# Original Article =

# Self-concept and role function in patients with head and neck cancer

Autoconceito e função do papel em pacientes com câncer de cabeça/pescoço Autoconcepto y función de rol en pacientes con cáncer de cabeza/cuello

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Nursing theory; Adaptation, psychological; Role; Head and neck neoplasms

#### **Descritores**

Teoria de enfermagem; Adaptação psicológica; Conceito de papel; Neoplasias de cabeça e pescoco

#### **Descriptores**

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#### **Abstract**

Objective: To analyze self-concept adaptation and role function models in patients with oral cavity cancer.

**Methods**: This is a qualitative study conducted with patients at a cancer reference hospital in Fortaleza, CE, Brazil. The interview was used as a data collection technique, using a semi-structured instrument, based on Callista Roy's theoretical framework. Data verification occurred based on thematic content analysis.

Results: Two thematic categories emerged: Feelings involved in the daily life with the disease and Loss of social and family roles in the face of head and neck cancer. Slope in self-esteem, adaptive responses in self-physical, negative feelings in self-personal, positive adaptation in self-personal, positive adaptation, mediated by belief and religiosity were revealed in the category of feelings involved. Concerning loss of social and family roles, changes in roles were identified in the relationship with the family and society, due to the work situation, and the distance between the family and the need to continue radiotherapy cycles.

Conclusion: It was found that effective responses in the self-concept model are found in the possibility of clarifying the focus that should be attributed to meeting this condition on screen as a way of promoting adaptation to the new condition of life.

#### Resumo

**Objetivo:** Analisar os modos de adaptação de autoconceito e a função do papel em pacientes em tratamento de câncer de cavidade oral.

**Métodos:** Estudo qualitativo, realizado com pacientes de hospital de referência em câncer, em Fortaleza, CE, Brasil. Utilizou-se da entrevista como técnica de coleta de dados, a partir de instrumento semiestruturado, tendo como base o referencial teórico de Callista Roy. A verificação dos dados ocorreu a partir da análise de conteúdo temática.

Resultados: Emergiram duas categorias temáticas: Sentimentos envolvidos no cotidiano da doença e Perdas de papéis sociais e familiares frente ao câncer de cabeça e pescoço. Revelaram-se declive na autoestima, respostas adaptativas no self-físico, sentimentos negativos no self-pessoal, adaptação positiva no self-pessoal, adaptação positiva, mediada pela crença e religiosidade, na categoria de sentimentos envolvidos. No tocante às perdas de papéis sociais e familiares, identificaram-se alteração de papéis na relação com a família e sociedade, em decorrência da situação trabalhista, e distância entre o convívio da família e necessidade de continuar os ciclos de radioterapia.

Conflicts to interest: nothing to declare.

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Conclusão: Constatou-se que as respostas eficazes no modo de autoconceito se encontram na possibilidade de esclarecer o enfoque que deve ser atribuído ao atendimento a essa condição em tela, como forma de promover adaptação à nova condição de vida.

#### Resumen

Objetivo: Analizar los modos de adaptación de autoconcepto y función de rol en pacientes en tratamiento de cáncer de cavidad oral.

Métodos: Estudio cualitativo, realizado con pacientes de hospital de referencia en cáncer, en Fortaleza, estado de Ceará, Brasil. Se utilizó la entrevista como técnica de recolección de datos, a partir de un instrumento semiestructurado y con base en el marco referencial teórico de Callista Roy. La verificación de datos se realizó a partir del análisis de contenido temático.

Resultados: Surgieron dos categorías temáticas: Sentimientos relacionados con la cotidianidad de la enfermedad y Pérdida de roles sociales y familiares frente al cáncer de cabeza y cuello. Se observó declive de la autoestima, respuestas adaptativas del yo físico, sentimientos negativos del yo personal, adaptación positiva del yo personal, adaptación positiva, a través de las creencias y religiosidad, en la categoría de sentimientos relacionados. En lo que se refiere a la pérdida de roles sociales y familiares, se identificó la alteración de roles en la relación con la familia y la sociedad, como resultado de la situación laboral, y la distancia entre la convivencia de la familia y la necesidad de continuar con los ciclos de radioterapia.

Conclusión: Se constató que las respuestas eficaces del modo de autoconcepto se encuentran en la posibilidad de aclarar el enfoque que debe ser atribuido a la atención de esta condición, como forma de promover la adaptación a la nueva condición de vida.

# Introduction =

Cancer is a global public health problem, with 20 million cases worldwide. In Brazil, it is estimated that 600,000 new events are occurring, of which tumors in the head and neck region are the most frequent in men.<sup>(1)</sup>

Head and neck cancer (HNC) has involvement in the anatomical sites of the upper aerodigestive tract that includes nasal cavity, sinus of the face, lips, salivary glands, bones of the craniofacial complex and larynx, with different multifactorial causes for development, among the most competitors, are smoking, alcohol consumption, synergy, in addition to genetic inheritance, sun exposure for a long period, and human papillomavirus. HNC is a heterogeneous group of malignant neoplasms, each of which is distinguished by having epidemiology, genesis, pathological characteristic, treatment and prognosis. Therefore, it was decided to investigate oral cavity cancer in this study, as it is the most recurrent among the other types. (1)

Estimates show 11,180 cases and 4,010 in women in triennium 2020-2022. These values correspond to an estimated risk of 10.69 new cases per 100,000 men, occupying the fifth position. Diagnosis and treatment have a direct impact on the routine and quality of life of individuals, with changes in communication, swallowing (nutrition), sucking, breathing, deformities (mutilation), in addition to non-acceptance of facial image, emotional problems and little social interaction in patients with their oral cavity affected. (3)

Surgery and radiotherapy are the most effective treatment measures for these types of cancers, followed by chemotherapy, which can prolong recovery time and adaptation. However, whatever the chosen method, there may be sequel or adverse effects due to their aggressiveness. In the meantime, patients with oral cavity cancer have complex physical and psychosocial alterations, such as depression, anxiety, uncertainties and lack of hope, when compared to other patients with different types of tumors. (4)

Patients with this type of cancer go through different stages and encouragement, and it is essential to understand their adaptation to a new health and life condition. Thus, Sister Callista Roy's adaptation theoretical model allows to deepen the understanding of patients' behavioral responses and adaptation problems. Roy describes that adaptation is necessary for stability of a person receiving care in terms of health, environment and nursing goal. This theoretical model presents four adaptive models: physiological, self-concept, role function, and interdependence.

The physiological model is how a person responds as a physical being to environmental incentives. (6) The self-concept model focuses on psychological and spiritual aspects of a person. It is the combination of convictions and feelings at a given time. It includes two components: the self-physical (encompasses sensation and body self-image) and the self-personal (encompasses self-consistency, self-ideal and self-ethical-moral-spiritual). (6) The role function model guides social aspects related to functions that a person perform in society, while

the interdependence model refers to interactions related to giving and receiving affection, respect, and value. (5)

Therefore, despite extensive scientific production involving other methodological theories and care models that encompass aspects such as quality of life, sexuality, body image, coping strategies, there is a scarcity of studies that consider, in particular, self-concept and role function adaptation models in patients with oral cavity cancer. (7) Therefore, studies of this nature become relevant, in order to clarify the focus on patient care in these respective ways of facing or adapting to the new condition of life, as well as to assess consistency, nature of relationships, structure and assumptions of this theory in a specific public. (7)

Therefore, this study dazzles nursing a way to intervene in the adaptive problems generated, forwarding strategies for care actions and empowering patients to develop coping mechanisms that can reduce negative responses and playing a new role, besides favoring experience with the disease and clinical treatment of HNC. Thus, this study aimed to analyze self-concept and role function adaptation models of patients undergoing oral cavity cancer treatment.

### **Methods**

This is a descriptive and qualitative study carried out at a reference hospital in cancer based in the city of Fortaleza/CE, Brazil, from May to June 2019.

Sixteen patients over 18 years old, of both sexes, diagnosed with oral cavity cancer and under radiotherapy, who lived in Fortaleza or nearby municipalities have been included. Patients unable to communicate verbally were excluded. The number of participants was defined when data collection did not produce new information, becoming redundant.

Data were obtained through by recording interviews, subsidized by a semi-structured instrument, addressing sociodemographic and guiding issues (age, sex, and occupation): what changed in your life with the diagnosis of HNC? How do you perceive your health status these days?

Data collection occurred, initially, using the schedule list of radiotherapy sessions. Participant approach took place in the waiting room for therapeutic sessions; when verifying that patients met the inclusion criteria, an approximation contact was made, research presentation, objectives, method to be used and, finally, invitation to participate in the study and beginning of the interview, individually.

After data collection, the statements recorded were transcribed. Subsequently, all statements were submitted to pre-analysis, material exploitation or coding, treatment of results, inference, and interpretation. In these stages, the units of meaning were organized into analytical tables, accounting for recurrence in terms of record units, within each transcribed interview and between them, also seeking adherence to categorization. Next, data inference and interpretation were performed based on Roy's theoretical framework. (6)

The study was developed after approval by the Research Ethics Committee of *Universidade Federal do Ceará*, according to Opinion 2,926,620 and Certificate of Presentation for Ethical Consideration (*Certificado de Apresentação para Apreciação Ética*) 52850416.6.0000.5528/2018. The units of record of participants' statements were identified by vowel I, plus the number corresponding to the order of all interviews, in order to preserve participant confidentiality and anonymity.

#### Results

Thirty men and three women were interviewed. Individuals' ages ranged from 35 to 90 years old, with a mean of 56.93 years. Concerning education, most of interviewees had low education level, with an average of 5.61 years studying. As for occupation, eight were away from work activities due to sick leave, six due to retirement and two due to unemployed. Concerning treatment modality, eight were performing only radiotherapy, six radiotherapy associated with chemotherapy and two radiotherapy after surgery.

In this study, two thematic categories were nominated: Feelings involved in the daily life with the

disease and Losses of social and family roles in the face of head and neck cancer.

### Feelings involved in the daily life with the disease

In this thematic category, five subcategories emerged, represented by the thematic nuclei: low self-esteem due to changes in the clinical condition in the self-physical; positive feelings and adaptive responses to coping with the disease and treatment; negative feelings that affect the self-personal adaptation model; positive responses in the self-personal; and positive solutions based on the hope of healing and continuity of life.

Concerning perception of low self-esteem due to changes resulting from the diagnosis, progression and therapy employed, sadness and dissatisfaction were noted in the following statements.

"I'm feeling terrible." (I4)

"I lost my voice; I had a difficult time eating, drinking water, and I don't feel the taste of food, I eat because I don't taste it. That's what bothers me." (16)

"It's changed a lot, my whole life [...] my routine."
(I7)

"I can't do anything because I went blind. Now I can't even work anymore, life is difficult." (I2).

"It's something unstable, sometimes I'm fine, other times, no!" (I2).

Some patients demonstrated, in the self-physical subcategory, positive feelings and adaptive responses of coping with the disease and treatment in relation to body image:

"I'm thinner, I've lost a lot of weight, but I think I'm better. I'm finding myself more courageous."
(13)

"I told the doctor I would look like Chuck, because they're going to remove bones, eye, palate, operate the nose. In this surgery, I had facial paralysis and I got more horrible. I don't feel sad. With regard to surgery, I have no problem, I just want my health back." (16)

"It hasn't changed anything; I just feel like it's hard here (touching the chin). It's a hardness that even affects the way of talking." (I2).

On the other hand, negative feelings were identified that affected the self-personal adaptation model, as observed in interviewees' statements:

"Anxious (sometimes), introspective, distressed (so so), frustrated, nervous (kind of). I am very lonely because I live alone. There are days I don't even want to get out of bed." (I2)

"I'm sad, I'm not feeling well because I'm eating badly." (I3)

"I lost an eye, see? The way is to accept I have only one, it's not easy yet." (I2).

"I feel ashamed when I go to a place for a celebration. I'm not going to Mass anymore because I know people are whispering, it's embarrassing!" (I8)

It was also observed that some participants demonstrated positive responses in general, which can be considered a positive self-personal adaptation model.

"I hope everything works out. That's what everyone expects, I hope it's fast." (I1)

"Practically, the tumors are gone, I have no more tumor, I'm fine." (I3).

"(...) this fact was very complicated, it changed me, but now I'm fine. I ride the bus, I go out, I get used to it, I make fun of it. My life now is just enjoying and getting healed." (I6)

"Everything is changing, I am recovering from it as well as my health. I already feel victorious. You realize when you're winning." (I13).

"Today, I try to see my life as if I wasn't sick, like a normal person [...] It's not because I'm sick that I'm going to die today or tomorrow. [...] I cried the first week, but then I put it to my head that I'm going to live like every day was the last. [....] I'm closer to my children, I'm living more at home, things I didn't do before, it's a bright side." (I14).

Patients developed positive responses, based on the hope of healing and continuity of life, through religion and religious beliefs, demonstrating that when they find support, they can improve their self-concept.

"I hope to get better, God willing." (I2)

"Okay, thank God. I trust in the scriptures: do not be afraid of what you are about to suffer... be faithful unto death, and I will give you the crown of life." (I3)

"No, the person gets more tired, because having a disease changes us a lot. God willing, I will get better, I have faith in treatment and in God." (I13).

"I will get better some time! God willing, I'm still at the beginning." (I7)

"I hope to restore my health. One thing I'm sure, God has healed me, I came from there from my city just to get the trophy and I only leave here with it." (I5).

Attachment to religiosity and belief in God positively influence patients' perceptions of treatment, often translated as an opportunity for survival.

# Losses of social and family roles in the face of head and neck cancer

With regard to the social aspect, it was noticed that, considering the situation of crises, there was a change in roles in the relationship with the family and society, demonstrated by the conflict that, when perpetuated, leads to role failure.

"I don't feel good being taken care of by others. If I were able to see, things would be different [...] it's bad not to be able to work and do anything!" (111).

"I stopped working, people look different to the face. Nobody wants to keep an employee with an ugly wound like that. So, how am I going to support my family?" (I4)

"I will not be able to work anymore and, when I undergo operation, I will not have a normal life, several things will change." (I12).

It was observed that all participants gave negative responses in the role function, envisioned as distancing from the role, due to treatment, family distance and need to continue radiotherapy cycles.

"[...] the person moves away from the family to undergo treatment, it is very painful [...] the trips too; I have to move from the countryside, then when I come back, my children are already asleep." (I3)

"I've moved away from the family. You can't keep coming and going, it's tiring, it's painful due to fatigue and longing. My routine is this [...] I had to quit my job [...] I stay here the whole week." (I1)

The answers, as revealed in all statements, showed that work was important and that functional limitation caused frustration and impotence. Moreover, it is emphasized that family support is decisive in coping with the disease.

# **Discussion**

This study is limited by not showing other qualitative studies that explored adaptation of self-concept and role function in patients with PPC. Most participants had not undergone reconstructive plastic surgeries, showing to be a residual stimulus in the modification of negative adaptation responses. Moreover, it is cited the fact of disregarding the support network in an analysis of adaptive models as another restriction of this research.

It was found that studies related to Roy's theory in individuals with oral cavity cancer are still few explored. Bearing that in mind, this study can contribute and improve the ways of adapting, with regard to consistency, relationships, structure, assumptions, congruence and significance for oncologic nursing practice in this specific public. Thus, it is possible to intervene in negative responses and behaviors, in order to promote better adaptation, during diagnosis, treatment and post-radiotherapy follow-up.

Considering that cancer is an unexpected event, triggering countless feelings, both in clients and family members, which provide unpleasant sensations, because it involves a new situation, it is necessary to promote adaptation, in a positive or negative way, whether active or passive. (9,10) Thus, each individual reacts in a particular way, since they are influenced by their own expectations, life history and everyday experiences. Related to this fact, all interviewees reported feeling good and happy, before the illness and changes in body image. (3)

As observed in the statements of this study, the moment of disease diagnosis can trigger different feelings and reactions such as despair, nervousness, concern and stress. These feelings, according to Roy, are fundamental for generating adaptive responses, processed through four channels: perceptual and informative process, learning, judgment, and emotion. Thus, this regulation favors mechanisms to be constructed throughout treatment of oral cavity cancer. In this regard, understanding illness as a process that encompasses biological, psychological, environmental, social and spiritual components is essential to assist individuals by offering care, in addition to purely technical aspects.

With regard to the self-concept adaptation model, elements of the physical being, personal being, spiritual being were observed in all statements. Thus, with regard to the person's physical self, appearance and health status, radiotherapy, chemotherapy and surgical treatments can alter self-image, as they often cause changes in the organ and skin, and, in more severe cases, cause the appearance of ulcers. (12,13) It was noted that the responses arising from this condition are negative in self-concept,

resulting from clinical manifestations of this therapeutic modality, such as fatigue, exacerbating episodes of anguish, anxiety and fear in the face of the unknown. (14)

Thus, these changes affect the subject in full and drastically in interpersonal relationships, damaging the individual's social integrity, corroborating Roy's theoretical assumptions. The aesthetic aspect plays an important role in the social interaction of individuals. Facial deformities appear to have more impact than other physical disabilities in oral cavity cancer. (15) Patients with facial deformities must receive psychological support to deal with the subsequent negative impact on self-esteem, in addition to the frequent states of tension and fear, resulting from mutilation, ignorance about the disease and the possibility of death.

A study points out that changes caused by cancer or surgery cause impact and amazement for those who see it, in addition to the feeling of exclusion and embarrassment in those who have them. Thus, it was observed that the tumor's site determines shame, as the head and neck region is exposed, making adaptation difficult in a positive way, from the personal being. Cancer manifests itself in an open way, being something that cannot be hidden from the eyes and judgments of others, motivating individuals to distance themselves from work activities, as seen in statements about social and family role loss due to HNC.

Patients reported a negative perception of appearances, which shows an ineffective response, in the self-concept adaptation model. The physical changes resulting from treatment made participants respond, unsatisfactorily, to this experience. However, it was found that spirituality and religiosity influence the willingness and hope to cope with the disease and maintain life. Therefore, these data corroborate the philosophical assumptions pointed out by the theory, in which people have a mutual relationship with the world and God, in addition to using the creative capacity of perception, enlightenment and faith to face problems in search of adaptation.

Regarding the role adaptation model, it was found that, in the midst of oral cavity cancer treatment, patients find it difficult to adapt to such con-

dition, facing losses observed by conflict, failure and distancing from the social role they played. Thus, considering that it is a social need to know who you are in relation to others, (18) roles are guidelines given to people, so that they act in a manner compatible with social functions. Therefore, the social function is defined as a set of activities that are expected of a person, due to the role, and implies a certain position in the social space. (19)

In this context, it is understood that the body is a construction susceptible to changes that depend not only on the biological factor, but also on the meanings of everyday life built by the social environment. A study revealed that patients with this type of cancer felt different, corresponding to 91.3%; sixteen of them reported sadness, after altering the image, equivalent to 69.5%, promoting conflicts that hindered family, social and group relationships. (3)

In another study, there was a potential relationship with facial changes, since people's faces are the expression of identity and when it changes, the subjects feel that their self-image is distorted. There is a feeling of embarrassment and concern with the assessment of others about the real or imagined physical form. Supporting the aforementioned, in another survey, the interviewees showed shame in relation to the image after the onset of the disease, as they had apparent physical changes. Accordingly, it is understood that a body image without physical changes is synonymous with balance and well-being, which is related to the feeling of happiness and emotional balance.

There was a feeling of despair about appearance. However, with the aesthetic treatment received, this feeling is being replaced by overcoming and accepting, considered an effective response, since, for patients, health, at this moment, has become the most important objective. The fact that they feel good, despite their appearance, disappoints that they are developing coping mechanisms that make them achieve positive responses and, consequently, adapt to the disease and treatment itself.<sup>(6)</sup>

Negative behaviors are driven by conceptions of uselessness and loss of family role, resulting from the impediment of performing activities that were socially obligations. (22) This reveals an ineffective re-

sponse to role change, causing patients not to adapt in this respective mode.

Thus, individuals' lives are structured around the functions they have or aspire to. However, the change of roles depends on the adaptive functioning, which can have negative consequences, in case it cannot change. In this regard, there is a need to lose yourself in order to find yourself again. There is a willingness to live stubbornly that gives coherence. Surviving cancer, seen as a new chance for life, is characterized as an opportune moment to learn new values, overcome limitations, loss of roles, and facial disfigurements. Anyway, enjoy the survival victoriously.<sup>(23)</sup>

#### Conclusion

Participants revealed important issues, experienced with regard to self-concept adaptation and role function models, which are capable of influencing adjustment to the new health and life condition. Some revealed ineffective behaviors in self-image and role-playing. Concerning social and family role loss, which the majority proved to be ineffective, there is a need for greater attention in order to successfully develop adaptation. Thus, it is relevant to build assistance together, in line with economic, social, educational and cultural peculiarities. In this context, a comprehensive approach should be emphasized as a health model, emphasizing the importance of nurses in identifying adaptation problems, in order to promote assistance aimed at coping mechanisms to achieve adaptation.

#### **Collaborations** =

Caldini LN, Medina LAC, Silva RA, Lima MMS and Caetano JA contributed to study design, data collection, analysis and interpretation, writing of the article, relevant critical review and intellectual content and approval of the final version to be published. Barros LM and Melo GAA collaborated with relevant critical review and intellectual content and approval of the final version to be published.

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