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RESEARCH

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Social representations of patients with head and neck cancer before the alteration of their body image

Representações sociais de pacientes com câncer de cabeça e pescoço frente à alteração da imagem corporal

Representaciones sociales de pacientes con cáncer de cabeza y cuello frente a la modificación de imagen corporal

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ABSTRACT

Objective: It intends to explore the social representations (SR) of patients with head and neck cancer before the alteration of their body image. Given that it is a stigmatizing disease, cancer brings another problem when localized in the head and neck area. **Methodology:** It is a descriptive study, with a qualitative approach, that employs the SR theory in 23 patients, all of which were diagnosed with cancer and with alteration of the body image. **Result:** Five units emerged from the content analysis: Mirror, Mirror on the Wall: Reflection of a reality; Mirror, Mirror on the Wall: Day-to-day changes; Mirror, Mirror on the Wall: Shame of the current image; Strength of Faith; and Reinforcing care of the self after body alteration. **Conclusion:** It shows the importance of the nursing professionals in being aware of the SR of these patients in order to, from this new knowledge, in practicing care, exercise a holistic and humanized service as possible.

Descriptors: Nursing, Self-perception, Social Psychology, Head and Neck Neoplasia.

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RESUMO

Objetivo: pretendeu-se explorar as representações sociais (RS) de pacientes com câncer de cabeça e pescoço frente à alteração da imagem corporal. O câncer por ser uma doença estigmatizante, traz consigo outra problemática quando localizado na região da cabeça e pescoço. **Metodologia:** Trata-se de um estudo descritivo, com abordagem qualitativa, empregando-se a teoria das RS em 23 pacientes, todos diagnosticados com câncer e com alteração da imagem corporal. **Resultado:** Na análise de conteúdo emergiram cinco unidades: Espelho, Espelho Meu: Reflexo de uma realidade; Espelho, Espelho Meu: Um cotidiano de mudanças; Espelho, Espelho Meu: Vergonha da imagem atual; A força que vem da fé; e Reforçando o cuidado de si após alterações corporais. **Conclusão:** mostra-se a importância do profissional de enfermagem em conhecer as RS desses pacientes para que a partir desse novo conhecimento possa, na prática do cuidado, exercer um atendimento mais holístico e humanizado possível.

Descritores: Enfermagem, Autopercepção, Psicologia Social, Neoplasias de Cabeça e Pescoço.

RESUMEN

Objetivo: El objetivo fue explorar las representaciones sociales (RS) de los pacientes con cáncer de cabeza frontal y el cuello del cambio en la imagen corporal. El cáncer a una enfermedad estigmatizante trae consigo otro problema cuando en la cabeza y el cuello. **Metodología:** Se trata de un estudio descriptivo con un enfoque cualitativo, utilizando la teoría de la RS en 23 pacientes, todos con diagnóstico de cáncer y el cambio en la imagen corporal. **Resultados:** En el análisis de contenido emergieron cinco unidades: Mirror, Mirror: Como reflejo de una realidad; Espejo, espejo: Un cambio diario; Espejo, espejo en la pared: La vergüenza de la imagen actual; La fuerza que viene de la fe; y el fortalecimiento de cuidar de sí mismos después de los cambios corporales. **Conclusión:** muestra la importancia de los profesionales de enfermería para satisfacer las RS estos pacientes por lo que a partir de este nuevo conocimiento puede, en las prácticas de atención, tomar una atención más integral y humana posible.

Descriptores: La Enfermería, La Autopercepción, La Psicología Social, Neoplasias de Cabeza y Cuello.

INTRODUCTION

Cancer is the name given to a grouping of more than 100 different types of diseases that, generally, have a disordered growth of abnormal cells with invasive potential. Its genesis occurs by extrinsic and intrinsic factors. These causal factors might act jointly or sequentially to initiate or promote cancer.[1]

Head and neck cancer comprehends a heterogeneous group of malign neoplasia, originated in the most part at the upper aerodigestive tract. A bigger subgroup of head and neck carcinoma that appears in the mucous membranes of the mouth and the pharynx is referred to as "oral cancer". Each neoplasia differs from the others for having its own epidemiology, genesis, pathological character, treatment and prognostic.[2-3]

In Brazil, the estimative for the year of 2016-2017 points to the occurrence of approximately 600 thousand new cases of cancer, including the cases of non-melanoma skin cancer. Head and neck cancer stays in 5th place (oral cavity) for the male sex and in 8th place for the female sex (thyroid gland). This data emphasizes even more the magnitude of the problem of cancer in the country.[4]

Cancer diagnosis and its treatment directly affect an individual's quality of life. Head and neck neoplasia, given their complexity and localization, interfere in the anatomical and physiological characteristics, being able to promote alterations that compromise aesthetic appearance, function related to eating, breathing, and to communication and social interaction.[3,5]

The different forms of treatment and localization of the lesion, the size of the extension and the stage of the disease create the possibility of several complications, such as xerostomia, radiation caries, osteoradionecrosis, mucositis, deforming resection, aphonia and reduction in olfactory function, being able to compromise significant psychosocial functions for the patients and their family. Additionally, the cancer itself might create anatomical and physiological alterations in an advanced stage.[2,5,6]

The diagnosis and treatment become something dreadful for these patients, since the patients face the possibility of their own death. This makes them reflect about their values, their spirituality and their life in general.[6] Hence has come questioning about the phenomena of the social representations in these patients, as this is about a pathology that affects the facial aesthetic of the subjects stricken by it, who feel in a certain way intimidated by the worship of beauty in society.

The following guiding questions were elaborated to conduct the study: What are the social representations of patients with head and neck cancer before the alteration of their body image?; and What are the implication of these representations for their own care?

To answer these questions, the following objectives were defined: Identify the social representations of a group of patients with head and neck cancer before the alteration of their body image in a distinguished state facility, Hospital Ohir Loyola; and Analyze the implications of these social representations for one's own care.

METHODS

It is a descriptive study with a qualitative analysis, viewed under the prism of the social representations. The descriptive study requires from the researcher a series of data about what is the aim of the study. This type of study intends to show the facts and phenomena of a specific reality.[7] We have chosen to follow the qualitative approach, as the interpretation of the collected data and the attribution of meaning are basic in the process of qualitative research, and, therefore, do not require the use of statistical methods and techniques.[8]

The social representations are forms of knowledge that reveal themselves as cognitive elements, but not only so. They are elaborate and shared social processes, which contribute to the construction of a common reality and enable communication between individuals.[9] [...] "the individual has

an active and autonomous role in the process of construction of society, and is likewise created by it. They also take part in its construction".[10]

Social representations constitute forms of socially formulated knowledge that are created by the groups of individuals to establish communication between themselves, and to understand everything that is strange and unfamiliar to them. Human beings are beings that question, seek answers, experience and share realities represented by themselves as much as they are affected by the external environment, which also influences their represented reality.[11]

The data collection was conducted by two techniques: free association of words and semi-structured interview. The semi-structured interview combines open and closed-ended questions, in which the respondent has the possibility to elaborate on the proposed theme, without answers or prefixed conditions by the researcher.[12] The instrument for data collection in the interviews was an interview script that guided the collection of information with questions related to the object of investigation.

The content analysis technique was employed in the research. This technique is [...] "a set of techniques of communication analysis that seeks to obtain indicators that allow the inference of knowledge relative to the production/reception conditions of these messages".[13]

Among the several investigation techniques present in the content analysis, we have chosen to utilize the thematic analysis, in which were gathered the common themes that repeated the most in the collected material. This technique is called categorical analysis, which consists in counting the frequency in which the accounts in an interview recur.[14]

During the research, 23 patients were interviewed. They were from a distinguished oncological hospital in the public healthcare network of the state of Pará. They were undergoing radiotherapy treatment and/or were hospitalized, and had body alteration in the head and neck area due to the tumor itself or due to the surgical procedure.

The study obeyed all the required criteria in a research project according to measure 466/12, especially what concerns free and informed consent, having been approved by the Ethics Committee under number 851.370.

RESULTS AND DISCUSSION

Characterization of the subjects

In the sociocultural analysis concerning the sex of the respondents, we have observed a higher frequency of the male sex with 60.80% (14), against 39.13% (9) of the female sex. According to the literature, the occurrence is higher in men than in women on a 5:1 basis, over 40 years of age, and the main risk factors are consumption of tobacco and of alcoholic beverages.[15]

The age of the respondents varied from 21 to 84 years, prevailing the age group between 40 to 59 years, which represented 47.82% of the total. Epidemiological evidences show that the incidence of HNC increases with age, being considered rare in young patients. Only 4 to 6% of the cases occur in individuals with less than 40 years of age, yet this incidence has increased in several countries according to new research.[3]

Most of the respondents come from the Pará state's countryside (69.56%), while those from the capital totaled (17.39%) and those from other states represented (13.04%) of the sample. This information is important, since the place of origin of the patients influences their customs and habits, thus reflecting their social representations.

On what concerns the marital status of the respondents, it was evidenced that most (43.47%) live in a situation of stable union/married. As for their number of children, a variation between 0 and 17 children was seen, and most of the respondents declared that they had more than 1 child.

The obtained result referring to the religion of the respondents was that 47.82% self-declared Catholic, there being the same percentage (47.82%) for Evangelicals and 4.34% of Protestants. As for the level of education of the interviewed patients, it was seen that none had completed high school and 69% declared to have incomplete middle school, which demonstrates low school level among the participants. The socioeconomic and educational level influence the emergence and evolution of disease, as the low level of instruction interferes in the process of self-care and in the disease prevention efforts.

The great majority of the respondents (39.13%) are rural workers. The [...] "occupational factors – such as working in an external environment (with prolonged sun exposure), exposure to Asbestos and other chemical substances – also have been associated with head and neck cancer".[16] And around 100% of them have stopped their daily activities and work, either by medical recommendation, or for shame of their alteration or for being impaired.

The analysis of the sociocultural profile of the respondents of this study is important as it has the purpose of comprehending the cultural context in which they are inserted, as well as the social representation related to patients with head and neck cancer before the alteration of their body image, so that we might provide more adequate and humanized care to these clients. After the thematic analysis, 5 categories were found:

Mirror, Mirror on the Wall: Reflection of a Reality

Among the several reasons for sadness, illness overall is one of the main causes responsible for bringing sorrow to people, as it can lead to incapability and debility that move the diseased away from their daily life, their family and their life plans. Diseases such as cancer may cause sadness, distress, low self-esteem and even depression.

So, this leads us to believe that the opposite of this, the absence of infirmities, turns health into a condition for happiness. Concerning this fact, we realized that, through the analysis of the results of all 23 interviewees, that is, 100% of the respondents stated that they felt well and happy before falling ill and with alteration in their body image.

[...] Before, I was cheerful, I liked to play, I liked to work, to live life, right! (E1)

It was normal, satisfying, cheerful, eh! I thought I had nothing. (E10).

[...] "happiness is a basic emotion characterized by a positive emotional state, with feelings of well-being and pleasure".[17] The term "happiness" has been translated as subjective well-being.[18] Therefore, the fact that the subjects are healthy makes them able to exercise the activities that provide them pleasure and well-being. As we can understand from the statements below:

[...] I enjoyed going out, playing, studying, with my family. And today, after I got sick, as I said, everything changed. (E4)

I felt good, as I'm saying I like my activities, I like to dance, to go to the elderly's association, I liked to run, to play soccer, I enjoyed everythinh from the elderly, now I can't do it anymore [...]. (E6)

Health is a basic elemento for our well-being, as it is just with it that we can exercise the several activities that provide us feelings of wholeness, satisfaction, cheerfulness and pleasure. We only realize how essential it is when we fall ill and are unable to exert our functions, creating sadness and discouragement.

The constant search for an ideal body pattern, associated to happiness, is the main cause of alteration of perception of the body image, since [...] "we live the worship of image, of pose and of beauty as a way of maintaining health, joy and well-being".[19] Seen in this manner, we understand that the body is a construction susceptible to changes that depend not only on the biologic, but also in the meanings of the daily life built by the social environment.[13,20] Among the respondents, 21 of them stated that they felt "diferent", that is, showed an altered perception of their body image, corresponding to 91.3%. Additionally, 16 of them referred to sadness after the alteration of their image, equal to 69.5%.

Ugly now, because I've got this. (E3)

I see myself differently, right! From what I was. (E9)

Now if I look myself in the mirror I'll just... only God knows... A ghost. I'm not that person I was at first, you know? Because of this disease that broke me down little by little. (E18)

These aesthetic alterations modify the perception of body image that individuals have of their own body, and that will lead them to build a tortuous self-concept that affects their social life, taking into consideration that there is a valorization of a body considered "ideal" in our society.

These alterations affect the subjects in their totality and drastically in their interpersonal relations.[21] [...] "The literature states that the aesthetic aspect plays an importante role in the social interaction between individuals, and facial deformities seem to cause much more impact than other physical incapacities.".[22]

[...] Because something like this here, when it happens to us, we get very depressed. (E1)

Like, I have a photo album, memories and such... and I was a normal person.(E4)

Besides the several difficulties and obstacles that the patients of the head and neck clinic face for being ill, they also have to live with feelings of rejection, shame, exclusion, isolation, submission and passivity, feeling condemned because of their physical alteration.[23]

From the statements of the respondents, we can say that their social representations have emerged through their experiences/livingness related to the loss of their identity and happiness, which stimulated the construction of their concepts of abnormality and unhappiness because of their disease and the alteration of their image.

We know that the daily life of nursing is providing care for hours, what entails a relation with these patients, usually apprehensive and undermined because of this pathology, so, they yearn for attention, safety and even emotional support from the nurse.

That way, it is fundamental that a care planning for these patients is carried out by the nursing team, anticipating moments of dialogue that will serve as assistance in overcoming these adversities. As much as essential is the establishment of a relation of trust and help, in which the clients are able to have their questions answered, speak about their new reality, about their expectations and both their negative and positive feelings.

Mirror, Mirror on the Wall: Day-to-day changes

The oncologic patients, due to their state of infirmity, might face great difficulties, such as: alteration of the body image, social isolation etc. These alterations may culminate in psychological suffering, which can be observed by symptoms

of depression, anxiety, despair, feelings of fear and uncertainty about the future and dissatisfaction with their body image.[25]

In this category, it was observed that 91.3% (21) of the respondents reported changes in their daily life because of the disease. We realized through the statements that their lives changed completely, that they feel weakened, dependant and prevented of exercising their work activities. All 23 respondents had to stop working and even halt their leisure activities. Everything due to the hospitalization and to the treatment that leaves them impaired.

My life before, I went to school, I went out, I had my activities that I did gymnastics, I was never still, never felt pain or anything… Today everything is hard. (E9)

For me everything became bad, see. For me it ended half of my life. (E1)

It changed because now I can't do anything. Now I'm paralytic. (E5)

The patients with cancer stated that they face several difficulties, resulting from the change in habits, from the limitation and from having to move away from what provided them pleasure. The account that their activities became restricted to the space of their own home or of the hospital shows that these patients ended up being excluded from social interaction. These transformations in the routine of the patients complicate the situation they are in (falling ill) and maximize their feelings of anguish and uncertainty about their possibilities as a Being.[26]

A lot of things changed because now I can't work anymore, right? I depend on my children, husband. (E8)

I worked a lot, I walked, danced, jumped, I did everything. (E11)

[...] I was a collector of recyclable materials in the city where I live in, but the sun ruined me and created what you're seeing. It was a normal life until this appeared, right? (E18)

The act of working is one of the forms by which the subjects express themselves, identify with themselves and become fulfilled as a Being in the world. The disease generates physical incapacity, interfering and preventing the exercise of the daily activities of work, what triggers feelings that repress the quality of their existence. Therefore, not only does the pathology affect the personal fulfilment of the individuals, which is obtained through work. There is also the fact that the financial difficulties resulting from this absence from working life during the treatment period worry those whose family depends on their income, and especially those that know they will need to stay away indefinitely from their activities, even after their hospital discharge.[26]

In our society, we all play several roles. Some of these roles such as occupation or profession are responsible for the construction of our identity. [...] "Our capacity to perform accordingly to the social expectations, as well as to our own expectation about the specific behaviors of our role, or our role performance, is easily compromised by illness and by lesion".[27] [...] "Therefore, all those whose roles are altered or compromised are at risk of disturbance in their self-concept".[27]

For these patients to live in a capitalist society, the impossibility of working, of supplying their own needs and of providing good financial conditions to their family makes them feel like a disposable human being, a depending person without autonomy, a being that does not comply anymore to the productive requirements of a consumerist society.[26] There are studies that show the correlation between the low level of schooling and precarious socioeconomic conditions. For this population, the impact of the disease is even more severe, because the patients and their relatives already find themselves in a condition of social vulnerability, facing difficulties when accessing goods and services to satisfy their basic needs, such as the slowness in the Unified Health System (SUS) service.[28]

This context can be a producer of feelings of incapacity and disgrace towards society, becoming a difficulty factor for one to retake or even reinsert oneself in work activities, as well as in the social activities of leisure and in interpersonal relationships, highlighting social isolation as a recurring defense mecanism.[21]

These several transformations in the patient's life require a reorganization of plans. All of these factors singly or jointly can cause discomfort, suffering, loss of self-esteem, social isolation and even depression. Over this, the nurse must understand that taking care of severe patients is something complex and even more complicated when the life and work conditions of these patients are precarious. This professional must adequate the need of the patients to their new reality, which implies a singular experience, since each patient has socioeconomic determinants that impose on them adverse life conditions towards other subjects.

Mirror, Mirror on the Wall: Shame of the Current Image

The face of a person is their identity, and when it is altered, the subject feels a distortion in their self-image; from this, comes a feeling of embarrassment and worry with the evaluation of other people over their real or imagined physical form.[29] We can observe that 69.5% (16) of the respondents felt shame because of their image after the emergence of the disease, as all of them had apparent physical alterations.

It changed, like, I felt kind of shameful with this thing in my face, right? I felt, like, worried with this thing in my face, because of its appearance, right? (E14)

The alterations caused by the cancer itself or by surgical interventions [...] "disfigure the face of an individual, causing impact and surprise to those who see them and a feeling of exclusion and embarrassment in those that have it".[30] The localization of the tumor is what determines this feeling of shame, since, as it has already been said, the head and neck area leaves the person exposed. [...] "In these patients the disease manifests itself literally in a wide open way, being something they cannot hide from the observation and judgment from others".[21]

It was shameful. It was very sad. [...] I couldn't walk in the middle of the crowd. I felt shame, right. [...] Too much shame. It was this big [...] it expanded almost to the size of my hand, weighing almost a kilo. I barely walked on the street. I didn't because I felt shame. I isolated myself because I was ashamed. (E20)

This unity shows how hard it is for the patients to live with the alteration in their image in the head and neck area. The appearance, in this situation, triggers negative feelings that start to affect the patient's self-esteem and produce internal conflicts.

And because it really is a piece that you didn't have, you are born alright, huh... a piece that becomes part of you, those people think it's ugly and all[...]. (E5)

There is a difference, because when I was without it I looked at myself in the mirror and it seemed all right. (E7)

Look, this disease is uncomfortable anyway. And we feel the prejudice. People look at you with a difference for sure, for sure. (E13)

[...] "The facial deformity and the limited movements, aside from impairing the aesthetic and functionality, can also interfere significantly in interpersonal communication". Aesthetically, the disharmony between facial mimic and speech is embarrassing, not only for the subjects stricken by the disease but also for those that surround them.[31]

These patients end up having to face prejudice and stigma that might occur in several ways: revolt, social isolation for fear of being humiliated, contempt for the opinion of others, feelings of negative character, resignation etc. The definition of stigma on what concerns cases of body image altered by oncological surgeries [...] "can be defined as: a depreciative attribute, a disadvantage, an uncommon characteristic that is not well accepted by society, which makes the individual be ostracized by the community".[32]

The patients face an even greater difficulty in becoming absent from home, because there is the feeling of shame due to the exposition of their transfigured face, which makes them vulnerable to the judgment of others, which in turn creates feelings of rejection and social alienation. Many times, such situation might create risk for important depressive behaviors.[21]

Every mutilation and deformities suffered by the subjects alter their aesthetic. This causes a barrier in social relations and interactions that affect the emotional state of the patients and their life overall. The person becomes isolated and sad not just due to the fact of being physically ill, but also for having to face unwanted judgment and evaluation, which in its turn sickens the soul as well.

That way, health professionals must seek to understand what these patients are experiencing, because they might be at risk of also judging them and hurting directly or indirectly through a simple look, since [...] "there are looks that kill.[23] Well, there are looks so intense towards them that the individuals feel completely threatened and even violated in their innerness. Likewise, looking in someone else's eyes in a welcoming, comforting and sympathetic manner can transmit the sensitivity to be exercised by the nurses and other professionals.

In this moment when there is a loss of the ideal body image, strategies to overcome this situation and help from relatives to face the new reality are necessary. Likewise, the nurse's assistance is indispensable, not only in technical work, but also in psychological support and in not judging, so that these patients feel holistically accepted, well cared for and supported.

STRENGTH THAT COMES FROM FAITH

The oncological patient goes through several traumatic events, losses and limitation, which cause situation of stress, anguish and fear.[33] In the face of such physical, psychic and emotional suffering, the human being tends to search for answers in religion and also seeks emotional support to face the adversities imposed by the disease.[34-35]

Cancer diagnosis causes a strong impact in the lives of those who have it. To deal with this condition, patients employ different coping strategies as attempts to overcome the cause of distress. Coping is defined as a cognitive and behavioral effort from the individual aimed at the process of administration of the internal and external demands (person-environment) that are evaluated as overload and distress.[36-37]

[...] "Overall, religion is a reflexive and symbolic means to reorder reality, either for the proximity of death, or for solving afflictions".[38] We observed from the statements of the respondents that at the moment of despair and affliction they attach themselves to their faith seeking comfort and answers. The interviews resulted in 43.4% (10) of the individuals searching for strength and hope in religion.

[...] I trust our lord Jesus Christ very much, and he doesn't let fall those that trust him. (E6)

I see myself differently, right! Because of my eye like this, but I don't give up hope because God is going to bless me, cure me from faith in God. (E9)

There are times that I pray to God to give me strength, you know? There are times when I get too sad and so I ask strength from God, you know? Well... And so living life is got to be the way God wants. (E10)

For most of the patients, that irreversible pathology which medicine cannot cure is treated as a disease of spiritual nature that can be treated in this domain, since the cause, for exceeding medical competence, would be in the realm of religion.[38]

Both for the Catholics and for the Evangelicals, the cure for irreversible and severe infirmities is achieved by the grace of God, as nothing is impossible for him. The faith placed in the belief of physical and spiritual salvation is what strengthens and gives hope to the patients. In the Bible, the group of books used by these two religions, several passages reveal cure and even resurrection achieved by faith.

The patients diagnosed with cancer must be understood holistically, "considering their religious/spiritual aspects, so that they are respected as much in their singularity as in their beliefs and values". And religious coping figures as an important component in the adherence to the treatment, in the combat of the problem, in the reduction of distress and anxiety, and in the search of meaning for their current situation[36]

In moments of adversity, the patients manage to gather strength from their weaknesses, especially when they are involved in a social environment that offers them some kind of help, turning their reality into a bearable one, as is the case of the support given by religious groups of the subject's own faith, that promote a feeling of belonging and aggregation inserting the subject in social life.[34]

There are researches showing that religiosity is associated to psychological well-being, happiness and satisfaction with life. And those persons that are religious have lesser incidence of cases of depression, suicide thoughts and drug abuse. It is worth noting that risk populations such as elderly or diseased in palliative care manage to achieve higher quality of life when they exercise their spirituality or religiosity in their daily life.[17,34]

Although there are not enough studies that prove that the participation of religion has decisive effectiveness in the healing process, its influence on the individual's well-being is undeniable. It improves quality of life and reduces the rates of depression and suicide thoughts. Therefore, faith is the support and the strength to bear the moments of affliction and suffering. This is so because, from the discovery to the treatment of the disease, the subjects go through hard times when they think (in many cases) that they will not be able to overcome this adversity.[34]

Consequently, respecting the individual's belief, and taking it into consideration, contribute to a better professional-patient relation. [...] "It is desirable that the nurse know the sources of strength of the patients, encouraging them and reinforcing their faith, in order to promote the comfort and safety that spirituality or religion offer".[39]

However, despite the interest in appreciating the subjectivity of professionals in palliative care units, incompetence to deal with the religious aspect during service still prevails. The lack of preparation and ability to recognize the patient's requirements, as well as the fear of influencing the patient's beliefs, leads to denial or rejection of the spiritual dimension.[40]

Reinforcing Care of Self after Body Alterations

Foucault says that care of one's self involves the knowledge that the patients have of their own life condition, of their health and their limits. This self-control is indispensable in the process of several other internal cares of the self: political, biological, social and psychic. The empirical concept on care is related to the way that the persons experience their practices and observe the others. Common sense, observation and experience allow understanding about what is care and, thus, builds the social meanings of self-caring.[41]

Care of self promotes the self-reflection of the individuals, the overflow of their emotions, absorption of their experiences and their self-perception as a subject, whose subjectivity and sensitivity are being put into operation. Therefore, self-knowledge and care of self are part of the process of learning how to care.[42] This care is necessary to establish physical-functional autonomy and conservation of one's mental independence.

Autonomy is understood as one's competency to do things for oneself, of being able to choose and expose thoughts, and acting with compromise. It corresponds to the right to make their own choices and being the main actor in their process of health/disease and, then, assuming the consequences of the change in their state of health. Therefore, it is the right of oncological patients to be informed about their diagnosis, treatment and prognosis, so that they might understand and decide how they will manage the process of caring of themselves during this stage of their life.[43]

In this context about one's care of self and autonomy to manage this care, we can observe that the patients have an important role in their health/disease process through their decision-making ability and change of habits, as we could observe in the statements given, in which we noticed that there was an accentuated change in their attitude. About 100% (23) of the respondents said that they began to worry more about caring for themselves and changed habits from empirical knowledge and due to medical orientations.

Look, even more care because today, now that we've got the problem of this disease, then we've got to take more care, since we can't do what we used to do anymore, right? I worry more because we've got our family. And we worry with ourselves, with our family. (E13)

And not going out in the sun, try not to stress myself, I can't go out in the sun, or drizzle, or eating remorse food. All that can alter it. (E4)

Ah! I think every care. I think it's about never waiting until the last minute to care for the disease. I tried to avoid many thing, I used to drinks lots of alcoholic beverages. Now it's towards a totally different life. (E15)

Look, I didn't worry much before because I didn't know what kind of disease it was. I discovered about is later, and then we began to take the most necessary care. For example, I didn't even care to wash my hands, grab something, now we've got to be washing our hands, using alcohol gel, these things, right? To guard against the situation of the disease. (E16)

It is through this care for themselves that the subjects regulate their w=own wills and actions according to utility and benefits for their life, as it involves the patients in practices that avoid, reduce and prevent damage. [...] "The social representations must be seen as a specific manner to understand and communicate what we already know".[11] Therefore, the social environment assists in the construction of concepts and knowledge that affect the practices of the patients to care for themselves.

These practices and concepts are built by empirical knowledge, through orientations given by others and knowledge from the individuals themselves that was acquired during their life experience. The scientific ones are built through orientation from the professionals as well as by scientific means. Thus, [...] "caring for oneself goes through dialogue with oneself and through dialogue with others".[42]

From this, Mostardeiro et al. highlight that the proximity the nurse has with the patient, during the process of care, might stimulate feelings of hope and valorization of life. [44] The care with the patient must go beyond technical assistance; it needs to establish a bond of trust and complicity.

It is indispensable that the professionals valorize their patients as beings that think and feel and that are able to manage their own lives.[45]

The nurse has the function of promoting the biological, psychic and social development of the patients through the disclosure of information, education for health and intensification of life skills. This way, they will promote to the subjects a greater control over their own health, as well as the ability to choose situations that lead to a better health. It is essential to capacitate people to learn to deal with the adversities that the diseases cause on them in several stages of life, what includes, for example, facing chronical diseases, as well as valorizing the patient's care of self and helping to achieve autonomy in care.

Care of self valorizes the subjectivity of human beings and requires that the nursing team support the persons in caring for their health, aiming to provide for a better quality of life. It is important that the professional, besides providing assistance, also valorize the autonomy of the patients in the process of care of themselves, in order for them to be as independent as possible.[43]

The research through the social representations was necessary for better perception and comprehension of the feelings that intertwine and run through the soul of these patients with alteration of their body image due to the disease and surgical interventions, with the intention of detecting and planning actions that allow us to meet this expectations and yearnings.

[...] "the nurse is the member of the health team that usually remains alongside the patients during all the health-disease process, what makes them a prime element for the success of the treatment".[6] Therefore, it is of great importance that the nurse have a sensitive observation towards the physical and emotional changes that the patients are through, taking into consideration their biopsychosocial aspects to offer them a holistic service.

We believe that, through the results of this study, nursing can improve its assistance to its clients, seeking to provide an increasingly humanized and integral service. Through this, nursing can also devise actions that work on the self-esteem of the patients with alteration of body image, providing them better quality of life, through care directed to their physical, psychic and social well-being.

CONCLUSION

This study has evidenced the social representations of patients with head and neck cancer before the alteration of body image. When carrying it out, we had the task of not only explaining the facts, but of going beyond it, aiming to understand and reflect on the human feelings of those that face and live a new reality and what it means for them. Therefore, the way the subjects expose the phenomenon that they live, in a specific time and space, reveals their world and their experiences. This research can contribute for the nursing professional in the development of a critical thought that might facilitate the relation with the patients and understand their social representations, devising strategies over this that can improve the care directed to this specific social group.

We have observed that the patients with head and neck cancer go through several negative experiences before, during, and after their treatment. This affects them directly, not only in the physical field, but also in the diverse areas that shape their being, their spiritual, economic, social, emotional and familiar sides are impacted. This makes the patients have a

new look about their life and about the environment that surrounds them.

In the first thematic unity, we have seen in the statements of the respondents that most of them related the disease to feelings of sadness and anguish, also reporting to have felt "different" from others. This shows how much cancer is a disease that causes a psychological shock in the persons that acquire this pathology. Sadness, discouragement, lack of hope and even depression are observed. Besides all of this, it also causes an alteration in the perception of their body image, as it is something that is visible and that causes irreversible deformities, as well as bringing changes to the patient's life overall.

In the second thematic unity, it was observed how much head and neck cancer alters the life of the patients. They have their daily life completely changed due to the treatment, having to abandon their homes to be hospitalized, they need to give up their jobs, the activities that provide them pleasure, and often become dependent on the care of others, their body image is altered, they change their habits completely, and even state that their life ended and that they feel paralytic. We understood that this disease impairs their basic needs and that these patients experience a cruel reality in which they may even lose the joy of living.

In the third unity, we have noticed from the statements that the patients feel ashamed for their image, they feel ugly and judged by the looks of others, for their scars or anatomical deformations created by the pathology or by onco-surgery, but that is not what defines this problem, the way that they face this situation is. We know that the discovery of cancer is something very impacting and hard to any person, as it is something that generates fear and uncertainty about death. Besides this aspect, the patient still has to deal with the impairment of their appearance and with prejudice and lack of understanding from others that do not comprehend their situation and pathology. This intensifies the psychological damage and creates a greater obstacle to be faced by the diseased.

In the fourth thematic unity, we realized through the statements that having a cancer that causes deformation in the identity and life of a subject is something very painful, and in this moment religiosity becomes a great ally to face this pathology, because it functions as a support in the search for healing, it is the foundation that upholds them and gives them strength to continue in the treatment journey, and also helps to maintain hope on the future. This way, we observed that the support that comes from faith in God has become an element of great importance for these patients, as it helps them to face their fears and reduces their suffering.

In the fifth thematic unity, we analyzed by their statements that the patients reported not having the due care with their health before the emergence of the disease, but began to worry more with the care of themselves and that also changed their habits after being diagnosed with the pathology. From empirical knowledge and medical orientation, they began to take care of themselves changing eating habits and their attitude towards sun protection, among other preventive measures, with the objective of achieving some improvement in their clinical picture or also aiming to avoid complications.

In this sense the nursing team must be prepared to provide integral care, that is, not only physical, but psychic as well, giving courage and offering support for the patients so that they are able to face and overcome their problems and difficulties. Having in mind a humanized care that considers the beliefs, values, feelings and emotions of the patients. This way, the professional must have the capacity and ability to detect, feel and interact with the client, establishing an integral and individualized relation of trust and support.

What we could understand from the statements of these patients is that they need a sensitive listening, in which they may express what they are feeling, their anguish and fear. Most of all, they must be treated ethically, with respect, dedication and love. After all, caring is putting oneself in the other's place; it is being attentive, watching for the other, understanding their experiences and living, and so being capable of providing a humanized and holistic service.

REFERENCES

1. Instituto Nacional de Câncer (BRASIL). Câncer: O que é; 2014.
2. Lopes A, Iyeyasu, H. Oncologia para a graduação. 2ed. São Paulo; Tecmed; 2008.
3. Alvarenga ILM, Ruiz MT, BertelliIII ÉCP, Ruback MJC; Maniglia JV, Bertollo EMG. Avaliação epidemiológica de pacientes com câncer de cabeça e pescoço em um hospital universitário do noroeste do estado de São Paulo. Revista Brasileira Otorrinolaringol. [internet]. 2008 JANEIRO/FEVEREIRO. ISSN 0034-7299. Available at: http://dx.doi.org/10.1590/S0034-72992008000100011.
4. Instituto Nacional de Câncer José Alencar Gomes da Silva (BRASIL). Coordenação de Prevenção e Vigilância Estimativa 2016: incidência de câncer no Brasil / Instituto Nacional de Câncer José Alencar Gomes da Silva. Rio de Janeiro: INCA, 2015.
5. Sommerfeld CE, Andrade MGG, Santiago SM, Chone CT, Carvalho GM, Aquino Y et al. Qualidade de vida em pacientes com câncer de cabeça e pescoço. Rev. Bras. Cir. Cabeça Pescoço, [Internet] 2012 Dec. V.41, nº 4, p. 172-7. Available at: http://www.sbccp.org.br/wp-content/uploads/2014/11/REVISTA-SBCCP-41-4-artigo-04.pdf.
6. Mohallem AGC, Rodrigues AB. Enfermagem oncológica. Barueri (SP): Manole, 2007.
7. Tatiana Engel Gerhardt e Denise Tolfo Silveira; Métodos de pesquisa / coordenado pela Universidade Aberta do Brasil – UAB/ UFRGS e pelo Curso de Graduação Tecnológica – Planejamento e Gestão para o Desenvolvimento Rural da SEAD/UFRGS. – Porto Alegre: Editora da UFRGS, 2009.
8. Prodanov CC, Freitas EC. Metodologia do trabalho científico métodos e técnicas da pesquisa e do trabalho acadêmico [internet]. 2. ed. Novo Hamburgo: Fev, 2013. Available at: http://www.feevale.br/Comum/midias/8807f05a-14d0-4d5b-b1ad-1538f3aef538/E-book%20Metodologia%20do%20Trabalho%20Cientifico.pdf.
9. Jodelet D. Representação Social: um domínio em expansão. RJ: Ed UERJ, 2001. Available at: https://pt.scribd.com/doc/61566294/Representacoes-Sociais-Cap-01-Jodelet.
10. Alexandre M. Representação Social: uma genealogia do conceito. Rio de Janeiro - v.10 - nº 23 - p. 122 a 138. Dec 2004. Available at: http://www.sinpro-rio.org.br/imagens/espaco-do-professor/sala-de-aula/marcos-alexandre/Artigo7.pdf.
11. Moscovici S. Representações sociais: investigações em psicologia social/ Serge Moscovici: edited in English by Gerard Duveen:

translated from English by Pedrinho A. Guareschi. -5th ed. Petrópolis, Rj: Vozes, 2007.

12. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 10 ed. São Paulo: Hucitec/ABRASCO, 2007. 269 p.
13. Bardin L. Análise de conteúdo. Lisbon: Edition 70; 1977.
14. Caregnato RCA, Mutti R. Pesquisa qualitativa: análise de discurso versus análise de conteúdo. Texto Contexto Enferm, Florianópolis, 2006 Oct-Dec; 15(4): 679-84.
15. Fernandes GM, Bergmann A, Oliveira JF. Análise epidemiológica de população com câncer de cabeça e pescoço: influência sobre as complicações pós operatórias. Rev. Bras. Cir. Cabeça Pescoço, v.42, nº 3, p. 140-9, Sep 2013.
16. Boing AF, Antunes JLF. Condições socioeconômicas e câncer de cabeça e pescoço: uma revisão sistemática de literatura. Ciênc. saúde coletiva [online]. 2011, vol.16, n.2, pp. 615-622. ISSN 1413-8123.
17. Ferraz RB, Tavares H, Zilberman M L. Felicidade: uma revisão. Rev. psiquiatr. clín.[online]. 2007, vol.34, n.5, pp. 234-242. ISSN 1806-938X.
18. Scorsolini-comin F, Santos MA. O estudo científico da felicidade e a promoção da saúde: revisão integrativa da literatura. Rev. Latino-Am. Enfermagem, Ribeirão Preto, v. 18, n. 3, p. 472-9, Jun. 2010.
19. Slomka M. Corpo e juventude: a nomeação do outro na escola. Master's Dissertation, in Education- Research in Ethics, Otherness and Language in Education, Universidade Federal de Porto Alegre, Porto Alegre, 2006.
20. Paixão JA, Lopes MF. Alterações corporais como fenômeno estético e identitário entre universitárias. Saúde debate [online]. 2014, vol.38, n.101, pp. 267-276. ISSN 0103-1104.
21. Leitão BFB, Duarte ÍV, Bettega PB. Pacientes com câncer de cavidade bucal submetidos à cirurgia: representações sociais acerca do adoecimento e tratamento. Rev. SBPH, Rio de Janeiro, v.16, n.1, Jun. 2013.
22. Cadena SMD, Guerra CMF. Aparência Facial e a imagem ideal. Rev. Dental Press Estét. 2006 jan./feb./mar.;3 (1):27-38. Available at: http://www.dentalpress.com.br/cms/wp-content/uploads/2009/04/v3n1_2.pdf. Retrieved in May 12, 2015.
23. Mostardeiro SCTS, Pedro ENR. O cuidado de enfermagem em situações de alteração da imagem facial. Rev Gaúcha Enferm. Porto Alegre (RS) 2011 Jun;32(2):294-301.
24. Nogueira, MLF. Afastamento por adoecimento de trabalhadores de enfermagem em oncologia. Dissertation (Master in Nursing). Universidade Federal do Estado do Rio de Janeiro- UNIRIO, Rio de Janeiro, 2007.
25. Santana JJRA, Zanin CR, Maniglia JV. Pacientes com câncer: enfrentamento, rede social e apoio social. Paidéia (Ribeirão Preto) [online]. 2008, vol.18, n.40, pp. 371-384. ISSN 0103-863X.
26. Siqueira KM, Barbosa MA, Boemer MR. O vivenciar a situação de ser com câncer: alguns desvelamentos. Rev. Latino-Am. Enfermagem [online]. 2007, vol.15, n.4, pp. 605-611. ISSN 1518-8345.
27. Taylor CR, Lillis C, Lemone P, LYNN P. Fundamentos de Enfermagem: A Arte e a Ciência do Cuidado de Enfermagem; 7.ed. Editora Artmed, 2014.
28. Carvalho CSU. A necessária atenção à família do paciente oncológico. Revista Brasileira de Cancerologia, 54 (1), 97-102. 2008.
29. Santos VM, Mezzaroba C. A percepção da imagem corporal: algumas representações de corpo na juventude. EFDeportes.com, Revista Digital. Buenos Aires - Año 18 - Nº 182 - Jul 2013.
30. Mostardeiro SCTS, Pedro ENR. Pacientes com alteração da imagem facial: circunstâncias de cuidado. Rev Gaúcha Enferm. Porto Alegre (RS) 2010 Mar;31(1):100-7.
31. Silva MFF, Cunha MC, LazarinI PR, Fouquet ML. Conteúdos psíquicos e efeitos sociais associados à paralisia facial periférica: abordagem fonoaudiológica. Arquivos Int. Otorrinolaringol. (Impr.), São Paulo, v. 15, n. 4, p. 450-460, Dec. 2011.
32. Queiroz MS. Câncer e deformidade facial: estigmas da diferença que causam sofrimento e dificultam o convívio social. Master's dissertation. Universidade Federal de Pernambuco. CCS. Odontologia, 2010.
33. Mansano-schlosser TC, Ceolim MF. Qualidade de vida de pacientes com câncer no período de quimioterapia. Texto contexto - enferm. [online]. 2012, vol.21, n.3, pp. 600-607. ISSN 0104-0707.
34. Geronasso MCH, Coelho D. A influência da religiosidade/espiritualidade na qualidade de vida das pessoas com câncer. Saúde Meio Ambiente v. 1, n. 1, Jun. 2012.
35. Bousso RS, Poles K, Serafim TS, Miranda MG. Crenças religiosas, doença e morte: perspectiva da família na experiência de doença. Rev. esc. enferm. USP [online]. 2011, vol.45, n.2, pp. 397-403. ISSN 0080-6234.
36. Fornazari AS, Ferreira RER. Religiosidade/Espiritualidade em pacientes oncológicos: qualidade de vida e saúde. Psicologia: Teoria e Pesquisa, 26 (2), 265272. 2010
37. Costa P, Leite RCBO. Estratégias de enfrentamento utilizadas pelos pacientes oncológicos submetidos a cirurgias mutiladoras. Revista Brasileira de Cancerologia, 2009.
38. Borges ZN. Entrelaçamentos entre espiritualidade, religiosidade e crenças pessoais na doença renal crônica e no transplante de órgãos. Revista Sociais e Humanas, v.22: 1-13, 2009. ISSN 2317-1768 on line.
39. Nascimento LC, Santos TFM, Oliveira FCS, PAN R, Flória-santos M, Rocha SMM. Espiritualidade e religiosidade na perspectiva de enfermeiros. Texto Contexto Enferm, Florianópolis, 2013 Jan-Mar; 22(1): 52-60.
40. Gobatto CA, Araujo TCCF. Religiosidade e espiritualidade em oncologia: concepções de profissionais da saúde. Psicologia USP, São Paulo, 2013, 24(1), 11-34.
41. Foucault M. "A ética do cuidado de si como prática da liberdade". In: Ditos & Escritos V – Ética, Sexualidade, Política. Rio de Janeiro: Forense Universitária, 2004.
42. Nascimento KC, Erdmann AL. Compreendendo as dimensões dos cuidados intensivos: a teoria do cuidado transpessoal e complexo. Rev Latino-am Enfermagem 2009 Mar-Apr; 17(2).
43. Rocha LS, Beuter M, Neves ET, Leite MT, Brondani CM, et al. O cuidado de si de idosos que convivem com câncer em tratamento ambulatorial. Texto contexto - enferm. [online]. 2014, vol.23, n.1, pp. 29-37.
44. Mostardeiro SCTS, Terra MG, Silva AA, Soccol KLS, Souto VT. Cuidado de enfermagem ambulatorial a pacientes com alteração da imagem facial. Rev enferm UFPE on line. Recife, 8(1):114-20, Jan., 2014.
45. Cortez EA, Teixeira ER. O enfermeiro diante da religiosidade do cliente. Rev. enferm. UERJ, Rio de Janeiro, 2010 Jan/Mar; 18(1):114-9.

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