

## THE SEXUALITY OF PATIENTS WITH ONCO-HEMATOLOGICAL DISEASES

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Melo AS, Carvalho EC, Pelá NTR. The sexuality of patients with onco-hematological diseases. Rev Latino-am Enfermagem 2006 março-abril; 14(2):227-32.

*We interviewed 20 patients staying at a hospital unit, by means of a data collection instrument that is based on the eclectic model, with a view to characterizing the biological, psychological and sociocultural aspects involving human sexuality which are affected in patients with onco-hematological diseases. The research complied with ethical requirements for studies involving human beings. The results revealed that these clients presented problems related to biological aspects, mainly with respect to the phase of sexual desire (60% of the sample), sexual excitation (75%) and orgasm (75%). The psychological aspects related to sexual self-image were affected in 60% of the sample; problems related to social aspects (85%) were mainly due to the fear of acquiring an infection as a result of the low immunity provoked by the disease and treatment. These clients demonstrated alterations in their sexual function and in the way they expressed their sexuality.*

**DESCRIPTORS:** *sexuality; nursing diagnosis; hematologic diseases; medical oncology*

## LA SEXUALIDAD DEL PACIENTE PORTADOR DE ENFERMEDADES ONCO-HEMATOLÓGICAS

*Con el intento de caracterizar los aspectos biológicos, psicológicos y socioculturales que involucran la sexualidad humana afectados en las personas portadoras de patologías onco-hematológicas, entrevistamos a 20 pacientes internados en una unidad hospitalaria por medio de un instrumento de recopilación de datos basado en el modelo ecléctico. La investigación cumplió con las exigencias éticas para estudios con seres humanos. Los resultados evidenciaron que esta clientela presenta problemas relacionados a aspectos biológicos, respecto a la fase del deseo sexual (60% de la muestra), de la excitación sexual (75%) y del orgasmo (75%). Los aspectos psicológicos que se refieren al auto-imagen sexual se mostraron comprometidos en 60% de la muestra; la presencia de los problemas relacionados a los aspectos sociales (85%) principalmente ocurrió debido al miedo de adquirir una infección en consecuencia de la baja inmunidad provocada por la enfermedad y tratamiento. Esta clientela demostró alteraciones en la función sexual y en la manera de expresar su sexualidad.*

**DESCRIPTORES:** *sexualidad; diagnóstico de enfermería; enfermedades hematológicas; oncología médica*

## A SEXUALIDADE DO PACIENTE PORTADOR DE DOENÇAS ONCO-HEMATOLÓGICAS

*Com o propósito de caracterizar os aspectos biológicos, psicológicos e socioculturais que envolvem a sexualidade humana, afetados nas pessoas portadoras de patologias onco-hematológicas, foram entrevistados 20 pacientes, internados em uma unidade hospitalar, por meio de um instrumento de coleta de dados baseado no modelo eclético. A investigação atendeu às exigências éticas para estudos com seres humanos. Os resultados evidenciaram que essa clientela apresenta problemas relacionados a aspectos biológicos quanto à fase do desejo sexual (60% da amostra), da excitação sexual (75%) e do orgasmo (75%). Os aspectos psicológicos que se relacionam com a auto-imagem sexual apresentaram-se comprometidos em 60% da amostra; a presença dos problemas relacionados aos aspectos sociais (85%) deu-se, principalmente, pelo medo de adquirir infecção decorrente da baixa imunidade provocada pela doença e tratamento. Essa clientela apresentou alterações na função sexual e na maneira de expressar a sua sexualidade.*

**DESCRIPTORES:** *sexualidade; diagnóstico de enfermagem; doenças hematológicas; oncologia*

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## INTRODUCTION

Cancer, characterized as a disease that affects various body parts and requires complex treatment, with sometimes devastating effects for the organism, hazards human sexuality<sup>(1)</sup>.

In physiological terms, the alterations blood cancer and intense chemotherapy provoke in different organic systems, manifested by signs and symptoms, jeopardize these patients' sexuality. Moreover, this type of disease demands frequent hospitalizations and incidence levels are higher among young adults.

In this clientele, the psychological effects of a cancer diagnosis confirmation should also be taken into account, accompanied by the cultural connotation of pain, suffering and death. This provokes changes in sexual and family relations<sup>(1)</sup>.

Sexuality is considered as a personal and human dimension that comprises not only genitality, but goes beyond the limits of genital impulse and is characterized as a profound and all-inclusive aspect of human personality, present from conception until death and including everything we are and what we do<sup>(1-3)</sup>. It consists of three interrelated and inseparable aspects - biological, psychological and social<sup>(2)</sup>.

The biological aspect considers an individual's capacity to give and receive sexual pleasure; thus, it covers the functioning of sexual organs and the physiology of human sexual response<sup>(1,4)</sup> which comprises desire, excitation and orgasm<sup>(4-5)</sup>.

The psychological aspect refers to sexual self-image, characterized by the images people hold of themselves as men and women. These are influenced by the body image, which is the mental image people hold of their physical self<sup>(1)</sup>.

The social aspect involves the social gender role, which is a person's behavior as expected by the groups that person is part of, as well as the sexual role, that is, the way we picture how we feel as men or women to other persons and to ourselves. In this relation with the social environment, besides sexual behavior, sexual relations should also be included<sup>(1, 6-7)</sup>.

The North American Nursing Diagnosis Association's taxonomy (NANDA) considers alterations related to human sexuality in two nursing diagnoses: "Altered Sexuality Patterns", defined as "the state in which an individual expresses concern regarding his/her sexuality"<sup>(8)</sup> and "Sexual Dysfunction", conceived as "a state in which an individual experiences a change in sexual function that is viewed as unsatisfying, unrewarding, inadequate"<sup>(8)</sup>.

Based on these considerations, we hope to contribute to the construction of Nursing knowledge about human sexuality, stimulating nurses to take into account that the sexual dimension of human beings needs a systematic assessment.

## OBJECTIVE

Characterize the biological, psychological and sociocultural aspects involving human sexuality which are affected in patients with onco-hematological diseases.

## MATERIAL AND METHODS

This study was approved by the Research Ethics Committee at the University of São Paulo at Ribeirão Preto College of Nursing (Protocol 0270/2002)<sup>(9)</sup>. The phase described in this paper was developed at a medical-clinical hospitalization unit, in the hematology sector of a public hospital in Ribeirão Preto/SP, Brazil. The target population consisted of adult patients with onco-hematological diseases who were hospitalized and were sexually active before finding out about their current medical diagnosis, who had been hospitalized more than twice due to their disease, had been under chemotherapy for more than three months and possessed at least one of the nursing diagnoses on human sexuality presented by NANDA<sup>(8)</sup>.

During the six-month data collection period, 58 patients were hospitalized in this sector, 34 of whom did not comply with the inclusion criteria and three of whom were excluded due to HIV since, although they presented evidence of sexuality problems, it would be difficult to distinguish whether these problems were related to the onco-hematological disease or to the presence of the HIV virus. One of the remaining 21 patients refused to participate.

The data collection instrument was based on the eclectic model, that is, a multifocal approach was used, based on the characterization of individuals as biological, psychological, social and spiritual beings<sup>(10)</sup>. The search for data, through interviews and physical examinations, emphasized the biological and psychological aspects involving sexuality<sup>(1,10)</sup>, as well as social and spiritual aspects<sup>(1-2, 6-7)</sup>.

The diagnostic process was used to detect sexuality problems of patients with onco-hematological diseases, more specifically the phases of data analysis and synthesis<sup>(10)</sup>. During data analysis, aspects of patients' sexuality were categorized and their gaps were identified. When detected, these were solved by recurring to the data source. During data synthesis, these data were grouped and NANDA's taxonomy<sup>(8)</sup> was used to elaborate the nursing diagnoses on sexuality.

In order to detect a nursing diagnosis in a clinical environment, literature recommends that at least two competent nurse diagnosticians be present to observe the same client<sup>(11)</sup>. Thus, besides the researcher, two other clinical nurses participated in data collection, who are active in care delivery to hematological patients, are specialists in hematology and develop research on the nursing process and hematology. They took turns to collect data according to their availability. The researcher was present at all data collection sessions and was always accompanied by one of these two other nurses.

For the interviews, the researcher visited the patient in advance, presented herself, explained about the theme and the research objectives and requested permission to collect data. If the subject accepted, the researched informed that she would be accompanied by another nurse and, next, scheduled the data collection session on the date and time suggested by the patient.

After the interview, the two nurses analyzed data independently, according to literature recommendations<sup>(11)</sup>. While analyzing and synthesizing data, the nurses identified the presence of the nursing diagnoses "Sexual Dysfunction" and "Altered Sexuality Patterns" and their respective defining characteristics.

What the identification of nursing diagnoses in patients is concerned, the nurse diagnosticians agreed in all analyses, including in patients who did not attend to the study inclusion criteria.

With respect to the identification of defining characteristics for the studied diagnoses, inter-observer agreement corresponded to 98% for "Sexual Dysfunction" and 97% for "Altered Sexuality Patterns"<sup>(9)</sup>.

Agreement levels for the two nursing diagnoses under study were considered satisfactory for this kind of study<sup>(11)</sup>. The description of sample characteristics presents coinciding data for each patient by the two nurse diagnosticians.

## RESULTS AND DISCUSSION

The sample consisted of 11 men (55%) and 09 women (45%). The predominant age range was from 18 to 27 years. In terms of civil status, 55% were single, 35% married and 10% lived with a partner. As to education level, 50% had either finished basic education or not, characterizing people with low education levels. Ten percent of the subjects were illiterate.

With respect to biological aspects of sexuality, 60% of the sample indicated problems related to the sexual desire phase, 75% to sexual excitation and 75% to orgasm.

Subjects mentioned a decrease in sexual desire after the change in their health status; four of them reported that, before their current health condition, the stimuli that started the sexual relation came from themselves and their partner and that, nowadays, the relation only starts if the partner wants to. They also argued that, often, they only participate in the relation to satisfy their partner. These data evidence the perception of decreased sexual desire, an aspect that is not directly evidenced by NANDA, although it can be contemplated in the Sexual Dysfunction diagnosis through the defining characteristic: "actual or perceived limitations imposed by disease and/or therapy"<sup>(8)</sup>, however, without mentioning what sexual response phase the problem occurs in.

The decrease in sexual desire can be influenced by organic or psychological factors. Organic factors are mainly characterized by lower levels of the testosterone hormone, which is responsible for sexual appetite, due to chemotherapy, as well as by the lack of disposition resulting from severe anemia experienced by this clientele and by the presence of nausea and vomiting. Psychological factors are marked by constant suffering, fear and preoccupation due to the disease and treatment<sup>(6, 12)</sup>.

In the group of subjects who presented alterations in the sexual excitation phase, 66.7% were men and 33.3% women. Fifty percent of men affirmed difficulties to maintain and 50% to reach an erection; among women, the main problem was related to the lack of vaginal lubrication, provoking pain during sexual relations. Like sexual desire, excitation is not directly treated by NANDA, but can also be contemplated in the defining characteristic: "actual or perceived limitations imposed by disease and/or

therapy", present in the Sexual Dysfunction diagnosis, as it is one of the phases of sexual response<sup>(8)</sup>.

Sexual excitation problems among men are also influenced by the decrease in testosterone levels and by the onco-hematological disease itself, due to the frequent presence of anemia, which alters the vascular mechanisms of the erection, and to negative emotional factors. In physiological terms, testosterone levels can be reverted two to three weeks after chemotherapy<sup>(6,12)</sup>.

For women, vaginal lubrication problems can result from the reduction in estrogen hormone levels, also due to chemotherapy, whose clinical manifestations include decreased vaginal humidity and, rarely, a reduction in the diameter of the vagina<sup>(3, 13)</sup>.

What the orgasm phase is concerned, 80% of the sample perceived alterations in achieving sexual pleasure; however, 75% mentioned they were sexually unsatisfied, even after changing their sexual practice to continue achieving pleasure. Three subjects interrupted sexual activity because of difficulties to obtain pleasure. In NANDA, these data are contemplated in two defining characteristics of the Sexual Dysfunction diagnosis: "inability to achieve desired satisfaction" and "alteration in achieving sexual satisfaction"<sup>(8)</sup>.

Alterations most frequently mentioned by the subjects included the need for greater stimulus and concentration to achieve pleasure and changes in position during the relation. These changes refer to passiveness during the sexual act, arguing that the achievement of pleasure started to depend on their sexual partner.

Literature does not indicate that chemotherapy provokes changes in the orgasm phase; this will only occur when neurological effects are present, such as neuropathies that affect the nerves governing the orgasm reflex. However, problems in this phase can be caused by pain during the relation or due to an emotional block provoked by the disease itself<sup>(13)</sup>.

Weakness and fatigue are frequent symptoms in patients with onco-hematological diseases, resulting from anemia and undesirable effects of chemotherapy, such as nausea, vomiting, intestinal constipation and diarrhea<sup>(14)</sup>. In turn, this situation influences sexual life and interferes in one or more human sexual response phases.

The psychological aspects involved in sexuality, which are related to the sexual self-image,

are affected in 60% of the subjects, who mentioned that they did not feel attractive/sensual to their partner, due to physical alterations provoked by the disease and chemotherapy, such as changes in skin color and texture, baldness and weight variations. These aspects can be covered in one of the defining characteristics for the Sexual Dysfunction diagnosis, that is, "seeking confirmation of desirability"<sup>(8)</sup>.

These changes provoke concerns about social acceptance. In the study sample, women indicated that, to avoid feeling disdained, they used scarves, wigs, hats, earrings, makeup and clothes to make themselves more attractive; moreover, they mentioned they were always asking their sexual partner if they still like them. One patient told that she liked to get compliments from her partner, while another woman said she was always looking in the mirror to see how different she was. A male patient also reported this behavior, while other male participants mentioned they ask their partners if they still feel the same way about them, in spite of the change in physical appearance.

Not feeling oneself attractive is one of the most negative effects of cancer treatment, characterized by the change in how people perceive their own body. For young and single patients, this experience can be physically and emotionally hard and can culminate in depression<sup>(12)</sup>.

As to the social aspects involving sexuality, 85% of the sample referred to some kind of problem interfering with their sexual activity or sexuality. These aspects can be observed in one defining characteristic of the nursing diagnosis Altered Sexuality Patterns: "reported difficulties, limitations or changes in sexual behaviors or activities"<sup>(8)</sup>.

The main difficulty or limitation characterized as a source of preoccupation that affects sexuality was the fear of acquiring an infection as a result of low immunity levels (70.6%). Other concerns mentioned were the possibility of infertility (11.8%), fear of not satisfying the sexual partner (5.9%) and of coping with sexual relations (5.9%); one patient affirmed she faced difficulties but could not give specific information (5.9%).

Due to frequent cases of neutropenia in these patients, which makes them vulnerable to infectious processes, patients protect themselves by using condoms during sexual relations and masks in specific places and situations, as well as by hospital isolation and even restrictions on kissing.

These protection measures interfere in patients' sexual behavior, not only during the sexual relation, but also in the way they express their sexuality, which is manifested by difficulties to find people to relate with, due to the use of masks and isolation.

One of the patients who believe difficulties are related to the possibility of infertility said he hid this fact from his girlfriend. In these cases, feelings of guilt are common, which can impair sexual relations<sup>(1)</sup>.

The fear of not satisfying the sexual partner and of coping with sexual relations may be related to a lack of communication between partners, who should mutually express their sexual feelings and not wait for the other person to discover his/her anxieties and needs<sup>(1)</sup>.

Besides these difficulties, it should be highlighted that 70% of the sample mentioned decreased sexual activity and even interruption after discovering the disease. Four subjects indicated they had stopped all sexual activity after the disease appeared.

At the start of treatment, these patients' sexual activity is related to the feeling of weakness and downheartedness, as highlighted in literature<sup>(1,14)</sup> and, later, to constant hospitalizations, lack of privacy, fear of infection and other psychological aspects related to the disease, which are also mentioned in literature<sup>(15)</sup>.

What the performance of sexual and social roles is concerned, 40% of subjects in the sample were concerned about their female or male role and about changes in their social role. Male subjects revealed a loss of socially valued personal characteristics in men, such as the absence of a beard and a muscular body, while women were worried about their femininity. One female subject mentioned she only had sexual relations if she is using a wig or scarf. With respect to social roles, the impossibility to do housework and perform their roles as mothers was mentioned as the greatest source of concern, arguing that the lack of these activities provokes a feeling of incapacity to be a woman. In NANDA, these data are contemplated in the defining characteristic "alterations in achieving perceived sex role" of the Sexual Dysfunction diagnosis<sup>(8)</sup>.

Patients with onco-hematological diseases no longer perform their social roles because they move away from their living routine and adopt the role of

'sick person', characterized by efforts to get treatment, seek care, comply with prescriptions and cooperate with doctors<sup>(1,12)</sup>.

Through their reports, these patients demonstrated that they are obliged to abandon, even if temporarily, their roles as fathers, mothers and professionals. During treatment, they live in hospital and, at home, they mention that they cannot perform even their family roles due to the effects of chemotherapy and related drugs.

With respect to sexual relations, 30% of the subjects reported changes in their relation with their sexual partner, mainly due to a lack of communication between both partners. This finding can be observed in the characteristic "alteration in relationship with significant other", proposed by NANDA as part of the nursing diagnosis Sexual Dysfunction<sup>(8)</sup>.

The lack of communication about feelings between both partners, characterized as sexual isolation, impairs the relationship<sup>(1)</sup>, as mentioned above. Three patients evidenced this fact, mentioning that the subjects of conversations were disease, treatment and family.

On the other hand, it should be highlighted that seven patients indicated their sexual relation changed for the better after the disease, as they felt more valued by their partner.

These results demonstrate that, during treatment, patients with onco-hematological diseases present problems related to sexuality and the sexual function.

## CONCLUSION

The characterization of onco-hematological patients' sexuality allows us to conclude that both disease and chemotherapy provoke signs and symptoms that collaborate to bring about alterations in sexual functions and in the way sexuality is expressed.

Alterations in sexual functions were centered in decreased sexual desire, erection and vaginal lubrication difficulties and alterations in achieving sexual satisfaction, provoked by the clinical picture of anemia, by chemotherapy and by the influence of the situation in the emotional sphere. These alterations are contemplated in the defining characteristics of the Sexual Dysfunction diagnosis, although the sexual response phases of desire and excitation can be incorporated to clarify this process.

As to alterations in the way sexuality is expressed, the fear of acquiring a disease due to a severe weakening of the immune system stands out, which frequently happens in onco-hematological diseases. However, it should be mentioned that this and other difficulties indicated by this sample lead to alterations in sexual behavior, ranging from decreased frequency of sexual activity to the extreme decision to interrupt sexual life after the diagnosis of the disease; these aspects are contemplated in the

defining characteristic "reported difficulties, limitations, or changes in sexual behavior or activities" of the nursing diagnosis Ineffective Sexuality Patterns.

These results strengthen the need to help these clients in aspects related to Human Sexuality, mainly by alerting nurses to prepare themselves to work in this area; to avoid their graduation with merely "fluid and limited notions of human sexuality, without a guiding base"<sup>(16)</sup>, without the competences needed to identify this kind of clinical evidence.

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