

HOW MUSIC THERAPY IS PERCEIVED IN A PEDIATRIC AMBULATORY CHEMOTHERAPY UNIT IN A PERUVIAN HOSPITAL: EXPERIENCE REPORT

*COMO A MUSICOTERAPIA É PERCEBIDA EM UM AMBULATÓRIO PEDIÁTRICO DE
UMA UNIDADE DE QUIMIOTERAPIA EM UM HOSPITAL PERUANO: RELATO DE
EXPERIÊNCIA*

*CÓMO SE PERCIBE LA MUSICOTERAPIA EN UNA UNIDAD DE QUIMIOTERAPIA
PEDIÁTRICA AMBULATORIA DE UN HOSPITAL PERUANO: INFORME DE UNA
EXPERIENCIA*

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Abstract - This report presents descriptions of how music therapy was perceived in a pediatric ambulatory chemotherapy unit. These descriptions were collected through interviews with caregivers, hospital volunteers and members of the medical team to explore the interviewees' experiences of the impact of music therapy interventions on the children, the hospital environment, the caregivers and the interviewees themselves. Twelve themes emerged from the interviews with *attention*, *enjoyment* and *relaxation* being the key themes to describe the benefits of music therapy. Between and during medical procedures, active and receptive music therapy interventions provided a supportive distraction from the challenging environment, thereby helping the children to better cope with the situation and providing possibilities to encourage social engagement and interactions. The music therapy interventions not only had a positive impact on the children, but also on the people around them and on the atmosphere of the hospital environment. Through music therapy, children's cooperation during medical procedures improved, which facilitated the staff in carrying out the procedures. These findings support music therapy as having an ability to create meaningful moments in an intense and high-tempo medical unit and contribute to the child's treatment process from a holistic perspective.

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Keywords: music therapy, pediatrics, oncology, experience report.

Resumo - Este relato apresenta a experiência de fazer as entrevistas para compreender como a musicoterapia é percebida numa unidade de quimioterapia pediátrica ambulatorial. As entrevistas foram realizadas com cuidadores, voluntários do hospital e membros da equipe médica para explorar as experiências dos entrevistados sobre o impacto das intervenções musicoterapêuticas nas crianças, no ambiente hospitalar, nos cuidadores e nos próprios entrevistados. Doze temas emergiram da análise, sendo a atenção, o prazer e o relaxamento os temas-chave para descrever os benefícios da musicoterapia. Entre e durante os procedimentos médicos, as intervenções musicoterapêuticas ativas e receptivas proporcionaram uma distração de apoio no ambiente desafiante, ajudando assim as crianças a lidar melhor com a situação e proporcionando possibilidades de encorajar o envolvimento social e as interações. As intervenções musicoterapêuticas não só tiveram um impacto positivo sobre as crianças, mas também sobre as pessoas à sua volta e sobre a atmosfera do ambiente hospitalar. Através da musicoterapia, a cooperação das crianças durante os procedimentos médicos melhorou o que facilitou para a equipe a realização dos trabalhos. Estas descobertas apoiam a musicoterapia como tendo a capacidade de criar momentos significativos numa unidade médica intensa e de grande fluxo e contribuir para o processo de tratamento da criança a partir de uma perspectiva holística.

Palavras-Chave: musicoterapia, pediatria, oncologia, relato de experiência

Resumen- Este informe presenta descripciones de cómo se percibió la musicoterapia en una unidad de quimioterapia pediátrica ambulatoria. Estas descripciones se recogieron mediante entrevistas con cuidadores, voluntarios del hospital y miembros del equipo médico para explorar las experiencias de los entrevistados sobre el impacto de las intervenciones de musicoterapia en los niños, el entorno del hospital, los cuidadores y los propios entrevistados. De las entrevistas surgieron doce temas, siendo la atención, el disfrute y la relajación los temas clave para describir los beneficios de la musicoterapia. Entre y durante los procedimientos médicos, las intervenciones de musicoterapia activa y receptiva proporcionaron una distracción de apoyo del entorno desafiante, ayudando así a los niños a sobrellevar mejor la situación y proporcionando posibilidades para fomentar el compromiso social y las interacciones. Las intervenciones de musicoterapia no sólo tuvieron un impacto positivo en los niños, sino también en las personas que los rodeaban y en la atmósfera del entorno hospitalario. Gracias a la musicoterapia, la cooperación de los niños durante los procedimientos médicos mejoró, lo que facilitó al personal la realización de los procedimientos. Estos resultados apoyan que la musicoterapia tiene la capacidad de crear momentos significativos en una unidad médica intensa y de alto ritmo y contribuir al proceso de tratamiento del niño desde una perspectiva holística.

Palabras Claves – musicoterapia, pediatría, oncología, informe de experiencia

Introduction

The purpose of this paper is to share experiences of clinical music therapy practice in a pediatric ambulatory chemotherapy unit, collected through interviews with caregivers, hospital volunteers and members of the medical team, and to share the interviewees' descriptions of the impact of music therapy interventions on the children, the hospital environment, the caregivers and the interviewees themselves. In this article, the authors have chosen to use the word 'child' instead of 'pediatric patient' to emphasize the person, not the disease. The word 'caregiver' was chosen to describe the person accompanying the child.

Pediatrics is the field of medicine focusing on children and their diseases (Sundhedsstyrelsen, 2018). A child's pattern of health differs from those of an adult and, therefore, a child's symptoms, treatment, prognosis and recovery process are also different (Sanfi & Bonde, 2014; Sundhedsstyrelsen, 2018). The typically long-lasting treatments for children diagnosed with cancer cause both the child and the family to struggle with a great deal of uncertainty and stress (Aasgaard, 2002; Sanfi & Bonde, 2014). Besides hospitalization, isolation and side effects, there are many psychological, social and existential consequences associated with the cancer diagnosis (Aasgaard, 2002). Being in hospital can be a highly stressful experience that can increase the perception of pain (Longhi et al., 2015). It is therefore important to provide a supportive environment and take into consideration the child's whole experience of the time spent at the hospital as this has an impact on the child's physical and mental health (ibid.).

Research in pediatric oncology music therapy is growing as the field expands and the demand for non-pharmacological approaches to symptom management continues to increase (Hilliard, 2006). The American Music Therapy Association (2018) describes music therapy as an established healthcare option that uses music to address physical, emotional, cognitive and social needs of individuals of all ages. Working as a music therapist in a pediatric hospital setting involves a broad range of ages,

developmental levels, and a wide diversity of diseases and needs of the children (Sanfi & Bonde, 2014). According to psychotherapist Irvin Yalom (2005), a *here-and-now* approach is required in a hospital setting, with a focus on helping the child to deal with problematic behaviors rather than going into the child's history. Music therapy aims to support the child in managing medical procedures, to decrease the child's experience of anxiety and pain, and to work to minimize negative experiences of repeatedly painful procedures that can become traumatic (Longhi et al., 2015; Sanfi & Bonde, 2014; Whitehead-Pleaux et al., 2007). Music therapy can provide a supportive interaction where the child can express feelings and thoughts, and receive support to better cope with the situation (ibid.).

This report is an extract from the Master's thesis of the first author of this publication (Helander, 2018). It is based on her final internship, which took place in the pediatric ambulatory chemotherapy unit at the public hospital Instituto Nacional de Enfermedades Neoplásicas (hereafter abbreviated to INEN), during the fall of 2017. INEN is the largest hospital in Peru for treating children and adults affected by neoplastic diseases. This unit is a fast-paced, intensive and stressful environment with a variety of needs, sounds and emotions at the same time. Both active and receptive music therapy interventions were used between and during medical procedures.

Description of the interviews

This report aims to describe how music therapy can contribute to the child's treatment from a holistic perspective, through exploring the service users' descriptions of the impact of music therapy and connecting these descriptions to the needs of the children. The interviews were conducted inside the pediatric ambulatory chemotherapy unit at INEN with caregivers, hospital volunteers and members of the medical team. The interviews were conducted during three separate days over a period of three weeks in November 2017, and included verbatim quotes and interviewees' personal descriptions of their experiences of music therapy. The interviews were designed and

carried out in Spanish, thereafter transcribed and translated into English. The design and translation were carried out in collaboration with music therapist Erik Baumann, who also conducted the interviews. This choice was taken to limit the influence of the first author of this publication, who also was the music therapist carrying out the music therapy interventions. This music therapist wrote down her experiences of the sessions and the impact of the interventions at the same time as the interviews were conducted, i.e., directly after the music therapy interventions.

All persons present in the unit during the music therapy interventions were invited to take part in the interviews. Potential interviewees were informed on the work at the outset of each interview, as well as the confidentiality and the assurance of anonymity of the participants. A total of 14 people agreed to be interviewed, including three nurses, one medical secretary, seven volunteers from the NGO *Aprendo Contigo* providing educational activities in the hospital units, three caregivers from three different families. Written informed consent was given by all participants. All interviewees were Peruvian, between the age of 20 and 60.

Responses from the interviewees were divided into four sections based on their descriptions of the impact of music therapy on the children, the environment, the caregivers, and the interviewees themselves. Thereafter, similarities and differences in the interviewees' descriptions, as well as unique descriptions of their experiences were examined. The twelve emergent themes identified were: participation; motivation; attention; relaxation; enjoyment; discovering resources; support; pain management; cooperation during treatment; more energy; environmental impact; facilitating the work experience

The Impact of Music Therapy Interventions on the Children

The first ten themes were all presented in the interviewees' descriptions of the impact of music therapy on the children. When asking the volunteers if they found music therapy to be beneficial for the children, there was a unanimous response that the

interventions had a positive impact. The medical team and the volunteers noted that the interventions helped the children to relax and calm down and that the children enjoyed the musical activities. As one volunteer expressed: *“you can see their faces [are] more relaxed, they smile and look for the music with their eyes”* and *“the children are happier and smiling more”*. Many described the impact of music therapy in helping the children to calm down, that *“music therapy changed a lot the children with whom she [the music therapist] had worked”*, and as one volunteer mentioned *“the little blind girl got much more calmed and was entertained, and also the baby. They were the ones that were more stressed and it [the music therapy] calmed them”*.

The volunteers and the medical team found the interventions to provide a distraction for the children, describing music therapy as capturing the children’s attention, getting their mind off the medical treatment and focusing on something else. One volunteer said that music therapy took the children *“out of their sorrow, preoccupation”*, out of their pain and their restlessness. The volunteers found it easier to work with the children as they became more relaxed, stopped crying and became more motivated, participative and uninhibited after the intervention. The volunteers noticed that some of the children fell asleep to the music, or the music supported them through a medical procedure. The medical team also found that music therapy supported the children in receiving treatment and noted that children became more cooperative during medical procedures which facilitated the medical team in carrying out the medical procedures. The caregivers found music therapy to help both themselves and their children during the medical procedure.

The volunteers responded that not only was there an impact on the children’s cooperation during medical procedures, but also an improvement in the interactions between children and volunteers. As volunteers mostly worked with the children between, and not during, medical procedures, they found the children to be more participative, motivated and had better interactions with the volunteers during and after the music therapy interventions. One volunteer said that the interventions gave the children and caregivers an opportunity to *“participate in something different and*

identify musical skills that otherwise wouldn't always survive [would go unnoticed]". Another volunteer described responses from the children saying, "they wanted to play the guitar, participate and collaborate" and with music therapy, the children became "more willing to participate, more willing to talk, less inhibited". The caregivers also described the interventions to engage both their children and themselves. One caregiver said that in the musical activity, where his daughter was playing the guitar, he saw her "doing as normal" and recognizing her "as she is".

During the music therapy interventions, the children expressed happiness by smiling and laughing more and their body language became more relaxed. The volunteers found that with music therapy, the children were able to participate in a fun activity that at the same time cleared their minds and distracted them from unpleasant procedures and a stressful environment. The children enjoyed playing with the musical instruments and through "musicking" they became motivated, creative and discovered (musical) skills. Furthermore, the music therapy engaged the children and they participated more as the interventions provided and facilitated interpersonal relationships. The children became more communicative and interacted more with their caregivers, with the other children and with the volunteers. One caregiver said that his daughter was restless from the treatment, but during music therapy, she became happy and engaged in playing with musical instruments.

The volunteers found music therapy to have a positive impact, not only on the child with whom the music therapist was working, but the enjoyment of music spread to others in the room as well. The volunteers described much shared joy as music therapy provided opportunities for the children to play together with their caregivers or with the child in the next bed. One volunteer noticed that the interventions had a positive impact on the caregivers as well, and that the children enjoyed seeing their caregiver happier and more relaxed. The caregivers found music therapy to catch their children's attention, distracting them and engaging them. They described that both the children and themselves enjoyed music therapy and both became more calmed after the intervention.

The Impact of Music Therapy Interventions on the Environment

There was a unanimous response from the interviewees that the music therapy interventions changed the environment of the hospital unit in a positive way. The volunteers all responded that the room changed from a stressful to a more relaxed environment during music therapy. There was a bit more sound in the room during the music therapy interventions, but the room became calmer and relaxing during and after the interventions. The volunteers described the impact of music therapy in changing the room into a more joyful environment and expressed that *“the music makes you forget other sounds, like the machines or the crying. It makes ‘the hospitality’ [the hospital feeling] go away”*.

The Impact of Music Therapy Interventions on the Caregivers

Within this section, the interviewees found music therapy to have an impact on participation, attention, relaxation, enjoyment, discovering resources, and providing support. When asking the caregivers how they would describe their own experiences of the music therapy interventions, they all said it was both helpful for themselves and their children. When their children were distracted, happy and/or calmed, then the caregivers would feel calmed as well. One of the caregivers said that music therapy helped her clear her mind from worry and she felt more relaxed and calmer. The medical treatment was a new and uncertain experience for her and her child, but music therapy helped her through it. She said that music therapy *“catches his [the child’s] attention, he gets distracted, it makes me feel calmed. It [music therapy] clears your mind from whatever you were worrying about”*. Another caregiver described music therapy as a way for both the children and the caregivers to engage in an activity, which helped her and her child to relax. The third caregiver expressed joy by seeing his daughter happy and by recognizing her personality and *“seeing her as she is”*. The

interventions helped him and his daughter to calm down and relax, and provided a pleasant and enjoyable moment for them.

The volunteers agreed that the music caught the attention of the caregivers as well as the children, with the caregivers' facial expressions becoming more relaxed while listening to the music. The volunteers found the caregivers to be happier, smiling and expressing gratitude for the joyful activities. The music therapy interventions created an opportunity for children and caregivers to participate in something different. Some caregivers wanted to play along with their child, creating an opportunity for the family members to interact and share an enjoyable moment in the hospital. For a moment, they could disconnect from the hospital setting and medical treatment, relax, listen to music and enjoy the moment together with their child. The volunteers noticed caregivers expressing joy and pride when watching their children playing music. The caregivers sometimes took pictures and videos of their children's participation in the musical activities and enjoyed watching their children's responses to the interventions. Many caregivers were also surprised by the interventions and by the "hidden" musical skills of their children. Several of the volunteers said that the caregivers *"liked a lot their children's reactions towards what was happening; they took pictures, videos, and you could see they were happy"*.

The Impact of Music Therapy Interventions on the Interviewees Themselves

The medical team and volunteers found an impact of music therapy on themselves by providing relaxation, enjoyment and helping with the children's cooperation during treatment. When asking the volunteers if they found music therapy to affect their work experience, they all answered in the affirmative. They found the interventions *"to open a door"*, facilitating their interaction with the children and helping them to better care for the children. When the children were more relaxed, the volunteers found it easier to interact, accompany and work with them. Another volunteer said that the interventions *"helped me to care for them [the children] better,*

because when they cry you can't work with them". The music therapy interventions also gave the volunteers a fun activity with the children. When there were difficulties or painful procedures, they found it helpful to ask the music therapist to be present. The volunteers all responded that they would prefer music therapy in the future. The interventions did not only help the children with whom they were working, but it also helped the volunteers to continue working with other children in the room. The medical team also said it facilitated their work as the music therapy interventions supported the children before, during and after medical procedures which increased the children's cooperation during the procedures. The medical team described the interventions to be helpful, relaxing and positive, and would prefer music therapy in the hospital unit in the future.

Discussion

Based on the interviewees' descriptions, music therapy was found to be a distraction, shifting the attention and providing moments of enjoyment and/or relaxation between and during medical procedures. Children were able to better cope with the time spent at the hospital, with e.g., side effects, treatments and waiting time. These findings support previous research. In a study conducted by Whitehead-Pleaux et al. (2007), music therapy was found to help hospitalized children to better cope with the time spent at the hospital, support them between and during unpleasant and painful medical procedures, as well as facilitate their cooperation during the procedures. In a review of research studies, Hilliard (2006) summarizes the practice of music therapy in the area of pediatric oncology. In addition, a patient/family feedback survey was conducted on pediatric oncology music therapy, and its findings support the review of previous studies. Music therapy was found to help children's adjustment to long-term hospitalization and illness, and also to support children during medical procedures by distracting them from pain and anxiety (Hilliard, 2006). Caregivers described family bonding as the most important benefit from taking part in music therapy, followed by

the role of music therapy in developing children's coping abilities and providing opportunities for self-expression. Furthermore, caregivers highlighted the importance of the function of music therapy to be flexible in its structure in order to accommodate and individually address the particular needs of the child at different stages of treatment (ibid.).

Studies have shown that it is not only the child who needs support to cope with the stressful experiences of receiving treatment and undergoing medical procedures (Aasgaard, 2002; Longhi et al., 2015; Sundar et al., 2016). A caregiver's fear and stress can have an impact on the child and his/her perception of the situation, resulting in a more negative and painful experience for the child. Therefore, it is important to include the caregivers when focusing on the holistic experience of the child (ibid.). In the study conducted by Whitehead-Pleaux et al. (2007), it was demonstrated that seeing their child suffer during treatment can cause suffering for the caregivers as well. In the present report, the caregivers expressed that when they saw that their children were distracted from the treatment, happy and/or calmed, then they could become relaxed as well. One of the caregivers noted that music therapy helped her and her child through the medical treatment, which was a new and uncertain experience for them.

In the study by Hilliard (2006), the author emphasized that children and their caregivers need experiences that offer a sense of normalcy and control in an often chaotic environment, during an unpredictable and challenging time in their lives. The caregivers reported that music therapy played an important role by providing an opportunity for the children to express themselves, to connect with the outside world and the normal part of themselves. This had a positive impact on their mental health and overall well-being and recovery (Hilliard, 2006). In this study, caregivers described group interventions as particularly helpful to normalize the hospital environment by providing social interaction. Due to a weakened immune system in children diagnosed with cancer, children can often become isolated and interacting with peers can be difficult to arrange (ibid.). In the present report, one caregiver expressed joy of seeing his child acting normally and recognizing her personality while participating in the

musical activities. All caregivers described a great joy by watching their children participating in interactions with the other children and being creative and playful.

In a literature review of music therapy research and applications in pediatric oncology treatment, the authors highlight the enjoyment of music and a positive change in mood and comfort level (Standley & Hanser, 1995). The children enjoyed playing musical instruments during which they could be noisy, use their imagination and creativity. In music, they could make choices, retain a sense of control and were able to do something enjoyable that kept them busy instead of feeling stressed or bored. The caregivers responded that their children became more playful, expressed joy, and were distracted from their treatment and illness. Music therapy also provided an opportunity for the children to express themselves and supported both the children and their caregivers in feeling less anxious while also providing an opportunity for them to interact with each other and participate in an enjoyable activity. This helped normalize the situation during the time spent at the hospital (ibid.). These findings connect to the study conducted by Longhi et al. (2015) where caregivers emphasized the positive impact of music therapy on interacting with their children during a stressful and challenging time in their lives. In the present report, interviewees described both observing and experiencing the joy of music. Music therapy providing a positive and joyful activity where the focus shifted from the unpleasant treatment to pleasurable interactions. As described by the interviewees, enjoyment can be a rare experience for both the children and their caregivers. Through music therapy, the children could take part in an enjoyable moment, either by playing instruments or by listening to the music. Between medical procedures, music therapy provided an activity where playfulness and creativity could be supported in a social interaction.

As found in the present report, music therapy could also provide a moment for relaxation, a break from the hospital environment, sounds and stress. Fatigue is a common side effect of the chemotherapy treatment. The child, as well as family members, need a break from being worried, afraid, anxious, or feeling pain, among other emotions (Longhi et al., 2015; Sanfi & Bonde, 2014). In the present report, music

therapy was described as a meaningful and joyful distraction that could also help to create a relaxed space for the children and others in the hospital setting. Similarly, Millett and Gooding (2017) examined music therapy in the hospital setting and its impact on children and their caregivers. They found that playing or listening to music reduces pre-operative anxiety in both children and caregivers (Millett & Gooding, 2017). According to the interviewees for the present report, music therapy interventions not only had a positive impact on the child with whom the music therapist was working, but also on the other children and staff who were present in the room. People working in the ambulatory unit described the interventions as being helpful and relaxing for them as well. The interventions facilitated their work, helping them to better care for the children. Improved cooperation, as well as increased participation and interaction with the children, were described by both volunteers and the medical team. This corresponds with the outcome of previous studies of music therapy with children in hospitals, including the studies by Sundar et al. (2016) and Whitehead-Pleaux et al. (2007). In these studies, the hospital staff found music therapy to have a positive impact on their work experiences. When the child and the surrounding atmosphere were calmer, it was easier to perform medical procedures. This provided efficiency of care as well as job satisfaction by the staff (Sundar et al., 2016; Whitehead-Pleaux et al., 2007).

With music therapy improving the hospital environment and creating a distraction during medical procedures, it can help children to become less anxious, stressed and experience less pain (Longhi et al., 2015; Sundar et al., 2016). These findings resonate with the present report, with all interviewees finding music therapy to have a positive impact on the environment. Several interviewees pointed out that the music therapy interventions changed the environment of the hospital unit in a positive way. The interventions motivated and inspired others in the room to play along, or the music would help to provide support, joy or relaxation. The persons working in this setting all expressed a desire for music therapy to be offered in the ambulatory unit in the future. It is important to note that the four months of music therapy, that took place in the ambulatory unit for this report, was the first time that music therapy had ever

been implemented at INEN. Although music therapy was a new and unknown intervention in Peru, the established hospital teams did report on the therapeutic value of music therapy at INEN, and were favorable to collaborating with the music therapist in treating the children. Canga et. al. (2012) also highlighted the role of music therapy in the hospital environment and the relevance of using environmental music therapy (EMT) in an ambulatory chemotherapy unit as a non-invasive mind-body intervention that considers the physical, psychological and cultural needs of patients, caregivers and staff. Although studies find music to have a positive impact on the hospital environment, Aasgaard (2002) points out that the music therapist needs to be mindful of the constant changes that occur in the surroundings, as well as in the children, and how music will influence the people present in the hospital unit. When music enters the hospital environment, it can disturb some people or other activities in the environment, or it can provide a positive distraction from the hospital setting (Aasgaard, 2002). Nevertheless, the diversion – positive or negative – is important to keep in mind. When implementing more sounds into an already loud and intense setting, it is necessary that the music therapist “tunes in” and improvises not only musically, but also accordingly to the environment (ibid.).

Conclusion

This report aimed to share experiences of clinical music therapy practice in a pediatric ambulatory chemotherapy unit, through interviews with caregivers, hospital volunteers and members of the medical team, and to share the interviewees’ descriptions of the impact of music therapy interventions on the children, the hospital environment, the caregivers and the interviewees themselves. Music therapy was found to have a positive impact on participation; motivation; attention; relaxation; enjoyment; discovering resources; support; pain management; cooperation during treatment; more energy; environmental impact; facilitating the work experience.

Active and receptive music therapy interventions provided something different in this hospital unit, a supportive distraction, where the children's attention could shift from the stressful and unpleasant situation into moments of enjoyment and/or relaxation. Music therapy provided an activity where the children could be motivated, creative and engaged in a supportive interaction, and where caregivers could be involved as well. As a result, the children were able to better cope with the time spent at the hospital, with side effects, treatments and waiting time. The children became more cooperative during medical procedures, which facilitated the staff in carrying out the procedures.

Finally, it is important to highlight that the music therapy interventions have an impact on more than that child with whom the music therapist is working. This is strength of the interventions, but also requires the music therapist to keep up with and adjust to changes in the environment and in the child. When working with a *here-and-now* focus within a holistic approach to the child's treatment in this clinical setting, it requires multiple attention points for the music therapist while building an interaction with the child, and being prepared to end the interaction at any time due to external circumstances.

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