ABSTRACT
Purpose: To describe the social representations of adolescents about the cancer disease process.
Method: A descriptive study with a qualitative approach, based on the Theory of Social
Representations, conducted with 31 adolescents undergoing cancer treatment in a public hospital
in Belém do Pará. The study was performed with individual interviews, submitted to inductive
thematic analysis.
Results: Three thematic categories were identified: cancer as a psychosocial disease; the experience
of falling ill and suffering cancer; and coping with the body changes resulting from the disease.
Conclusion: The study contributed to the understanding of the social representations about cancer
in adolescence, supporting the nurse in the construction of knowledge with the adolescent with
cancer, for a better quality care.

DESCRIPTORS: Nursing; Nursing care; Health of the adolescent; Oncology; Social Psychology.

*Article extracted from the master's dissertation entitled “Having cancer and its repercussions for self-care: a study of Social
Representations”. State University of Pará, 2013.
REPRESENTAÇÕES SOCIAIS DE ADOLESCENTES SOBRE O PROCESSO DE ADOECER E ADOLESCER COM CÂNCER

RESUMO
Objetivo: descrever as representações sociais de adolescentes sobre o processo de adoecimento de câncer.
Resultados: identificaram-se três categorias temáticas: o câncer como doença psicossocial; a vivência do adoecer e adolescer com câncer; e o enfrentamento das alterações corporais advindas do adoecimento.
Conclusão: o estudo contribuiu para a compreensão das representações sociais sobre o câncer na adolescência, subsidiando o enfermeiro na construção de conhecimentos junto ao adolescente com câncer, para assistência de maior qualidade.

DESCRITORES: Enfermagem; Cuidados de enfermagem; Saúde do adolescente; Oncologia; Psicologia social.

REPRESENTACIONES SOCIALES DE LOS ADOLESCENTES SOBRE EL PROCESO DE PADECER CÁNCER

RESUMEN:
Objetivo: describir las representaciones sociales de los adolescentes sobre el proceso de padecer cáncer.
Método: estudio descriptivo con enfoque cualitativo basado en la Teoría de las Representaciones Sociales y realizado con 31 adolescentes en tratamiento oncológico en un hospital público de Belém do Pará. El estudio se efectuó con entrevistas individuales, sometidas a análisis temático inductivo.
Resultados: se identificaron tres categorías temáticas: el cáncer como enfermedad psicosocial; la experiencia de padecer cáncer en la adolescencia y cómo hacer frente a los cambios corporales devenidos por la enfermedad.
Conclusión: el estudio contribuyó a comprender las representaciones sociales sobre el cáncer en la adolescencia, ayudando al enfermero a elaborar conocimientos junto con el adolescente que padece cáncer, para brindar una asistencia de mayor calidad.

DESCRIPTORES: Enfermería; Cuidados de enfermería; Salud del adolescente; Oncología; Psicología social.
Adolescence is the period of life that marks the transition between childhood and adulthood. For this phase several chronological limits are considered; for legal purposes, the Statute of the Child and Adolescent conceptualizes the adolescent as the person who is between 12 and 18 years old. Among other definitions, this study used the concept of the World Health Organization (WHO), adopted by the Ministry of Health (Ministério da Saúde, MS), which limits adolescence to the second decade of life, that is 10-19 year old age group.\(^1\)

In general, adolescence is already marked by the natural difficulties of this stage of life, with physical, emotional and socio-affective modifications; however, by adding a serious context such as the diagnosis of cancer, everything can become even more difficult.

In Brazil, the José Alencar Gomes da Silva National Cancer Institute (Instituto Nacional de Câncer, INCA) estimates, for the 2018-2019 biennium, the occurrence of approximately 600,000 new cases of cancer per year, of this total, 12,500 cases should occur in children and adolescents up to 19 years old, and in 2015 alone there were 35,000 cancer deaths in this age group, which confirms the magnitude of the problem in the country.\(^2\)

Usually, the oncological diagnosis transforms the adolescent’s daily life, and a new routine is offered, full of challenges and overcomings during the treatment, whose repercussions have a great impact on social and personal relationships. In this complexity of care, it is important that nurses assume their role in the process of care; it is essential, in addition to deep knowledge and constant updates on the disease, that the professional has much sensitivity, overcoming the mechanistic aspect of their duties, providing individualized care to address the real need of adolescents with cancer.\(^3\)

Nursing care should spread not only to the treatment itself, but also to the social aspects of the disease, considering that the adolescent is inserted in a context of his family and community, reflecting a holistic care, in addition to the hospital institution. A more refined understanding of the social representations of adolescents with cancer contributes to comprehensive care, respecting their individualities and specificities.\(^3\)

Thus, cancer can be considered as a psychosocial object because it is part of the cognitive realm of the individuals, who share experiences with their social group. Therefore, the health-disease process is a legitimate object for the use of the Social Representation Theory (SRT), as it is present in the daily life of each individual and it establishes links through this consensual knowledge with his or her group.\(^4\)

The social representations of cancer are anchored in social experiences, derived from their own personal experiences, throughout the process of illness and cancer treatment. Faced with an unfamiliar situation, everyone benefits from their previous knowledge and experiences shared with their social group.\(^5\)

Thus, the SRT applied well to this study, since Social Representation (SR) is “a form of knowledge, socially elaborated and shared, with a practical objective, and that contributes to the construction of a common reality to a social group”.\(^6,22\) Hence the suitability for studies that aim to understand the meanings of the diseases to certain social groups;\(^6\) in this case, adolescents with cancer, favoring the establishment of integration, adherence to treatment and relationships with people, especially if we consider that SR on cancer is strongly anchored in the social stigma that the disease still carries.

In this context, this study aimed to describe the social representations of adolescents about the cancer disease process.
A descriptive study with a qualitative approach, based on the Social Representations Theory according to the procedural aspect defended by Serge Moscovici and Denise Jodelet.\(^{(6-7)}\)

The participants were 31 adolescents undergoing cancer treatment in a public hospital, certified by the MS as a High Complexity Oncology Care Center (Centro de Assistência de Alta Complexidade em Oncologia, CACON), located in the city of Belém do Pará. The eligibility criteria were the following: (I) belonging to the age group of 10 to 19 years old; (II) having been diagnosed with cancer for at least three months; (III) being on cancer treatment or out of treatment for disease remission; (IV) if underage, having the permission of a parent or legal guardian.

The number of participants in this study was dimensioned considering that, in the SR research studies, the number of subjects constituting the sample should be significant and representative of their group, and a population of at least thirty subjects is recommended, since only from this quantity it is possible to characterize that a representation is really social.\(^{(7)}\)

Data was collected from January to March 2013, through semi-structured and individual interviews, recorded in digital media (MP4), with immediate transcription and care to preserve the reliability of the speeches.

The interviews were conducted in the nursing office of the CACON chemotherapy outpatient clinic. To preserve their anonymity, the participants were coded with the letter H for Men (Homens in Portuguese) or M for Women (Mulheres in Portuguese), in ascending numerical order, according to the sequence of the interviews, followed by their age.

The Free and Informed Consent Form (FICF) was signed by the adolescent, if already of aged and, in the case of children under 18 years old, by a parent or legal representative; in this case, also the consent of the participant was required, with signing of the Consent Form.

For data organization, the inductive thematic analysis technique was developed, in six stages: 1) Familiarization with the data, data transcription, active reading and annotation of initial ideas; 2) Code generation; 3) Search for potential topics; 4) Continuous review of the themes generating a thematic “map” of analysis; 5) Definition of the themes; 6) Report production through explanatory interpretation.\(^{(8)}\)

In compliance with the legal requirements, the project was approved by the Ethics Committee for Research on Human Beings of the undergraduate Nursing course of the State University of Pará, opinion No. 148,244.

**RESULTS**

The study revealed the process of cancer in 31 adolescents, of which 12 (39%) were in their early teens, aged 11 to 14 years old, and 19 (61%) were male. Regarding the diagnosis, 12 (38.8%) presented leukemia, seven (22.6%) bone tumors and the remainder other cancers, such as lymphomas. Regarding the treatment, 16 (51.7%) were exclusively on antineoplastic chemotherapy and the others were undergoing chemotherapy associated with other treatments such as surgery and/or radiotherapy.

From the speeches of the research participants, three categories emerged, with their respective subcategories, illustrated in Chart 1.
Chart 1 - Social representations of adolescents on the process of having cancer

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>SUBCATEGORIES</th>
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<td>I - Cancer as a psychosocial</td>
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<td>disease</td>
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<td>II - The experience of getting</td>
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<td>sick and having cancer</td>
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<td>resulting from the disease</td>
<td>3.b. Positive coping with the body changes</td>
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**CATEGORY I: CANCER AS A PSYCHOSOCIAL DISEASE**

**Subcategory 1.a: A disease that can lead to death**

In this study, in the testimonies of 16 respondents (51%), the word cancer was strongly anchored in social representations like “death” and “dying”, as in the following statements:

*This is a very bad thing, I think the treatment is bad; most people die, and then I think I’ll die too. (M11 - 15 years old)*

*A serious disease, I think when you think of the word cancer, you think you will die soon. (M15 - 17 years old)*

**Subcategory 1.b: A disease that can be cured**

Unlike the previous subcategory, nine adolescents (29%) positively conceptualized cancer, with a hope for cure, based on their beliefs and spirituality, observed through the following terms: “heal”, “healed”, “God”.

*It is a disease that is a big fight, for this disease only God has the cure. (M14 - 16 years old)*

*For me I think cancer [...] has a cure, some people believe in God and get out of it [...] I never stopped having faith in God. (H27- 17 years old)*

**CATEGORY II: THE EXPERIENCE OF GETTING SICK AND HAVING CANCER**

**Subcategory 2.a: The changes experienced**

In this study, 20 participants (65%) represented adolescence cancer through the changes experienced, using the terms “changed”, “I don’t do it anymore” and “can’t do it”. Some adolescents cited the changes that occurred in their ordinary social life during adolescence, as in the following statements:

*I found it very bad, because I see my friends go out, go to the mall, go to the beach, go to the party as I was going, and now I don’t do it anymore, now it’s bad for me that I got sick, I have to take more care of this disease [...] then I don’t go out much. (M14- 16 years old)*

*The hardest part was watching my friends continue their activities, passing the year and me falling behind. Seeing my friends go, have fun, and I can’t do it, it was terrible (H26- 18 years)*

In this process, changes were also mentioned in relation to the daily hospitalizations, with a consequent distance from the family, as in the following speech:
It was a little difficult, I had to stay here [in hospital], nobody likes being in the hospital, right? I had to spend some time away from the family [...] I thought it was boring, I wanted to stay more at home than in the hospital. (H27- 17 years old)

Subcategory 2.b: The support experienced

For seven respondents (22%), the relationship with their social group was positive, evidenced mainly by the support they received from friends and family members, which is remarkable in their statements using the terms “is/was/is good”, “support” and “help”:

People who were estranged approached me, they started to help me more [...] and the people who were close, encouraged me even more and maybe I helped them with something; right, and they helped me with something, it’s like an exchange. (H22- 19 years old)

I had a lot of support, from the friends and from the family, from the people around me, thank God they didn’t leave me at that moment, they gave me strength, they helped me a lot. (H25- 19 years old)

CATEGORY III: FACING THE BODY CHANGES RESULTING FROM THE DISEASE

Subcategory 3.a: The shame of the changed body

With cancer, the reference of body image is usually affected, which was noticed in 23 adolescents (74%), who based their speeches on the following terms: “shame”, “messed with me” and “messed with the look”. Most of the respondents reported shame related to alopecia, which was more observed among female adolescents, as in the following speeches below:

It was bad, right, because I liked my hair so much, my hair started to fall and fell a lot, spent a week falling, then stirred me a lot, I was desperate when the hair began to fall. (M2 - 16 years old)

At first it gave me depression, I didn’t even want to look at myself in the mirror, I don’t feel like it, I wanted to kill myself because of my hair, so everyone said it was going to grow back, but it didn’t get in my head. (M31 - 15 years old)

Other body changes were also cited as synonymous with altered body shame, as in the following reports:

Only those spots, which gave [pointing to the arm] it costs a lot to disappear, so I’m ashamed, then at school, this year that I studied I felt very ashamed, but I can hide it, like that, in the clothes. (M11 - 15 years old)

The part of the tumor that affected the appearance was the part also felt [...] I didn’t leave home, they invited me out and I didn’t leave, I stayed at home, because I don’t like anyone looking at me, so I felt ashamed. (H26- 18 years old)

Subcategory 3.b: Positive coping with the body changes

Unlike the previous subcategory, regarding the body changes, eight adolescents (26%) faced this process positively, using the terms “I prepared” and “I had no difficulty”.

At first it was hard, but now I’m taking everything in sports [...] I do not let myself be overwhelmed by anything that people say, before starting the treatment I already prepared for these changes that would appear. (H7 - 18 years old)
DISCUSSION

In the first category, through the reports of the interviewed adolescents, in line with other studies on the theme of cancer, it is possible to observe that, even with the technical-scientific advances in the diagnosis and treatment of cancer and with the increased life expectancy of these patients, it is still often found negative concept about cancer, usually associated with a disease that can lead to death.

The SRT recognizes the value of the subjective dimension, presented here by cancer, the cognitive aspect of the individual, which, according to this perspective, interferes with the social practices, attitudes and conducts related to the object of representation. The SRT framework allows clarifying how the process of assimilation of the facts that occur in the environment, how they are understood by the individuals and the groups, and how the knowledge built on these facts is expressed through their communication and their behavior.

The adolescence phase is socially conceived as vital, productive, and preparatory for the future, and the idea of dying is distant and remote, and is not much less recognized by those at the best moment of their lives. However, the context of cancer is considered as a threat to the dreams and goals, leading to strong psychosocial influence, related to social representations and limitations of the patient’s daily activities.

Despite this negative conception, some adolescents have defined cancer as a disease that can be cured, based on spirituality. The reports of M14 and H27 corroborate the study on cancer’s SRs for caregivers of patients with no possibility of cure, in which the majority of the respondents anchor in their religiosity the hope of recovery from the disease, to overcome the suffering of caring the other, bolstered by their faith and spirituality.

In order to endure the suffering from the disease and the treatment, spirituality is very important in coping with cancer, so the adolescent usually seeks a higher being, attributing each victory to his faith in God. This confidence that adolescents place in God is very significant, because the spiritual comfort that this relationship provides them strength to face the stress experienced with the disease process.

The SR of a given social group enables the exchange of knowledge and behaviors, leading them to familiarize themselves with fear and with the unknown in the face of a new stage of their life, that is, it will guide their future experiences in the face of this same situation, in a new contact with it.

In the second category of this study, having cancer was represented as a difficult process due to the withdrawal of their social group. Cancer during the adolescence usually leads to changes in the individual’s daily routine, caused by the very routine established with the treatment, which may influence affective bonds, favoring the separations and differentiations from their peers.

Thus, after becoming ill, the adolescent ends up suffering because of limitations due to the lack of freedom and the restriction of the right to action and decision, in addition to the emptiness left by the distance of relatives and friends, which can cause feelings of anguish, loneliness and even rejection to the treatment. Thus, it is important that the professionals working in oncology know each adolescent’s way of dealing with this experience, understanding this process and significantly assisting the health care measures directed to this clientele.

Considering that the social representations are not conceived in the individuality, but in a social context that participates in the process of their formation, adolescents have the hospital setting as an element in the construction of their social representations about cancer, where there is circulation of information on the disease and interaction with other patients and professionals.
The social representations are recognized as systems of interpretation that guide the relationship of the individual with the world and with others, guiding the conducts and social communications. Likewise, they intervene in various processes, such as diffusion and assimilation, as well as coping with the changes experienced, in this case, having cancer. Thus, the individual ends up anchoring and objectifying feelings about their context, that is, they anchor their common ideas, practices, and images about their reality and objectively organize their manifestations to enable some meaning. (5)

About the support experienced, the speeches of H22 and H25 refer to the importance of the support from family members and friends after the diagnosis of cancer in adolescence and the strength apprehended to face the disease arising from the support of their group. It is noticed that the impact of falling ill does not only affect the adolescent, it also affects the family and the friends, in a show of complicity and mutual help.

During cancer treatment, family support is of paramount importance for treatment effectiveness, emotional support and patient care are essential factors for a better recovery, and the presence and solidarity of the family and the friends are essential. (13)

Family support is important in ensuring a better outcome in the treatment of children and adolescents with cancer, requiring a real dedication to time, financial resources, modification of the routine of life, with the main goal of meeting the mutual needs of all involved in the disease process. (14)

In the third category of this study, coping with the body changes resulting from illness was highlighted. In this study, we observed the strong representativeness of hair as a symbol of femininity and beauty, leading to a disturbance in self-image and self-esteem, leading to despair and depression. Despite being characterized as a transient change, alopecia was one of the most striking occurrences, especially for female adolescents.

In a US study that reviewed the literature on the psychosocial impact of alopecia on cancer survivors, hair loss was defined as one of the most unsettling toxicities of the treatment. It was evidenced that alopecia influences the visualization of their bodies, interaction with their peers, conceptualizing self-image far beyond the treatment performed. The authors emphasize the importance of the health professionals and the family members in better understanding the psychosocial impact that alopecia causes on cancer patients, helping them to cope with this problem. (15)

Still in the third category, other types of physical modifications were mentioned, synonymous to the shame for the body changes, such as the consequent alterations of the treatment (skin blemishes), as well as the alterations arising from the disease (tumor). Their reports were fraught with concern about how they might look and how people might view them.

In this context, the practice of isolation is common, which is usually linked to the desire that the adolescent has to hide the body changes resulting from illness and treatment, concretizing his view of himself in relation to others, often associated with the “importance of the other’s gaze as a mirror to himself”. Thus, it is of paramount importance that the nurse understands and respects the meaning that this “new body image” represents for the patient. (12,36)

Despite these negative representations, cancer-related body changes can also be viewed positively, as identified in the participants’ speeches, in relation to coping with the body changes, from which an effective approach of the health professionals who assist them can be inferred.

In a study on the factors that contribute to the resilience of adolescents with cancer, the results showed that this clientele presents a more adaptive coping when compared to adolescents who never had cancer. The most commonly used coping strategy for adolescents with cancer was positive reevaluation, followed by seeking social support and acceptance of responsibility, suggesting that these individuals adapt well and have good
recovery from the circumstances of illness and cancer treatment.(16)

Understanding and interpreting the various objects and phenomena that constitute the reality of a given social group depends on the rules of thought and communication, and their outcome interferes with people's knowledge and action.(7)

When the representations are shared with others in the same social group, they are conceived as a reality, based on a consensus view, favoring daily exchanges and actions. Thus, sharing the same idea or image ensures a social bond and an identity.(6)

Among the limitations of this research it is worth mentioning that, because it is a study of social representations, it does not extend to all groups, but only to the social group researched and, since it is a national research, it has no international repercussion. In addition, the study had limitations related to the little updated literature on the subject.

**FINAL CONSIDERATIONS**

This study allowed the understanding of how the disease was inserted in the daily life of the social group of adolescents with cancer, favoring the nurse subsidies for a higher quality care, aiming at the completeness and individuality of their actions. The participants’ answers originated three categories that revealed the representational field within which the object is situated, in the cognitive act of its construction.

It was possible to realize that in the universe of adolescents considered “healthy”, friends, family, dating/flirting, school, parties, and physical beauty are important issues. However, when we add cancer to this routine, the adolescent inevitably fits into the hospital universe, with distancing and differentiation from their peers and restriction of their own age-related activities. Most of the participants represented the disease through feelings such as isolation, shame, rejection, fear of death and loss of their identity.

Despite this negative representation of having cancer, in this study we can perceive that there are still adolescents who face this process positively; with a hope for a cure, supported by their faith, accepting and adapting to the body changes and maintaining self-control, in this case, they mentioned as of utmost importance to have a closer proximity of family and friends, determining the strength learned to face the disease, coming from the support of their membership group.

Thus, it is essential that nurses, as well as the health team, have knowledge of these social representations, acting individually, through the construction of knowledge with the adolescent, so that he or she can prevent or mitigate the health problems, reworking their own way to make the problem less complicated, facing and living with the disease.

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