all these "ageist" ideas that the sexuality of older women recovering from cancer treatment is less important, is the crucial significance of the gender structuring of sexuality that pervades Brazilian culture. When nurses say "*sex is less relevant to older people*", they are primarily referring to women (their patients in this case). The social expectation of continued sexual desire and even multiple partners for men is in some ways seemingly more acceptable within the culture²⁴. By contrast women who have multiple partners would be strongly stigmatized. Although Ford et al.²⁴ showed in their study of male sexuality in São Paulo that there was a substantial class difference in the adherence to, and expression of, "macho" values which would denigrate the sexual role of older women, such values are still seen to pervade much of the thinking of these nurses. In terms of social strata the nurses would primarily be drawn from lower income members of the middle class. An important point seems to be that we are encountering sexual expectations that are almost taken for granted, rather than a real understanding of these women's actual sexual lives (as expressed not only in sexual behavior surveys but also some of our own interviews with recovering patients). A very important finding of this study is that nurses are too ready to dismiss the need to address sexual re-assurance among older women.

Perhaps as a welcome corrective to this emphasis on "sex as sexual intercourse" and the denigration of age, a small number (6/28) of nurses alluded to the crucial importance of love in dealing with patients' sexual adjustments. Four sets of links have been identified in the interviews; that women place much more emphasis on love than sex in the gender structuring of the sexual culture (maybe again suggesting that patients' purely sexual needs are not so important), that sex and love need to be seen together with some nurses asserting that sex without love is socially unacceptable especially for a woman, in more practical terms that being in a loving relationship with its social support is very impor-

tant for the patients in their recovery and that the process of the treatment of breast cancer has a major impact on relationships going beyond merely sex, affecting the quality and affection in the relationship, both positively and negatively in different couples.

In conclusion, the study has been able to identify a range of representations of sexuality which have a bearing upon the ways nurses in Brazil communicate with patients being treated and recovering from breast cancer. Some of those representations such as that based upon a purely bio-medical model, and those shaped by

assumed gender and ageist stereotypes may be expected to hinder nurses' ability to meet such women's re-assurance and the provision of useful guidance pertaining to their future sexual lives. The next aim is to use this information to assist in refining the training provided to nurses who work in this area. We assume that nurses' representations of sexuality have the potential to affect communication with the patient. In this sense, these results can contribute to improving capacity building of health professionals and to sensitize them to include sexual issues in the care of women with breast cancer.

Resumen

El desarrollo de nuevos tratamientos mejoró la supervivencia y la calidad de vida de los pacientes con cáncer. El estudio analiza las orientaciones que proporcionan las enfermeras sobre sexualidad a las pacientes, puesto que se considera un importante aspecto de la vida. El principal objetivo de este artículo es comprender las concepciones sobre sexualidad entre las enfermeras que trabajan con mujeres que han superado un cáncer de mama, después del diagnóstico y durante el tratamiento, considerando que estas concepciones pueden afectar la comunicación con el paciente. Este es un estudio cualitativo que entrevistó a 28 enfermeras que viven y trabajan en el sureste de Brasil. Las narraciones fueron sometidas a un análisis de contenido y se identificaron y discutieron las categorías de las concepciones. Se encontraron varias concepciones sobre sexualidad en los relatos de las enfermeras. Algunas de ellas pueden ocultar su habilidad para transmitir orientaciones relacionadas con la vida sexual de estas pacientes.

Neoplasias de la Mama; Sexualidad; Enfermeras

Contributors

E. M. Vieira, L. C. U. Junqueira and A. Giami participated in conceiving the study, data analysis and write-up of the article. M. A. Santos and N. J. Ford contributed with data analysis and article write-up.

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