



Music therapy in oncology: perceptions of children and adolescents in palliative care

A musicoterapia em oncologia: percepções de crianças e adolescentes em cuidados paliativos

Musicoterapia en oncología: percepciones de niños y adolescentes en cuidados paliativos

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ABSTRACT

Objective: to analyze the perceptions of children and adolescents with cancer in palliative care about music therapy. **Method:** field research with a qualitative approach, conducted with seven children and adolescents. The drawing-story technique was initially carried out based on drawings on feelings about hospitalization and the drawing story. Then there was the musical interaction, drawing on the meaning of music in the face of the hospitalization process, and the story of the drawing. For analysis, the content analysis technique was used. **Results:** before music therapy, the children and adolescents expressed feelings of sadness, fear and longing related to the breaking of the family bond during the hospitalization process. After receiving music therapy, they expressed feelings of pleasure and well-being that this experience can provide them, allowing them to express their deepest feelings. **Conclusion:** music therapy can benefit children and adolescents with cancer as it allows for the expression of feelings, enables the rescue of memories and provides hope in the face of the situation experienced, in addition to pain relief. **Implications for the practice:** music therapy contributes to the palliative process and can offer better quality of life to children and adolescents with cancer.

Keywords: Music Therapy; Palliative Care; Cancer; Child; Adolescent.

RESUMO

Objetivo: analisar as percepções de crianças e adolescentes com câncer em cuidados paliativos sobre a musicoterapia. **Método:** pesquisa de campo, com abordagem qualitativa, realizada com sete crianças e adolescentes hospitalizadas. A técnica de desenho-estória foi realizada inicialmente a partir do desenho sobre os sentimentos diante da hospitalização e a estória do desenho. Em seguida, houve a interação musical, desenho sobre o significado da música diante do processo de hospitalização, e a estória do desenho. Para análise, utilizou-se a técnica de análise de conteúdo. **Resultados:** antes da musicoterapia, crianças e adolescentes expressaram sentimentos de tristeza, medo e saudade relacionados ao rompimento do vínculo familiar durante o processo de hospitalização. Após receberem a musicoterapia, elas expressaram as sensações de prazer e bem-estar que essa vivência pode proporcionar, permitindo-lhes a expressão dos sentimentos mais profundos. **Conclusão:** a musicoterapia pode beneficiar a criança e o adolescente com câncer uma vez que permite a expressão de sentimentos, possibilita o resgate de lembranças e proporciona esperança diante da situação vivenciada, além do alívio da dor. **Implicações para a prática:** a musicoterapia contribui no processo paliativista, podendo conferir uma melhor qualidade de vida às crianças e adolescentes com câncer.

Palavras-chave: Musicoterapia; Cuidados Paliativos; Câncer; Criança; Adolescente.

RESUMEN

Objetivo: analizar las percepciones de niños y adolescentes con cáncer en cuidados paliativos sobre la musicoterapia. **Método:** investigación de campo con enfoque cualitativo, realizada con siete niños y adolescentes. La técnica del dibujo-cuento se llevó a cabo inicialmente basándose en el dibujo de los sentimientos sobre la hospitalización y en el cuento del dibujo. Luego hubo interacción musical, con dibujo sobre el significado de la música durante el proceso de hospitalización y el cuento del dibujo. Para el análisis, se utilizó la técnica de análisis de contenido. **Resultados:** antes de la musicoterapia, los niños y adolescentes expresaron sentimientos de tristeza, miedo y anhelo relacionados con la ruptura del vínculo familiar durante el proceso de hospitalización. Después de recibir musicoterapia, manifestaron las sensaciones de placer y bienestar que esta experiencia les puede brindar, permitiéndoles expresar sus sentimientos más profundos. **Conclusión:** la musicoterapia puede beneficiar a niños y adolescentes con cáncer ya que permite la expresión de sentimientos, posibilita el rescate de recuerdos es fuente de esperanza ante la situación vivida, además de aliviar el dolor. **Implicaciones para la práctica:** la musicoterapia contribuye al proceso paliativo y puede brindar una mejor calidad de vida a los niños y adolescentes con cáncer.

Palabras clave: Musicoterapia; Cuidados Paliativos; Câncer; Niño; Adolescente.

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Submitted on 02/01/2021.

Accepted on 06/02/2021.

DOI:<https://doi.org/10.1590/2177-9465-EAN-2021-0012>

INTRODUCTION

Palliative care is an approach that helps to improve the quality of life of patients who suffer from life threatening diseases and of their family members, through prevention, research and treatment of pain and other psychological, social and spiritual symptoms¹.

In pediatrics, palliative care becomes a specific field, being provided at any care level, requiring a wide-ranging assessment from the multidisciplinary team that encompasses the physical, psychological, social and spiritual dimensions. It is initiated at the time of diagnosis and continues throughout the illness process, regardless of whether conventional therapy is performed or not, being adapted to the values of the patient and the family, which is also included in the service. These are an important reality in the health area and of great relevance in the care of children and adolescents².

It is noteworthy that not all children and adolescents can benefit from curative cancer treatment, but the relief of suffering provided by palliative care can be achieved³. This approach becomes indispensable, especially given the impossibility of cure, because the cancer diagnosis is a situation that generates a lot of stress and involves a painful treatment⁴.

A number of research studies have been verifying the benefits of non-pharmacological interventions for cancer patients and/or in palliative care, with an emphasis on children and adolescents⁵⁻⁹. A review study aimed at identifying the Nursing interventions used in palliative care targeted at children and adolescents with cancer and showed that massage, music therapy, physical exercises and the use of therapeutic toys are highly relevant therapies in palliative care, especially when directed to a specific symptom⁵.

A study aiming to identify non-pharmacological interventions for fatigue in children and adolescents with cancer showed positive results for the practice of physical exercises, exercises accompanied by leisure activities, therapeutic touch and acupuncture⁶. Diverse scientific evidence on non-pharmacological therapies for the management of fatigue and psychological stress in children and adolescents with cancer also verified the benefit of interventions in the face of these problems⁷.

A systematic review study evaluated the use of complementary therapies to treat pain in cancer patients who were undergoing palliative care and verified the benefits of therapeutic massage, progressive muscle relaxation and guided imagery. However, it inferred the need for new research studies to assess the effectiveness of acupuncture¹⁰. In turn, a research study evaluated the association between the clown intervention and the levels of psychological stress and fatigue in children and adolescents with cancer and verified that this therapy can be beneficial for this population, considering that the total stress and fatigue level were improved⁸. In addition to the aforementioned, other interventions are also considered: hypnosis, meditation, art therapy, yoga, acupuncture, reiki and therapeutic touch².

Evidence on non-pharmacological interventions aimed at the child/youth population with cancer arouses interest in the topic, stimulates the professionals and highlights the

importance of conventional treatment associated with non-pharmacological therapy to improve quality of life in view of the health situation⁹.

In the context of the non-pharmacological therapies, music therapy stands out, since this intervention may allow for the relief of manifestations such as anxiety, pain and fatigue and side effects of the cancer treatment, consequently improving the quality of life of cancer patients. It can also reduce the need for anesthetic drugs, analgesics, and recovery and hospital stay time¹¹.

In this context, it is important to consider that non-pharmacological therapies can help children and adolescents with cancer to reduce the physical, psychological, social and spiritual symptoms, and that music can be one of the therapies used to alleviate suffering, pain and its tension, also allowing for a moment of relaxation and leisure. Thus, this research aims at analyzing the perceptions of children and adolescents with cancer in palliative care about music therapy.

METHOD

This is a field research, with a qualitative approach, carried out in the Pediatrics sector of a hospital located in the city of João Pessoa/Paraíba. The research followed the recommendations of the Consolidated criteria for reporting qualitative research (COREQ), allowing for the improvement of research rigor¹².

This institution was chosen for being a reference hospital for cancer treatment that has several sectors, including outpatient clinic, intensive care unit, operating room, urgency and pediatrics; and due to the fact that the main researcher carried out a volunteer project in the Pediatrics sector of this locus, based on art therapy and music therapy practices, which facilitated access to the service and closer contact with the professionals who worked there.

The sample was selected for convenience, and comprised seven participants who met the research inclusion criteria: being aged between eight and nineteen years old; being admitted to the hospital; and being in adequate clinical conditions to participate in the research activities. Those who were being monitored in the outpatient clinic, in the Intensive Care Unit, or who had previously participated in music therapy were excluded. It is noteworthy that the research was completed considering the proposed time interval for data collection, material quality, analysis of the connection between the each participant's empirical material, absence of new information and, consequently, data saturation.

In turn, the choice of the age group was due to the ease of understanding the questions by this population, considering that younger children might not understand what was asked or even be unable to express their feelings.

Data collection with the population aged over seven years old allows for better cognitive development and, consequently, enables greater approach to the experience⁴.

The data were collected from March to April 2019, using an instrument based on a number of studies¹³⁻¹⁴, and involving a script of questions for the drawing-story (D-S) technique. The D-S technique was developed by Walter Trinca and is a tool that unites free drawing and storytelling, thus allowing the individuals to reveal conflicting situations and emotional problems on a sheet of paper¹⁵. It is noteworthy that an adaptation was made to the D-S technique and that the sequence of five drawings was not used. Before data collection was initiated, the main researcher was properly trained to perform this activity. To characterize the sociodemographic data, an instrument with data on gender, age, race, schooling and diagnosis was also used.

The technique was performed at two moments: in the first, a drawing was requested on how each child and adolescent was feeling regarding their hospitalization; subsequently, they were asked to tell a story of the drawing they had made. Afterward, at the second moment, the musical interaction was conducted, through pre-selection by the participants themselves, the delivery mode being live, voice and guitar. When it was not possible due to the music choice, presentation of the music was made through a sound device. To choose the music, the collector asked about the music the participant would like to hear.

After the musical interaction, the interview involved questions about what the musical moments represented for each participant. To answer, the participants made a new drawing, telling the story. Both moments were carried out individually and were recorded on an MP3 player. It is to be noted that the sequence of stages was carried out in a single day, in the place where the child or adolescent was, and with a mean duration of approximately 60 minutes per participant.

The speeches and drawings were coded using primary and secondary colors (yellow, blue, light blue, purple, pink, green, red) chosen by the children and adolescents in order to maintain anonymity and confidentiality of the information.

Data analysis was performed using the content analysis technique, in accordance with the phases of pre-analysis, exploration of the material and treatment of results (inference and interpretation)¹⁶.

In this research, the ethical aspects pertinent to research studies involving human beings were considered, in accordance with Resolution No. 466/12, especially with regard to the Free and Informed Consent Form addressed to the person responsible for the child and to the Assent Form for the children and adolescents¹⁷, being approved by the Ethics Committee of the João Pessoa University Center-UNIPÊ (CEP/UNIPÊ) with CAAE No. 07136819.4.0000.5176.

RESULTS

The study participants were seven children and adolescents aged between eight and seventeen years old, of which three (43%) were female and four (57%) were male. Most of them, six (86%), were brown-skinned, and only one (14%) was white-skinned. All the children were attending school, and the majority

had completed Elementary School I, with four (57%), followed by those who were in Elementary School II, with one (14%), and only two (29%) were in High school. Three (43%) of the participants had leukemia and the others presented lymphoma, lower limb sarcoma, renal malignancy and thyroid cancer (14.3%).

With regard to the research data, the analysis of the empirical material allowed elaborating two categories that will be presented below:

CATEGORY I - Understanding the hospitalization process

In this category, the children and adolescents understood the hospitalization process based on negative feelings, as shown in Figure 1 and reports below.

In relation to the feeling of sadness for being hospitalized, it can be observed in the drawings, and especially in the statements by interviewees Green and Purple. Deponent Green shows several clouds and the presence of rain, meaning the tears and sadness of being ill and hospitalized, and deponent Purple verbalizes about the sadness in discovering the disease and in her hospitalization process.

When I was hospitalized for the first time, I cried every day, today I feel sad, but I don't cry anymore (VERDE).

This is me, and this is the hospital. I'm outside the hospital. I've already felt very sad to be in the hospital, but I got used to it (AZUL-CLARO).

Of course I don't like being here in the hospital, as much as I know this is where I'll be better [...] (AMARELO).

[...]. I'm in the hospital because I'm ill, and my mother is waiting if I can go home (VERMELHO).

This is me in bed, and this other bed is my brother's; I miss him so much. The hospital is not a bad place, there are people here who are taking care of us, but it's not my home, I feel alone here. This bed is empty because he's not here with me (AZUL).

I feel very lonely in this hospital. My mother can't come with me because I have a little brother and she has to stay with him, normally; the one comes is my aunt. I miss home and my mother (ROSA).

This is me crying. When I found out I was ill, I felt sad and groundless. When I'm admitted to the hospital, it's like I'm getting sicker (ROXO).

In the testimony by deponent Pink, we were able to perceive the homesickness and loneliness caused by moving from home to an environment in which the child does not have the presence of all family members and friends. In addition to that, her drawing represents the princess (deponent Pink) in a prison (hospital), that is, it represents the hospital as a solitary environment, in which the child does not feel free. Interviewee Light Blue also shows that she does not want to be in the hospital. In her drawing, she



Figure 1. Drawing made before music therapy about how children and adolescents were feeling regarding the hospitalization process. Survey Data. João Pessoa, 2019.



Figure 2. Drawing made after music therapy about what the musical moments meant for the children and adolescents. Survey Data. João Pessoa, 2019.

presents herself outside the hospital, although she is already used to the environment. In turn, deponent Yellow verbalizes not wanting to be in that place, but recognizes that it is the only place that can help him improve his health.

CATEGORY II - Perception about the effects of music therapy on your health condition

In this category, the effects of music therapy for children and adolescents with cancer in palliative care will be presented. In the interviewees' perception, music helps them to forget what they are going through and not to give up on life, making them remember their home and family members, feel free and allow pain relief, as shown in Figure 2.

The testimonies by the children and adolescents show different effects related to music therapy on their current health conditions. As it can be seen, when listening to the music, most of the participants remember their homes. Interviewees Red, Blue and Light Blue incorporate this perspective into their drawings, when the painting of the house is present. However, the perception of interviewee Light Blue is associated with maternal care, performed through musicalization for pain relief. It has an affective (maternal/family) and technical (promoting pain relief) characteristic. Also regarding the maternal bond, participant Yellow highlights it as a foundation for coping with the clinical condition and hospitalization and, based on music therapy, he feels strong not to give up and reminds him of his mother who never gave up on him.

When I hear this music, I close my eyes, I'm taken to the sea. The sea, the beach is where I feel good. I like to listen to this song, mainly when I'm hospitalized, or when I get bad news about my treatment. It makes me forget what I'm going through (VERDE).

I chose this song because it teaches me not to give up, and this flower is for my mom because she didn't give up on me like my dad did [...] (AMARELO).

This is me and my little sister at home, I miss her a lot, playing with her. I chose this song because I always sang it to her. I think that what I miss the most is her, and she liked it a lot, I've seen you singing outside, I always wanted to participate, but I couldn't leave the room. I was happy for this moment today (VERMELHO).

This is me at home playing, I miss home. I really like this song, I feel free when I listen to it, free from this hospital. My brother also likes it a lot, we used to listen to it together (AZUL).

[...] My mother used to sing this song to me when I felt a lot of pain. Sometimes, when she's not here with me I keep singing, until my pain goes away (AZUL-CLARO).

I drew myself crying again, but these tears are different [...]. This cry is of hope, and this song helps me get up and continue my treatment (ROXO).

I drew butterflies, because they symbolize freedom, I miss playing, being free. When we get sick we can't do anything else. This song I chose makes me imagine that one day I'll have this freedom, that I can fly (ROSA).

In relation to deponent Purple, although she presents tears in her drawing, she reports that they represent the hope in restoring her health with the cancer treatment, which strengthens her in the face of the current situation. The same can be seen in deponent Pink's drawing, in which she portrays butterflies, in order to represent a feeling of freedom, of flying, which is not present during hospitalization. In the statements by deponents Pink and Purple, it can be observed that music helps to change their perceptions about the hospital. For interviewee Green, music provides well-being, even in the face of sadness and bad news related to his health problem.

DISCUSSION

The hospitalization of children and adolescents can be considered as a stressful situation that interferes in the behavioral and emotional responses of these subjects, consequently influencing the development and results achieved with the assistance provided¹⁸.

Hospitalized children and adolescents, especially those with cancer, have a series of physical and psychological symptoms as a result of the illness process¹⁹. With hospitalization, daily and family activities are disrupted, and a new routine must be

followed, which generates a series of negative feelings, such as sadness and anxiety, associated with painful technical procedures (administration of medications and examinations), hospital restrictions, isolation, institutional routines, and missing friends and the family environment¹⁴.

The diagnosis of child/youth cancer and the hospitalization process affect the entire family structure and bring different reactions to the family. Reactions of surprise, denial, sadness, fear, anxiety, suffering, unpreparedness to deal with the situation, anger, depression and uncertainty surround this moment²⁰.

A study aimed at investigating the meaning of playing for children in hospital isolation found that loneliness, sadness and imprisonment define the environment. In addition to that, it was evidenced that, in this place, the patient suffers as a result of the disease and of the existing restrictions, feeling threatened by the presence of the health professional because they understand him as a performer of procedures²¹.

Although they are able to communicate what they feel, children and adolescents may need help expressing their feelings¹⁹. The offer of psychological support, practices that improve patient and family care, and that encourage playing can have great relevance for the well-being of children and adolescents¹⁸.

However, the implementation of measures that can improve the quality of life of this population by health professionals is still a challenge. There is a limitation on the part of health professionals to manage manifestations of child/youth cancer and, consequently, the lack of professional training to assist them²².

In this context, the drawing technique stands out, so that children and adolescents express their feelings and thoughts¹⁴. This technique can be implemented in different environments, whether the house or the hospital, to assist in diagnosis and treatment and allows for the revelation of valuable sensations for their life, whether positive or negative²³, which can assist the health professionals in understanding the real needs of children and adolescents, so that targeted and individualized care can be planned.

This research evidenced that music therapy can be beneficial during the hospitalization process of children and adolescents with cancer. From an iconographic point of view, this study showed a differentiated tendency in the content of the drawings made after the musical intervention, since a larger number of elements and colors arranged on the sheets of paper was explained. As for the characters, the imagery and affective connotation about the possibility of living outside the hospital context is notorious, especially in the home environment, with greater proximity to the family members who have a significant participation in the lives of the children and adolescents in this research.

Music therapy is considered as a resource for the reduction of pain²⁴⁻²⁶, blood pressure, respiratory and heart rate^{11,26}, anxiety^{11,24-26}, decrease in depressive symptoms²⁵⁻²⁶ and in the consumption of anxiolytics²⁵. It assists in cognitive, attention, memory and dexterity development and, unlike other therapies,

music is considered an efficient, non-invasive and painless therapy modality that has few side effects²⁴.

In vulnerable patients, as in the case of cancer patients, music reduces the imbalance in the face of hospitalization and the changes imposed by the new environment, routines, and social interaction with other subjects and the loss of bonds with close people, which may lead to recovery, as a result of its evident effects on the body, heart, and mind²⁴.

When music is listened to, differently than when there is activity without music, the individuals are led to total body relaxation and the body immediately releases natural morphine, thus helping to relieve pain, similarly to what happens with synthetic analgesics²⁵.

Although music is connected with the limbic system, which is responsible for emotions, motivation and affection, there is scarce scientific production on the effects of music on physiological, psychological and emotional changes, which raises the need for more research studies in the field of health²⁶, especially aimed at children and adolescents with life threatening diseases. Integrating the analysis of serum biomarkers with psychological measures in patient care has become increasingly emerging in the context of health, illness and personalized care²⁷.

In a study, the presence of hospital clowns during procedures in children and adolescents proved to be beneficial and helped to improve their psychological status, when compared to those who received only standard care. In the study, it was recommended to assess the impact of hospital clowns and its correlation with clinical data and biomarkers²⁸.

Other authors highlight the need for new studies to assess common biomarkers in cancer in order to assist in the use of interventions that contribute to the treatment of the psychoneurological symptoms²⁹.

A study with the objective of evaluating the effect of music therapy on the stress of chemically dependent individuals verified that, after the therapeutic intervention, there was a reduction in the levels of salivary cortisol, a biochemical marker of stress, thus reducing the stress of chemically dependent individuals, showing the benefits of music therapy in assistance³⁰.

As a therapeutic resource, music stands out among the integrative and complementary practices for promoting biopsychosocial changes, helping to treat patients and improve their quality of life. When used in patients with life-threatening diseases, it promotes improvements in communication and in the relationship between patient and family³¹.

Thus, from the drawings and testimonies it is possible to perceive the effects of music therapy during the hospitalization process of children and adolescents with cancer. Considering that this resource could transform negative aspects related to the situation experienced into positive aspects, helping the research participants to forget the process of illness and hospitalization and fight for life, to have hope in improving the condition, and in pain relief, contributing to the improvement of their quality

of life, even in the face of a life threatening situation and the hospitalization process.

FINAL CONSIDERATIONS AND IMPLICATIONS FOR THE PRACTICE

It was found that, before receiving music therapy, the children and adolescents expressed feelings of sadness, fear and longing related to the breaking of the family bond in the home scenario during the hospitalization process.

In turn, after receiving music therapy, they expressed the sensations of pleasure and well-being that this experience could provide them, allowing them to express their deepest feelings.

It was noticed that music therapy made it possible to rescue positive memories and hope to live better; it provided a space for communicating anxieties, fears and hopes; as well as it promoted pain relief. All of this can provide better quality of life for children and adolescents with cancer during palliative care.

The study limitations are attributed to the fact that the research was not carried out with children under eight years of age suffering from cancer in palliative care; with a random sample; failure to quantify the benefits of using music therapy in the illness of children and adolescents; the non-standardization of the type of music selected for the participants; and the reduced number of participants. However, the quality and richness of the empirical material in this study is highlighted, without compromising the research evidence.

This study offers contributions to the practice, as it investigates the perception of children and adolescents with cancer about a resource that can be used in various health institutions to benefit patients who are facing difficult situations, mainly those who suffer from a life-threatening disease that also requires non-pharmacological therapies to relieve pain and other symptoms they may come to experience.

AUTHOR'S CONTRIBUTIONS

Study design. Julia Helena Machado Franco. Carla Braz Evangelista.

Data collection or production. Julia Helena Machado Franco.

Data analysis. Julia Helena Machado Franco. Carla Braz Evangelista. Mariana de Sousa Dantas Rodrigues. Ronny Anderson de Oliveira Cruz. Indaya Machado Freire Franco. Mayara Limeira Freire.

Interpretation of the results. Julia Helena Machado Franco. Carla Braz Evangelista. Mariana de Sousa Dantas Rodrigues. Ronny Anderson de Oliveira Cruz. Indaya Machado Freire Franco. Mayara Limeira Freire.

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