

Dynamics of Implementation of Humanization in the Pediatric Radiotherapy Service of the National Cancer Institute José Alencar Gomes da Silva, Brazil

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Dinâmica da Implantação de Humanização no Serviço de Radioterapia Pediátrica do Instituto Nacional de Câncer José Alencar Gomes da Silva, Brasil

Dinámica de la Implementación de la Humanización en el Servicio de Salud Radioterapia Pediátrica del Instituto Nacional de Câncer José Alencar Gomes da Silva, Brasil

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ABSTRACT

Introduction: The treatment of childhood cancer is multidisciplinary and radiotherapy is part of this approach, being, in general, a critical procedure in children. The need to remain unaccompanied and motionless in the treatment apparatus, together with the fear of the nature of this therapy, makes the use of anesthesia common. Humanization measures were introduced in the radiotherapy routine to help children to feel more comfortable and confident with this treatment. **Objective:** To describe the dynamics of the humanization process. **Method:** A descriptive study addressing the implementation of humanization measures was developed, between May 2016 and December 2017, in the Radiotherapy Service of the National Cancer Institute José Alencar Gomes da Silva, RJ, Brazil. **Result:** The customization of the treatment masks, the use of matching costumes, the certificate of courage, the celebrations of festive dates and the improvements in the environment were the main humanization interventions carried out. There was a transformation in coping with the adversities inherent to the treatment, with clear benefits for the environment and the child's well-being. A trusting relationship was established between the child, his family and the professional team. Greater adherence, reduced absenteeism and an apparent reduction in the use of anesthesia for treatment were found. **Conclusion:** The actions implemented brought an unambiguous gain in the general well-being of those involved in the humanization process. The necessity of quantitative study on improving the flow of care in the Radiotherapy Service, either by reducing the use of anesthesia for treatment or the daily time spent in the radiotherapy device is highlighted.

Key words: humanization of assistance; pediatrics; neoplasms/radiotherapy; child.

RESUMO

Introdução: O tratamento do câncer infantil é multidisciplinar, e a radioterapia faz parte dessa abordagem, sendo, em geral, um procedimento crítico em crianças. A necessidade de permanecerem sem acompanhante e imóveis no aparelho de tratamento, aliada ao receio da natureza dessa terapia, faz com que o uso de anestesia seja comum. Para que a criança pudesse se sentir mais confortável e confiante com esse tratamento, foram introduzidas medidas de humanização na rotina da radioterapia. **Objetivo:** Descrever a dinâmica do processo de humanização utilizado. **Método:** Estudo descritivo sobre a implantação de medidas de humanização, entre maio/2016 e dezembro/2017, no Serviço de Radioterapia do Instituto Nacional de Câncer José Alencar Gomes da Silva, RJ, Brasil. **Resultado:** A customização das máscaras de tratamento, a utilização de fantasias correspondentes, o certificado de coragem, as comemorações de datas festivas e as melhorias no ambiente foram as principais intervenções de humanização realizadas. Houve uma transformação no enfrentamento das adversidades inerentes ao tratamento, com evidente benefício para o ambiente e bem-estar da criança. Uma relação de confiança foi estabelecida entre a criança, sua família e a equipe profissional. Maior adesão, redução do absenteísmo e aparente redução de anestesia para o tratamento foram os resultados constatados. **Conclusão:** As ações implementadas trouxeram inequívoco ganho para o bem-estar geral dos envolvidos no processo de humanização. Aponta-se a necessidade de estudo quantitativo sobre a melhoria no fluxo de atendimento nesse Serviço, seja por meio da redução do uso de anestesia para o tratamento ou no tempo diário no aparelho de radioterapia.

Palavras-chave: humanização da assistência; pediatria; neoplasias/radioterapia; criança.

RESUMEN

Introducción: El tratamiento del cáncer infantil es multidisciplinario y la radioterapia forma parte de este abordaje, siendo, en general, un procedimiento crítico en los niños. La necesidad de permanecer sin compañía e inmóvil en el aparato de tratamiento, combinada con el miedo a la naturaleza de esta terapia, hace que el uso de anestesia sea común. Para que el niño se sintiera más cómodo y seguro con este tratamiento, se introdujeron medidas de humanización en la rutina de radioterapia. **Objetivo:** Describir la dinámica del proceso de humanización utilizado. **Método:** Estudio descriptivo sobre la implementación de medidas de humanización, entre mayo/2016 y diciembre/2017, en el Servicio de Radioterapia del Instituto Nacional del Câncer José Alencar Gomes da Silva, RJ, Brasil. **Resultado:** La personalización de las máscaras de tratamiento, el uso de los trajes correspondientes, el certificado de valentía, las celebraciones de fechas festivas y las mejoras en el entorno fueron las principales intervenciones de humanización realizadas. Se produjo una transformación en el afrontamiento de las adversidades inherentes al tratamiento, con evidentes beneficios para el medio ambiente y el bienestar del niño. Se estableció una relación de confianza entre el niño, su familia y el equipo profesional. Se encontraron mayor adherencia, menor absentismo y una aparente reducción en el uso de anestesia para el tratamiento. **Conclusión:** Las acciones implementadas aportaron una ganancia inequívoca en el bienestar general de los involucrados en el proceso de humanización. Es necesario un estudio cuantitativo sobre la mejora del flujo de atención en este Servicio, ya sea reduciendo el uso de anestesia para el tratamiento o el tiempo diario en el dispositivo de radioterapia.

Palabras clave: humanización de la atención; pediatria; neoplasias/radioterapia; niño.

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INTRODUCTION

Childhood cancer accounts from 1% to 4% of cancer in general. The estimates of the National Cancer Institute José Alencar Gomes da Silva for Brazil indicate the occurrence of 8,460 new cases of tumor for each year of the triennium 2020-2022¹. Cancer treatment is multidisciplinary and nearly 40% of the children diagnosed will receive radiotherapy as part of their treatment in some point of the disease either curative or palliative².

Pediatric radiotherapy is a specialty in radiotherapy. In Brazil and worldwide, exclusively children-centered care is uncommon, they are typically consulted in clinics for adults and adjusted to their needs². This modality consists in the application of ionizing radiations for therapeutic purposes to eliminate or inhibit the growth of neoplastic cells causing them a lethal damage³. The incorrect targeting of the radioactive beam can cause toxicity in regular tissues and affect the child's health. It is critical that the child is still during the procedure and accessories can be utilized for that purpose which may increase the child's anxiety along the treatment⁴.

Great advances have occurred in the treatment in the last years and for children is becoming more complex due to rising availability of novel technology able to direct the prescribed dose to the tumor. However, pediatric radiotherapy scenario remains unsettled. Environments are not children-centered, equipment operate at low temperature and they need to remain still, unaccompanied in a cold room. It continues to be common the use of anesthetics reflecting difficulties children live due to the treatment's peculiarities. Nearly 40%-50% of pediatric patients need anesthetics or conscious sedation during radiotherapy⁴.

Much has been discussed about humanization of hospital care mainly because of vulnerability of the patient, especially children. In 2003, the National Policy of Humanization (PNH)^{5,6} was implemented in the National Health System addressing the following aspects: creative ability of each subject involved; humanize means to modify the mentality of the persons; the process is contagious and should be shared. PNH appeared as a policy developed to meet the wishes of the Brazilian society in regard to the quality of the care. Several studies have been published about humanization of care to the child hospitalized with positive results in building trust and well-being through playfulness with clowns, music and art⁷⁻⁹ among others. However, articles about health humanization associated with childhood radiotherapy and improvement of operational flow are less common.

Measures have been adopted to minimize and ease the adherence to the treatment after acknowledging the difficulties inherent to childhood radiotherapy, unfavorable environment and fragility of the child and its family during the treatment. Since 2016, humanization measures with ludic interventions were implemented with continuous changes in the routine of care of the pediatric population.

The objective of this study was to describe the implementation of initiatives of humanization in a pediatric radiotherapy of SUS and submit an acceptable, accessible and low-cost project to reduce the child's difficulties during radiotherapy.

METHOD

Descriptive study about the implementation of humanization in a pediatric Radiotherapy Service. Data were obtained between May 2016 and December 2017 at INCA's Radiotherapy Service in the municipality of Rio de Janeiro, Brazil. INCA's Institutional Review Board (IRB) approved the study, number CAAE: 83601618.2.0000.5274.

One of the authors was in charge of the observation and was present in every radiotherapy consultation. Patients were followed-up in weekly visits during the treatment when the authors investigated the impressions the child and family had about the humanization process. The same questions were asked in every visit weekly: whether the child was sleeping well, feeding regularly, if was fearing the treatment and whether the parents were confident, safe and happy with the process. After checking the visit log of the Service, it was found the daily frequency of the treatment and necessity of anesthetics and the general information of the child were collected from the hospital charts.

Of all the 188 children with diagnosis of cancer and younger than 18 years treated with radiotherapy, 142 who were subject of some type of humanization intervention during the treatment were investigated.

Radiotherapy treatment is applied daily, five days a week for a total period that can reach seven weeks. The duration is determined by the tumor histology and staging. Approximately from 10 to 20 minutes is the time at the treatment equipment that can double if anesthetics are administered.

RESULTS

At radiotherapy, most of the population receiving humanization initiatives were in the age range between four and seven years (n=50/142; 35.2%), followed by

12 to 16 years ($n=35/142$; 24.6%). The mean age at the treatment was 102.99 months or 8.5 years (CI:93.78-112.19; SD:55.47) with predominance of males ($n=80/142$; 56.3%) and Brown race ($n=76/142$; 53.5%). Most frequent neoplasms were in the central nervous system ($n=58/142$; 40.8%) and leukemia ($n=22/142$; 15.5%).

Immobilization devices to avoid wrong positioning related damages while in the treatment were utilized such as the thermoplastic mask indicated for head and neck radiotherapy which allows a strict immobilization avoiding movements very common in children. The masks are manufactured with the material warmed making it flexible to fit the child's face and customized with characters of the child universe as preferred (Figure 1).



Figure 1. Examples of customized masks: **A:** Spiderman; **B:** Captain America; **C:** Turtle Ninja; **D:** Alice; **E:** Wonder Woman; **F:** Batman

Because the patients have fully accepted, other humanization measures were planned by the pediatric radiotherapy staff to be gradually implemented at the service to create a welcoming environment and ludic atmosphere. The interventions adjusted to the pediatric population were:

1. Donation of costumes of their favorite heroes to wear during treatment and bespoke masks and matching costume (Figure 2).



Figure 2. Children in radiotherapy with customized mask and matching costume. **A:** Spiderman; **B:** Ninja Turtle; **C:** Captain America

2. Recorded children music or stories to be played during the daily treatment.
3. Daily log with male and female stamps (Figure 3A) in a *Badge of Courage* to show cooperation and adherence in the course of radiotherapy. The certificates were handed over at the end of the treatment (Figure 3B).



Figure 3. **A.** Child stamps; **B.** Badges of courage (boys and girls)

Note: Squares are stamped at each day the treatment is completed.

4. Optimization of waiting rooms at radiotherapy to favor playful activities with books, toys, games, drawing and painting pads.
5. Encounters to celebrate festive dates.
6. Celebration of the “Days of the Heroes”, when professionals wearing super-hero and princesses garments enter the waiting rooms bringing gifts.
7. Donation of stuffed toys depicting characters of the ludic universe of “princesses and super-heroes” as award at the end of the treatment in addition to the customized masks.

Some apparently inconspicuous initiatives were able to change the understanding and coping of a problem. The bulky and so far scaring equipment started to be known as *spacecraft* and entered into the ludic universe where the *superheroes* gained force and trust and fear became an adventure. When they donned the matching costume, the imagination took over and completed the transformation. Behavior changing was evident to anyone involved, a treatment so far feared was anticipated by the small patients who asked to go to the hospital in weekends too. Trust of family and team boosted and parents joined in more actively in their children treatment and helped to improve even more the welcoming environment. This translated into better adherence to the treatment, less missed visits and being still was part of the playfulness, speeding up the period lying in the equipment. Anesthetics for children who participated of the humanization process

reduced (n=48/142; 33.8%), 11 children (7.7%) felt stronger in the process and analgesia was discarded.

At the follow-up visits, positive manifestations were seen in parents and children, none of them had sleep disorders and feeding issues were associated to the irradiated area or concomitant chemotherapy. Fear of the treatment was not detected. Children and their parents showed confidence and satisfaction with the process.

DISCUSSION

When a child is diagnosed with cancer, its entire family is affected too. The impact of the diagnosis may bring uncertainty about the prognosis and the treatment can include several therapeutic modalities. Although radiotherapy is not invasive, stress and anxiety can affect the child, possibly leading to the use of anesthetics during the procedure. Strategies to bring distraction and good connection among the family and the health staff may avoid the anesthetics and the child might be able to accept the treatment more lightly.

The practices of humanization in health are being discussed worldwide and are frequent in the national scientific literature. Humanization can be understood as a close relation among professional and patients while constructing better care. Much has been published about humanizing the hospital environment for the child, making the procedures more acceptable and helping to cope with anxiety because of the hospitalization. Regardless of less common studies on humanization of childhood radiotherapy, Balazy et al.¹⁰ showed that the necessity of anesthetics diminished with the utilization of audiovisual system during the treatment, similar to Scott et al.¹¹ bringing together a professional team able to follow-up and clarify the child in every step of radiotherapy.

Low-cost and simple measures were proven to possibly change INCA's pediatric radiotherapy with behavior modification and diminishing children's fear and raise the family confidence and satisfaction. Anesthetics were used much less than reported in the literature and absenteeism has dropped too in the period.

CONCLUSION

INCA's Radiotherapy Service was motivated to act and deal with this reality, recognizing the pediatric radiotherapy inherent difficulties as a challenge to be beaten. Simple solutions were pursued through interaction and creativity of the staff, identification of what the institution was able to provide and optimization of the opportunities. Humanization was gradual and

interventions were introduced as a response to positive reactions from the children and their families as their demands were seen as warrantable.

This article revealed the clear improvement of the care to childhood health, but it did not evaluate quantitatively the global impact of the visits flow at the Radiotherapy Service. It is expected that a study evaluating the reduced use of anesthetics and treatment duration comparing the two periods, before and after the humanization process is conducted in the near future

CONTRIBUTIONS

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

DECLARATION OF CONFLICT OF INTERETS

There is no conflict of interests to declare.

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