

Perception of the Adolescent in face of its Condition of Oncological Sickening

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Percepção do Adolescente frente à sua Condição de Adoecimento Oncológico

Percepción de los Adolescentes ante su Condición de Enfermedad Oncológica

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ABSTRACT

Introduction: Cancer illness brings a tiresome routine due to aggressive therapies, and changes occur in the adolescent's life. **Objective:** Understand the perception of the adolescent in face of its condition of oncological sickening. **Method:** Exploratory, descriptive, and qualitative research, through the Collective Subject Discourse technique, conducted with 13 adolescents, from June to August 2019, at the Specialized Center for Pediatric Oncology of a university hospital. The individual interviews were recorded based on the following questions: What is it like to be sick to you? What do you think about your future? How do you relate to your family members and the health team? **Results:** Eight central ideas were identified, among them: being sick is bad because it limits normal life routines; the treatment is painful and changes my body image; being sick has a good side; be healed and resume plans for my life; the hospital and the team are welcoming; proper welcome and empathy are lacking; humanized care; family support. **Conclusion:** In the adolescent's perception, illness goes beyond the physical health condition, interferes, and limits theirs and their family quality of life, and therapeutic listening is essential for humanized care.

Key words: Adolescent; Neoplasms; Oncology Nursing; Qualitative Research; Health of Institutionalized Adolescents.

RESUMO

Introdução: O adoecimento por câncer traz uma rotina cansativa por conta das terapêuticas agressivas, e ocorrem mudanças na vida do adolescente. **Objetivo:** Compreender a percepção do adolescente frente à sua condição de adoecimento oncológico. **Método:** Pesquisa exploratória, descritiva, qualitativa, por meio da técnica do discurso do sujeito coletivo, realizada com 13 adolescentes, no período de junho a agosto de 2019, no Centro Especializado em Oncologia Pediátrica de um hospital universitário. As entrevistas individuais foram gravadas baseadas nos seguintes questionamentos: Para você, como é estar doente? O que você pensa sobre seu futuro? Como você se relaciona com seus familiares e com a equipe de saúde? **Resultados:** Foram identificadas oito ideias centrais, entre elas: estar doente é ruim porque limita rotinas da vida normal; o tratamento é doloroso e altera minha imagem corporal; estar doente tem um lado bom; ficar curado e retomar planos para minha vida; o hospital e a equipe de saúde são acolhedores; falta empatia e acolhimento adequado; humanização na assistência; e apoio familiar. **Conclusão:** Na percepção do adolescente, o adoecimento vai além da condição de saúde física, interfere e limita sua qualidade de vida e dos familiares, e a escuta terapêutica é essencial para uma assistência humanizada. **Palavras-chave:** Adolescente; Neoplasias; Enfermagem Oncológica; Pesquisa Qualitativa; Saúde do Adolescente Institucionalizado.

RESUMEN

Introducción: La enfermedad del cáncer trae una rutina agotadora debido a terapias agresivas, y se producen cambios en la vida del adolescente. **Objetivo:** Entender la percepción de lo adolescente ante su condición de enfermedad oncológica. **Método:** Investigación exploratoria, descriptiva y cualitativa, a través de la técnica de Discurso de Sujeto Colectivo, realizada con 13 adolescentes, de junio a agosto de 2019, en el Centro Especializado de Oncología Pediátrica de un hospital universitario. Las entrevistas individuales fueron grabadas basándose en las siguientes preguntas: ¿Cómo es estar enfermo para usted? ¿Qué opinas de tu futuro? ¿Cómo se relaciona con los miembros de su familia y el equipo de salud? **Resultados:** Se identificaron ocho ideas centrales, entre ellas: estar enfermo es malo porque limita las rutinas normales de vida; el tratamiento es doloroso y cambia mi imagen corporal; estar enfermo tiene un lado bueno; ser sanado y reanudar los planes para mi vida; el hospital y el equipo de salud son acogedores; carecer de empatía y bienvenida adecuada; humanización en el cuidado; y apoyo familiar. **Conclusión:** En la percepción del adolescente, la enfermedad va más allá de la condición de salud física, interfiere y limita su calidad de vida y familiares, y la escucha terapéutica es esencial para la atención humanizada. **Palabras clave:** Adolescente; Neoplasias; Enfermería Oncológica; Investigación Cualitativa; Salud del Adolescente Institucionalizado.

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INTRODUCTION

Cancer became a universal world health problem, one of the main causes of mortality, most of all for children and adolescents¹. In 2017, it was the sixth cause of mortality and ninth of morbidity worldwide for the age-range from 0 to 19 years². In Brazil, in this same year, there were 2,553 deaths for the same age-range³.

For each year of the triennium 2020-2022, the National Cancer Institute José Alencar Gomes da Silva (INCA)³, previews 8,460 new cases in the age-range from 0 to 19 years, an estimated risk of 137.87 new cases per million/year for boys and 139.04 per million/year for girls.

The disease in children and adolescents is associated with genetic, idiopathic factors, typically affecting the blood system cell, the central nervous system and supporting tissues, with short latency, accelerated growth and more invasive, but with better reaction to treatment and good prognosis, contingent upon the type and stage at the diagnosis. Nearly 80% of the cancers in children and adolescents are curable if early diagnosed and treated in oncology-focused hospitals³.

Considering the condition of sickening by cancer and to the tiresome routine because of aggressive therapies, the life of the adolescent and its family change due to several admissions, elevated stress levels, anger, rupture of family bonds, mental wear, pain, anguish, and fear of death⁵.

The nurse in this context, one of the closest professionals to the patients, plays a key role in the triad oncologic patient, family and nursing team, offering not only clinical, therapeutic, and technical support but also humanized care, comfort, symptoms relief and balance in order to achieve welcoming and open therapeutic listening⁶, which ensures the understanding of anguishes, fears, immediate emotional support and more effective care⁷.

Throughout the therapeutic process, the relation professional-patient is important, putting itself in the other's shoes and creating empathy to understand the needs of whom is being cared. Therapeutic listening is an essential tool and should be applied by a skilled professional because if misused, can cause negative consequences⁸.

Professionals need to be sensitive and humanized in face of the human suffering to promote a full and qualified care based in the adolescents' needs across all its dimensions⁹.

Within this scenario, the adolescent with cancer has reflections and questioning, facts that stimulate the research in this area, attempting to respond to the following question: What is the oncologic adolescent perception while sickening? The objective was to

understand the adolescent's perception during oncologic sickening.

METHOD

Exploratory, descriptive, qualitative approach study, adopting the technique of the discourse of the collective subject (DCS)¹⁰ carried out from June to August 2019, at the admission of the Pediatric Oncology Specialized Unit of a teaching hospital, a reference of the State of Pernambuco for children and adolescents with cancer. The two-story hospital admission has ten infirmaries with three beds each where under 18 years of age minors are treated for cancer.

The investigators created a questionnaire to profile the participants with sociodemographic and clinical questions about age, sex, education (Elementary I: from 1st to 5th grades, students in the age-range from 6 to 10 years; Elementary II: from 6th to 9th grades, students in the age-range from 11 a 14 years; High School: from 1st to 3rd grades, students in the age-range from 15 to 17 years), origin, family income (minimum wage = R\$ 998,00), diagnosis and year of diagnosis. The interviews were guided by the following questions: What is it like to be sick for you? What you believe your future will be? How do you relate with your family and the health team? Initially, three adolescents were interviewed to check whether the responses to the questions would meet the study goal.

A skilled investigator staff member with experience with adolescents and volunteer at the study site familiarized with them conducted the individual interviews in a secluded room at the same floor of the infirmary. The adolescent and its legal guardian were invited personally to join the study and were briefed about the study, its rights and anonymity, secrecy, and confidentiality of their narratives. The legal guardian who remained in the room during the interview with the adolescent signed the Informed Consent Form. Each recorded interview took in average 35 minutes, fully transcribed to secure the integrity of the speech. Later, the adolescents read their narrative, no revision was made.

Nobody refused to join the study. In the collection period, 13 adolescents were hospitalized at the study site and were enrolled because they have met the inclusion criteria: oncologic patient in the age-range of 12 <18 years defined by the Child and Adolescent Statute of the Brazilian Pediatric Society hospitalized at the study site during the collection period in favorable physical condition to be interviewed. Exclusion criteria was speech impairment.

Based in the Discourse of the Collective Subject (DCS), it was possible to tabulate and organize the content of

similar meaning encountered in the different narratives of the adolescents. Each response of the literal transcriptions and the entire recorded interview of the adolescent were reviewed and the extracts of the speeches that best reflected the response to each question were selected in addition to the key-words to produce the DCS. Next, the core ideas containing the words or linguistic expressions found in the narratives were identified, revealing the meaning and the anchoring, if present that translated the ideology or explicit beliefs of the verbal content¹¹.

At last, the key-words containing the core idea and/or anchoring of similar or complementary meaning were grouped to depict the perception of the collectivity; thus, the several discourses-synthesis were formed, they are the DCS drafted in the first person of the singular described in the results¹¹.

The narratives of the participants were coded with the letter A of the word adolescent followed by the number of the order of the interview to ensure the anonymity.

The recommendations of the Guideline Consolidated Criteria for Reporting Qualitative Research¹² (COREQ) to report important aspects of this study were followed and the bioethical principles pursuant to Ordinance 466/2012¹³ and 510/2016¹⁴ of the Health National Council of the Ministry of Health were complied with. The Institutional Review Board (IRB) of the “*Complexo Hospitalar HUOC/Procape*” approved the study, CAAE: 13218419.8.0000.5192 and report 3.360.038

RESULTS

13 adolescents joined the study in the age range from 12 to 17 years old, six males and six females. Nine were original from rural Pernambuco – PE, three from Recife metropolitan region, PE and one from another Northeast state.

Of the diagnoses found, nine were leukemia and lymphomas and four solid tumors. Nine were diagnosed during 2019 and three in 2016, 2017 and 2018, respectively. Of the 13 adolescents of the sample, six had family history of neoplasm. Nine adolescents claimed they were Brown, two, Blacks and two, Whites.

The family income of 11 adolescents was one minimum wage or less, two, the family income was two minimum wages. Nine did not complete elementary school, two did not complete elementary school-II and two completed high school.

From the analysis of the narratives, eight core ideas which reflect the perception of the adolescent with cancer about its sickening came up described in the DCS.

Question analyzed: What is it like to be sick for you?

a) Being sick is bad because it hampers the routine of a regular life

DCS: It is pretty awful, can't do anything, not even eat, only lying on bed, can't go where I really wanted. Stressful! This disease sucks, can't do anything, just watching TV, after the disease, school is out of the question, because the hospital is far from school and from home. Lost *Enem*. It is terrible because I like partying and I can't go with my friends. It is terrible to be sick, most of all with this disease, getting sick is bad! It is boring because you need to be hospitalized, there is nothing I can do and I'm here for four months without going home, stuck in the room, but what can I do? It really sucks! But needs treatment to be able to live, because anyone can die quickly (A1, A2, A3, A4, A6, A7, A8, A10, A11, A12).

For the adolescent, being sick with cancer is terrible because, in addition to changing its daily routine with hospitalizations, impedes its education, parties, living with friends and this is the loss it feels the most as reported.

b) Treatment is painful and changes my body image

DCS: I'm in pain and I am poked all the time when I lose my veins, I got nauseous after chemotherapy. Pulled away from everyone because of my hair falling, lost one leg for cancer, doctors said it was because I got here late, it took me one year until I found what I had. I was bored, had a hysterectomy because of the tumor, can't have babies anymore. People stare at me awkwardly, they think it is weird wearing a mask and without hair, I think they believe I can pass to another person (A1, A3, A6, A10, A13).

For the adolescent, cancer has been a devastating disease carrying the stigma of death, that mutilates, changes the body image and many times, begins to live with discrimination and prejudice.

c) Being sick has a good side

DCS: Look, I thought it would be worse, but I'm good. I'm well again. The good thing is that I sleep because of the medications for nausea, and I love sleeping. When I improve a little, I'm going to know the theater here, there is not one in my town. At least I will have more time to study at the hospital. It is good here, have many friends now (A5, A6, A7, A8, A9).

Despite the negativity cancer brings, the adolescent is still able to figure the positive side out of the possibilities the sickening scenario offers.

Question analyzed: What do you think about your future?

a) Be cured and resume my life plans

DCS: Be cured soon, don't have to come here anymore, do not need to stay here, want to get out, go back home. Be cured for good this time! And do not be poked and travel to other countries. Stay away from this boring thing! Cured of this disease, do esthetics college, I'm being delayed to attend college, but I think it will work. Cured for good, attend medical college and specialization in clinical oncology. Cured and attend law school, become a soccer player or a cop, a youtuber, continuing doing my videos, show my life at the hospital. Work to help my family. Be cured, get back to my normal life, if this happens, it is great (A1, A2, A3, A4, A5, A6, A7, A8, A9, A10, A11, A12, A13).

The results of the study showed that the adolescent with cancer does not think in its finitude, keeps the optimism and life plans after the cure. Prepares to resume the studies, attend college, travel, work to help the family financially and most of all do not need treatment anymore or hospitalization.

Question analyzed: How do you relate with your family and the health staff?

a) Hospital and staff are welcoming

DCS: The hospital is nice, I'm friend of the staff, all of them are great. I like it here and everyone who work here because it is cool, I have even a bed with air conditioning and they treat me and my mother well. They are swell, have no complaints of anyone. I love them all, they are great, I like here very much. I like being in the room with two friends in this hospital. All of them are nice (A1, A2, A3, A4, A5, A6, A7, A8, A9, A10, A11, A13).

The study results show that for the adolescent, the welcoming by the health professional, the comfort offered at the hospital and the possibility of creating affectionate bonds are important.

b) Lack of empathy and proper welcoming

DCS: The staff working here, sometimes they are cool, sort of. Earlier I was in a terrible hospital, I used to sleep in a chair, no food, the whole staff was boring. Here, just a few are grumpy, but it was worse in the other hospital, the doctor gave the

diagnosis of cancer when I was alone, didn't even wait my mother to come by and as far as I know, it is wrong, I'm a minor. I was desperate alone! The staff here, some of them are nice, some technicians are bad tempered, others don't care about me! When I'm admitted, don't like to be with my aunt, she is Evangelic and doesn't let me put lipstick, dressing nicely, she says I'm here to be treated and not to be pretty (A2, A4, A6, A7, A8, A11, A13).

In the adolescent's narrative, quite often, some professionals are indifferent, insensitive, and uncompromising, like some relatives who accompany them during admission.

c) Humanized care

DCS: When the toys room is open, I love going there with the volunteers. I like the night shift because the nurse brings films and popcorns, we do movies! It is cool, I count the days to meet her again! I only like one nurse who gives me the injection because she plays with me, no one else can poke me with the needle (A1, A7, A10).

When humanized care is provided to the adolescent, even painful moments are accepted more easily because humanization creates a professional-patient safety bond.

d) Family support

DCS: I always talk with my family through videoconference, I'm here all the time with my mom or with my dad, sometimes I would love to have both with me. Mom never leaves me, and I love her. We are dear friends, and she is always with me, occasionally I'm bothered because she keeps asking if I'm well. My family is always close to me, mom goes with me everywhere. My family is cool, but mom can't be with me often, she needs to work, then granny stays with me. My family is always with me, my aunt always stay with me when I'm at the hospital, mom needs to work. My grandmother is always with me helping and asking all the time if I'm well, telling me to eat, to leave the bed, to smile, she likes to boss me [laughs]. I would rather have my dad with me when my immunity is low and I'm admitted, mom cries all the time because she is worried, then I wish she could stay home and not see me in pain (A1, A2, A3, A5, A6, A7, A8, A9, A10, A11, A12).

From the adolescent discourse, the family expresses its affection and care, the bonds are strong regardless of the distance. The family takes shifts during hospitalization

because of work demands and are always checking whether the patient is feeling well and is painless, the family support and care is perceived by the adolescent.

The results show the perception of the adolescent about the aspects of its life related to hospital care, family and professional-patient bonds, the support it receives, the impact of sickening, its perspective of cure and resuming its regular life with plans for the future, like work, sons among others.

DISCUSSION

The change of daily life routine during the sickening process impacts more than the disease itself. As the adolescent perceives it, apparently, the fact of having cancer isn't that important, but the limitation and the impediment of not doing what it likes because of the illness and the treatment is because its routine changed¹⁵. Regardless of all the sickening-imposed limitations, what the DCS revealed is that the adolescent still keeps a positive perspective, able to leave suffering behind and foresees positive more than the negative aspects involving the disease and hospitalizations.

The life routines of adolescents with cancer changed because of the treatment and pushed them apart from social living and this can cause certain important emotional difficulties in their relations, changes of the body image that can make it less attractive¹⁶, for that reason, it is necessary to watch for some warning signs as isolation, low self-esteem among others that can reveal an off-standard adolescence.

Oncologic treatment requires invasive procedures, chemotherapy, radiotherapy, surgery, and other therapeutic approaches which cause adverse effects as nausea, edema, vomits, headache further to self-image changes as hair fall, mutilations that may negatively impact the psychosocial and emotional dimensions¹⁷. DCS portrays how painful, strenuous, and full of ambiguous feelings sickening by cancer can be.

And these self-images disturbances the treatment imposed as the patients felt can mirror a high level of resilience. Through adversity they learn to resignify their beliefs and strengthen themselves to cope with the disease and by living their problems, they found ways out and perceive that life is worth living¹⁸.

Within this perspective the discourse of the adolescent with cancer shows the main goal of the treatment, which is the cure and/or release for a safe hospital discharge and resuming its life; for this to occur, humanized therapeutic care can minimize the suffering and the emotional disturbance¹⁹ to avoid that they become an impediment throughout this trajectory.

Quite often, the route until the arrival at the oncology reference hospital is slow with consequences for the patient because of late diagnosis and delay of the treatment, either for lack of beds and/or cash to buy medication. The fragilities of the National Health System provoke delays of the treatment and care with overwhelming bureaucracy and poor guidance about the pathology²⁰.

The attitudes of the other, sometimes, are bothering and can intensify isolation feelings among adolescents with cancer. There is clear prejudice because of the sequelae caused by the treatment as the broken-down appearance, scars, and amputated limbs, possibly reflecting misinformation and curiosity about the disease. In this scenario, social networks can help to demystify it as the study results revealed^{21,22}.

The expectation about the future, as opposed to some ideas that only patients with possibilities of cure and with good life perspectives were able and could express their wishes and projects for the future, shows that those in palliation also have thoughts and plans for their future and hope for prolonged survival with quality, emphasizing the importance of devising strategies to organize the time with the family and friends²³.

Considering that the adolescent pursues the cure as a result of the treatment and better quality of life, the resilience in face of the adversities the sickening causes allows the readaptation and possibility of new perspectives and plans for the future²⁴.

DCS revealed the importance of the cure for life plans devised through it, that the daily life habits, damaged by the sickening will be reclaimed and professional projects are possible. Studies with adolescents survivors of cancer found similar data, the tough period of the treatment allowed to devise a new meaning of life and how they saw the post-treatment period as an opportunity to have a normal life⁹.

Social networks, on-line platforms for social interaction are part of the daily life of everyone in general and of the adolescents as well, through which they share, connect, produce, and consume digital contents; they ensure on-line living with other individuals with whom they talk about common subjects and entertainment²⁵.

The adolescents are able to devise their future because of the social networks. These technological tools facilitate the day-to-day communication with the outside world, with patients from other infirmaries and to minimize the longing for the family at home and even producing campaigns to raise funds for the treatment. Other adolescents spend their time showing other internauts their routine during sickening to encourage other persons going through a tough situation under the supervision of the responsible as the social network is not risk-free²⁶.

The relations the adolescent holds with its virtual and real friends mediated through the social network, despite the risks, brings the feeling of belonging, of connection with the peers and this can help to keep its self-esteem elevated, very important in the process of adolescence and sickening²⁷.

The social network has functional, effective, and relevant characteristics for the well-being of the patients with cancer to strengthen the support, improve the quality of life and self-esteem throughout the whole process of diagnosis, treatment, and post-treatment, making this journey less painful. Social campaign, among the normal functions of the daily life, is the most important the network offers²⁸.

In the adolescent's perception, professionals should have empathy in face of the human suffering, involvement in the relation professional-patient is critical to create bonds and trust to offer care and comfort not only for the adolescent but also its family associated with this process⁹.

The importance of humanized care and in family relations brought by the DCS showed that for the adolescent, health and humanized care are bound together and one can't proceed without the other. Understand how the family lives sickening make health professionals and especially the nurses to acknowledge the relevance of providing full and humanized care²⁰.

Reflect about the perception of the adolescent sickening allows changes of the caring practice of the nurses, making them humanized and welcoming, which makes difference in the treatment, minimizing physical pain, bring joy to the adolescents who anxiously wait for the care they are entitled to²⁹. Improve the mood after humanized care and utilization of non-pharmacological resources by health professionals as those reported show this difference.

The non-pharmacological therapeutic resources are important to minimize the discomfort of the patient: massage, routine change even in the hospital, compress, among others. Artistic activities also help improving the emotional expression, self-esteem, communication, social living with other patients, creating well-being. This is the reason why there are several support groups for children with cancer in the whole world doing the best to promote joy and help to cope with pain and forget for a while the environment where they are³⁰.

Because of the distance between the residence and the hospital, most of the patients were accompanied by their family as siblings, uncles and grandparents as this study concluded. Missing their parents who had to work to keep the family was felt and quite often the family member failed in showing the same humanized behavior; caring should be respectful for the other rather than imposing⁶.

Within the concepts of empathy and humanization, attention should be focused to the family accompanying the adolescent, not only to the health professionals; quite often, the family members forbid the use of simple objects as a lipstick, not because of the disease, but out of a mere whim⁶.

It is necessary to see the adolescent as an individual, as a person with perceptions and full ability to express them. Health professionals and family should hold an affectionate and effective relation with it, utilizing strategies to offer robust support, which requires the knowledge of the characteristics of the disease's course in order to grasp its feelings⁹.

Not always a problem or suffering for the team and family means the same for the adolescent. It is critical to understand that perspectives about problems and suffering cause diverse impacts. In the sickening process to cope with cancer the adolescent gathers its inner resources as hope and trust in addition to the social network, typical of this phase of life²⁴.

The adolescent as protagonist of its sickening condition is entitled to say what it feels, thinks, expects of life and how it means to get sick with cancer; only after listening and knowing its reality it is possible to reflect and rethink the humanization of the nursing care and of the whole health team³¹.

Cancer brings direct consequences to the patient and its family because of limitations in its autonomy. On the other hand, family and friends are key supporting sources in the sickening process. Most of all nurses who are mentioned among health professionals because they are present through the whole process with qualified therapeutic listening⁷ to promote a holistic and humanized care.

The study was conducted in one site alone, regardless of being a reference in the State of Pernambuco for cancer treatment of children and adolescents, which is a limitation because it will hardly reflect the realities of the country.

CONCLUSION

Through the discourse of the adolescents, the current study revealed their perception of sickening and cancer treatment and how their daily life routines were changed pulling them apart from family living and friends.

The adolescents' feelings of getting sick, typical of the age-range quite often are dissimilar of the family's and health professional's suffering, for the adolescent, sickening goes beyond the physical condition, it impacts the social, economic, family, hospital and psychological mean and in their perspectives for the future, demeans the quality of life, of how to live with the disease and for those involved in helping them in this trajectory.

The adolescent notices the health professional who provides humanized care with therapeutic listening as a differential and the use of non-pharmacological resources can minimize the physical pain and strengthens the bond professional-patient.

The current study has also contributed to understand that the adolescent should be seen as a protagonist of its sickening process and emphasized the importance of listening what living with cancer means, the narrative of its trajectory since the diagnosis with feelings like fear and insecurity until treatment, hospitalizations and care received. Discourses filled with pain, fight, resilience, and adaptation to a new routine the disease imposed without losing the hope of overcoming and reclaiming its future life plans.

CONTRIBUTIONS

All the authors contributed substantially for the study design/conception, collection, analysis and/or interpretation of the data, wording, and critical review. They approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

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